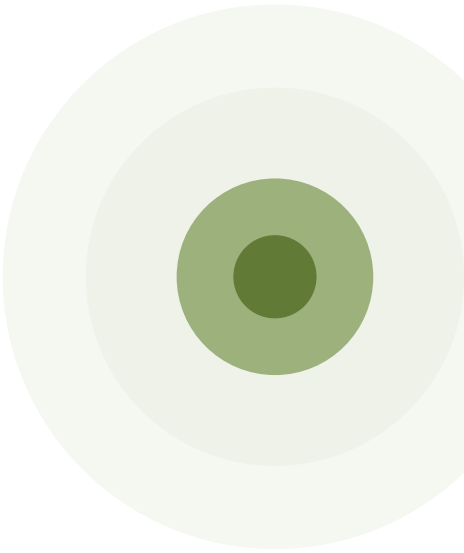
A GUIDE FOR AUTISTIC ADULTS AND THE PEOPLE CLOSE TO THEM

# Understanding Your Autism

A guide for adults after diagnosis



Written by Dr Kaleem Baig FRCPsych, Consultant Psychiatrist; Sarah Wilson, Psychological Therapist and Clinical Director; Sophie Locke, Assistant Psychologist
Version 1.1 · October 2026 · Next review October 2027
The latest version is always at umid.co.uk/resources

CONTENTS

# What is in this guide


Part 1: Start here . . . 3

Part 2: Understanding autism . . . 6

Part 3: Looking after your energy and wellbeing . . . 10

Part 4: Your mental health . . . 13

Part 5: Relationships, identity and community . . . 15

Part 6: Work, study, money and your rights . . . 17

Part 7: Further help and reading . . . 20

Words used in this guide . . . 22

Where this information comes from . . . 24

Ownership and use of this guide . . . 27

PART 1

# Start here

**IN THIS PART**

- What this guide is for and how to use it
- Where to find the most recent version
- Where to get help urgently
- The first steps many people find useful after a diagnosis
- The support UMID offers after diagnosis, including a free appointment to talk through what would help
- The words we use, and why

## About this guide

This guide is for adults who have recently received a diagnosis of autism from UMID, and for the partners, family members and friends who support them. It brings together what we have learned from the people we assess, from UK clinical guidance and from current research, so that you have one place to turn to in the weeks and months after your assessment.

You do not need to read it all at once. Part 1 covers the essentials. The later parts explain autism in more depth, look at energy, wellbeing and mental health, and set out practical information about relationships, work, study, money and your rights. Part 7 lists organisations and books, and the closing sections explain the words we use and where our information comes from.

This is a general guide. It is the same for every adult we diagnose, and it does not replace the individual report you received after your assessment. Where the two differ, your report describes you, and this guide describes what is broadly true for many autistic adults.

**ALWAYS CHECK FOR THE LATEST VERSION**

This guide is updated regularly. The most recent version is always available at umid.co.uk/resources. If you received this guide some time ago, please check there for the current edition.

## If you need help urgently

**IF YOU NEED HELP URGENTLY**

UMID is not an emergency or crisis service, and we are not able to respond quickly to messages. If you are in crisis, or worried about your safety or someone else's, please use one of these services straight away.

- **Call 999 or go to A&E** if your life, or someone else's, is at risk, or if you do not feel you can keep yourself safe. A mental health emergency should be taken as seriously as a physical one, and you will not be wasting anyone's time.
- **NHS 111** for urgent mental health help that is not an emergency. Call 111 and choose the mental health option, or use 111 online at 111.nhs.uk. You can also ask your GP surgery for an urgent appointment.
- **Samaritans**: call 116 123, free, at any time of day or night.

- **Shout**: text SHOUT to 85258 for free, confidential text support at any time. Many autistic people find texting easier than speaking on the phone.
- **CALM** (Campaign Against Living Miserably): call **0800 58 58 58**, open from 5pm to midnight every day, for free, confidential and anonymous support for anyone aged 18 or over who is affected by suicide or suicidal thoughts.
- **Childline**, if you are under 19: call 0800 1111, free, at any time.

## First steps after diagnosis

A diagnosis can bring relief, clarity and a sense of finally being understood. It can also bring grief for the years spent without that understanding, anger, doubt, or simply tiredness. Many people feel several of these at once, and the feelings often change over the following months. All of this is a normal response to learning something important about yourself, and there is no right way to feel.

If you are tired and want only the essentials, these are the steps many adults find most useful.

1. **Give yourself time.** You do not need to make any decisions straight away about who to tell or what to change.
2. **Keep your report somewhere safe.** You may need it later for your GP, your employer, a university or a benefits application.
3. **Consider sharing your report with your GP**, so that your diagnosis is recorded in your health record and you can ask for adjustments to how your care is provided. If you live in England, you can also ask your GP surgery to add a Reasonable Adjustment Flag to your NHS record (see Part 3).
4. **Notice what drains you and what restores you.** Understanding your own energy is one of the most useful things you can do in the first months (see Part 3).
5. **Read about autism from autistic people as well as professionals.** The National Autistic Society website and the books in Part 7 are good places to start.
6. **Think about who might need to know.** This could be a partner, close family, or an employer or university if adjustments would help. Part 5 and Part 6 may help you decide.
7. **Look after your mental health.** If you are struggling with anxiety, low mood or exhaustion, help is available, and it can be adapted for autistic people (see Part 4).
8. **If you are unsure what support would help**, you can book a free 30-minute appointment with our Clinical Director to talk it through (see the next section).

## Support from UMID after the diagnosis

Your feedback meeting will have covered the support options that may help you. Some people find that the diagnosis and the information in this guide are what they need. Others want further help, either now or at a later point. Both are fine.

After diagnosis, UMID offers psychiatric care for any mental health needs that occur alongside autism, occupational therapy and psychological therapies. These are arranged separately from your assessment, and current fees are listed on our website at umid.co.uk/our-fees.

If you are unsure what would help, you can book a free 30-minute appointment with our Clinical Director to talk through your support needs after diagnosis and which options would best meet them. To arrange this, or if you have any question about your assessment, please email umid@umid.co.uk.

## The words we use

In this guide we mostly say “autistic person” rather than “person with autism”. Research with the UK autism community found that many autistic adults prefer the word “autistic”, while others prefer “on the

autism spectrum" or "person with autism", and that no single term suits everyone. We have chosen identity-first language because many autistic people tell us it reflects that autism is part of who they are rather than something separate from them. You are welcome to use whichever words feel right to you, and to ask others to do the same.

PART 2

# Understanding autism

IN THIS PART

- What autism is, and what it is not
- Strengths and differences
- Sensory differences
- Social communication, and why misunderstanding runs both ways
- Focus, interests and routine
- Emotions and body signals
- Looking back on your life with new understanding
- Other conditions that often occur alongside autism

## What autism is

Autism is a lifelong difference in how the brain develops, which affects how a person experiences the world, thinks, learns and pays attention, communicates and relates to other people, and responds to sensory experiences. About 1 to 2 in every 100 people in the UK are autistic. Autism can be diagnosed at any age, and people of every gender and background are autistic.

A formal diagnosis is based on two broad areas. The first is differences in social communication and interaction, such as how you read and use unspoken signals, how conversations feel to you, and how you form and keep relationships. The second is patterns of focused interests, a strong need for predictability or routine, repetitive movements or habits, and differences in how you respond to sensory experiences such as sound, light, touch, taste and smell.

Every autistic person is different. Two people with the same diagnosis can have very different strengths, needs and experiences, and your own needs may change over your life and from one setting to another.

## What autism is not

Autism is not an illness, and it is not caused by vaccines or medicines. There is no cure and no medication or treatment that changes autism itself. UK guidance advises against using medication to treat the core features of autism. What makes the biggest difference is understanding, practical adjustments to your surroundings and routines, and support for any other difficulties you may have, such as anxiety or sleep problems.

BE CAUTIOUS ABOUT TREATMENTS THAT CLAIM TO CHANGE AUTISM

The National Institute for Health and Care Excellence (NICE), which sets standards for NHS care in England, advises that a number of treatments should not be used to manage the core features of autism in adults. These include chelation (a procedure to remove metals from the body), exclusion diets such as gluten-free or casein-free diets, vitamin, mineral and other supplements, hyperbaric oxygen therapy, oxytocin, secretin and antipsychotic medication. NICE also advises that antidepressants should not be used routinely for the core features of autism. Some of these treatments carry real risks. If you are offered a treatment that promises to reduce or cure autism, we would encourage you to discuss it with your GP or with us first.

## Strengths and differences

Many autistic adults describe real strengths that are connected to being autistic: deep and sustained focus, detailed knowledge of subjects that matter to them, honesty and a strong sense of fairness, noticing patterns and details that others miss, loyalty, and original ways of thinking. You may recognise some of these in yourself and not others.

At the same time, living in a world arranged mainly around non-autistic ways of communicating, working and socialising can be tiring and sometimes distressing. Noise, crowds, unclear expectations, sudden changes and the effort of fitting in can add up. Recognising both sides matters. The difficulties are real, and so are the strengths, and neither cancels out the other.

Some autistic people think of themselves as disabled, and value that word because it recognises the barriers they face and their right to support. Others think of autism mainly as a difference. Both views are valid, and you do not have to choose one in order to use the support and protections described in this guide.

## Sensory differences

Many autistic people experience the senses differently. You might be more sensitive than other people to some things (for example, finding certain sounds painful, lights too bright, or clothing labels unbearable) and less sensitive to others (for example, not noticing cold, or seeking out strong pressure or movement). Sensitivity can vary from day to day, and it often increases when you are tired, stressed or unwell.

As well as sight, hearing, touch, taste and smell, sensory differences can affect three less familiar senses:

- **balance and movement** (the vestibular sense);
- **awareness of where your body is in space** (proprioception); and
- **awareness of signals from inside your body**, such as hunger, thirst, temperature, pain or needing the toilet (interoception).

Understanding your own sensory profile can help you make everyday life more comfortable. The National Autistic Society suggests keeping a sensory diary to spot what helps and what overwhelms you, using tools such as ear defenders, noise-reducing headphones, sunglasses or weighted blankets, and having somewhere quiet to go when things become too much.

**STIMMING**

Many autistic people use repetitive movements or sounds, such as rocking, tapping, fidgeting or humming. This is often called stimming. People often say it helps them manage emotions and sensory input and helps them concentrate, and holding it back is one of the ways people mask (see Part 3). Unless it causes you harm, there is no need to suppress it, and many people find they feel better when they allow themselves to stim.

## Social communication, and why misunderstanding runs both ways

Autistic people often communicate differently from non-autistic people. You might prefer direct and literal language, find small talk tiring or pointless, need more time to process spoken information, find eye contact uncomfortable, or find it hard to know what others expect when the rules are unspoken.

For a long time these differences were described only as problems within the autistic person. More recently, researchers have described what is called the “double empathy problem”: when two people communicate in very different ways, misunderstanding can happen in both directions, and both people share responsibility for bridging the gap. Some studies have found that autistic people pass on information to each other as effectively as non-autistic people do, and that more information is lost when

autistic and non-autistic people are paired together. This research is still developing, but many autistic adults say it matches their experience and helps them see social difficulty as a mismatch rather than a personal failing.

## Focus, interests and routine

Many autistic people have strong, focused interests that bring deep enjoyment, expertise and calm. These interests are not something to be trained out of you. They are often a source of wellbeing, connection with others who share them, and sometimes a career.

Some autistic researchers have proposed a theory called monotropism, which suggests that autistic attention tends to focus intensely on a small number of things at a time rather than spreading across many. This can explain both the depth of focus many people enjoy and why switching tasks or being interrupted can feel so jarring. It is a theory rather than an established scientific finding, but many people find it a useful way of understanding themselves.

Predictability and routine often help autistic people feel settled and use their energy well. Sudden or unexplained change can be much more demanding than others realise. It is reasonable to ask for advance notice of changes, clear plans and time to adjust.

## Emotions and body signals

Some autistic people find it hard to recognise, name or describe their own emotions, or to tell the difference between an emotion and a physical sensation. This is sometimes called alexithymia. A review of studies found that it affected about half of the autistic people taking part, compared with about one in twenty of the non-autistic people, so it is common but not universal.

If this sounds familiar, you might notice that you realise you were upset only later, that stress shows up first as a headache, tiredness or a stomach ache, or that you find it hard to answer “how are you feeling?”. This is not a lack of feeling. Noticing physical signs, and linking them over time to what was happening, can help. It is also worth telling a therapist or doctor about it, because many questions in health care assume you can easily describe how you feel.

## Looking back on your life with new understanding

Many adults, especially those diagnosed later in life, find themselves looking back on past experiences in a new light. Times when you felt out of step with others, exhausted by situations others seemed to find easy, or blamed for being “too sensitive” or “difficult” may now make more sense.

This understanding can bring a great deal of self-compassion. Difficulties that once felt like personal failings can be seen as the result of being autistic in settings that did not understand or adjust for you. It can also bring sadness about the support you did not receive. Both reactions are understandable, and talking them through with people who understand, whether friends, other autistic people or a therapist, can help.

## Other conditions that often occur alongside autism

Autistic people are more likely than others to have some other conditions as well. Knowing this can help you recognise when something else might be going on and ask for the right help.

- **ADHD** (attention deficit hyperactivity disorder) is common. Research that pooled many studies found that, across the studies it included, about 28 in every 100 autistic people also had a diagnosis of ADHD. If you have long-standing difficulties with attention, restlessness, impulsiveness or organisation that feel separate from being autistic, it may be worth discussing with your GP.
- **Anxiety and depression** are common and are discussed in Part 4.
- **Sleep difficulties** are common and are discussed in Part 3.

- **Other conditions.** The NHS notes that some autistic adults also need support with conditions such as dyslexia, dyspraxia (developmental coordination disorder), learning disability and epilepsy, and research reviews have found epilepsy, eating and feeding difficulties and digestive problems to be more common in autistic people.

None of these is inevitable, and many autistic people have none of them. If you notice a change in your health, it is always worth checking with your GP rather than assuming it is part of being autistic.

PART 3

# Looking after your energy and wellbeing

IN THIS PART

- Masking and its costs
- Autistic burnout, and what the research does and does not yet tell us
- Meltdowns and shutdowns
- Managing your energy
- Sleep, movement and food
- Your physical health and getting health care that works for you

## Masking

Masking, sometimes called camouflaging, means hiding or compensating for autistic traits in order to fit in, avoid negative reactions or get through a situation. It can be deliberate or happen without your noticing. It might involve rehearsing conversations, copying other people's expressions and body language, forcing eye contact, holding back from stimming, or constantly monitoring how you are coming across.

Masking can help in the short term, for example at work or in unfamiliar places. Many autistic people describe it as exhausting, and some say that after years of masking they are no longer sure which parts of themselves are "real". Research has found that people who report masking more also tend to report more anxiety and depression. The link appears to be modest, most studies have measured masking and mental health at a single point in time, and the people studied do not represent every autistic adult, so researchers cannot yet say how much masking causes these difficulties. Even so, the pattern is consistent enough to take seriously.

You do not have to stop masking, and in some situations it may feel safer to continue. What helps many people is becoming aware of when they mask, noticing what it costs them, and finding places and people with whom they can relax and be themselves.

## Autistic burnout

Many autistic adults describe periods of profound exhaustion that they call autistic burnout. People describe losing energy and skills they usually have, such as the ability to work, cook, socialise or even speak, alongside increased sensitivity to sound, light and other input and a strong need to withdraw. It is commonly described as building up over time from the effort of masking, sensory and social overload, a lack of understanding and support, and the demands of everyday life.

It is important to be honest about what is known. Autistic burnout is not a formal medical diagnosis. Most of the research so far has involved interviews and surveys, and a recent review of 48 studies found that the people taking part were mostly white, female and diagnosed in adulthood, so it may not reflect everyone's experience. Burnout can also look similar to depression and can occur alongside it. Even so, the descriptions from autistic people are remarkably consistent, and the idea is increasingly recognised by researchers, the National Autistic Society and the NHS.

In the research, the things that helped people recover included rest, time alone, relief from sensory demands, a clearer understanding of themselves as autistic, and support from others who understood.

The National Autistic Society also suggests spending time on interests that restore energy, taking time off work or study where possible, and allowing yourself to unmask.

> **WHEN TO SEEK HELP WITH EXHAUSTION**
> If you have felt exhausted, low or unable to cope for more than a couple of weeks, if you have stopped enjoying things you usually enjoy, or if you are having thoughts of harming yourself, please speak to your GP. These can be signs of depression, which is treatable, as well as or instead of burnout. If you are in crisis, use the urgent help routes in Part 1.

## Meltdowns and shutdowns

When overwhelm becomes too great, some autistic people have a meltdown or a shutdown.

A **meltdown** is an intense response to an overwhelming situation, during which a person temporarily loses control of how they are behaving. It might involve shouting, crying, or physical agitation. The National Autistic Society is clear that a meltdown is not a tantrum and is not bad behaviour.

A **shutdown** is a quieter response, in which the mind and body withdraw. You might go very quiet, find it hard or impossible to speak, need to retreat from people, or feel unable to move or respond.

Both are signs that your system has gone beyond what it can manage in that moment. They are not failures and they are not your fault. What often helps is recognising the early warning signs (such as pacing, rocking, asking the same question repeatedly, or a sense of rising tension), reducing noise, light and demands, moving to somewhere quieter, and allowing plenty of time to recover. Over time, noticing patterns in what leads up to meltdowns and shutdowns can help you avoid some of them.

> **FOR PARTNERS, FAMILY AND FRIENDS**
> During a meltdown or shutdown, the most helpful response is usually to stay calm, reduce noise and demands, avoid asking lots of questions, and give the person space and time. Talking about what happened is usually better left until they have fully recovered. It can help to agree in advance, at a calm time, what the person would like you to do.

## Managing your energy

Many autistic adults find it helpful to think of energy as a limited budget. Some activities, such as a busy commute, a noisy office, a social event or an unexpected change, spend a lot of it. Others, such as time alone, a special interest, a walk or familiar routines, may restore it. Autistic people have developed practical tools for thinking about this, such as “energy accounting” and “spoon theory”. These have not been formally researched, but many people find them useful.

Some practical ideas:

- **Plan with your energy in mind.** Where possible, spread demanding activities across the week rather than stacking them together, and plan recovery time after them.
- **Build in rest before you need it.** Short breaks taken early are often more effective than trying to recover after you are already exhausted.
- **Create low-demand spaces.** A quiet corner at home, a comfortable place at work, or noise-reducing headphones can make a real difference.
- **Protect time for your interests.** They are not an indulgence. For many autistic people they are one of the most reliable ways to restore energy.
- **Use tools that reduce mental load.** Timers, reminders, calendars, lists, visual planners and automatic bill payments can free up energy for the things that matter to you.

## Sleep

Sleep difficulties are common in autistic people. For some, this means difficulty falling or staying asleep. For others, it means needing long periods of sleep to recover after demanding days. Either pattern can affect mood, concentration and how well you cope with sensory input.

Things that often help include a regular, calming routine before bed, and making your bedroom as comfortable as possible for your senses: temperature, light, noise, and the feel of bedding and nightwear. If sleep problems persist and are affecting your daily life, it is worth speaking to your GP about approaches that may help.

## Movement and food

Regular physical activity is good for mood, stress and general health. Research on exercise specifically for autistic adults is limited, so our advice here is general: choose activities you enjoy and that suit your sensory preferences, whether that is walking, swimming, cycling or something else, and build them into your routine in a way you can sustain.

Some autistic people eat a limited range of foods because of taste, texture or smell, or find it hard to notice hunger. If your eating is restricted enough to affect your health or weight, or you are worried about your relationship with food, please talk to your GP, who can refer you to a dietitian or other support.

## Your physical health and health care

Research shows that autistic people are more likely than others to experience a range of physical health problems and often find health services hard to use. Busy waiting rooms, telephone booking systems, unclear instructions and being asked to describe symptoms on the spot can all be barriers. This makes it especially important that your health care works for you.

Under the Equality Act 2010, NHS and other health services must make reasonable adjustments so that disabled people, including autistic people, are not put at a substantial disadvantage. Adjustments you might ask for include:

- an appointment at a quieter time, or a longer appointment;
- waiting somewhere quieter, or being called when the clinician is ready;
- communicating by email, text or online forms instead of by telephone;
- written information and clear explanations of what will happen; and
- bringing someone with you for support.

**THE NHS REASONABLE ADJUSTMENT FLAG**

The Reasonable Adjustment Flag is a national NHS record in England that shows you need adjustments to your care and can describe what they are. It is usually created by a GP, or by another health or care professional, together with you. You can ask your GP surgery to add one to your record so that other NHS services can see it.

Health and social care providers registered with the Care Quality Commission in England are now required by law to make sure their staff receive training in learning disability and autism. This is known as the Oliver McGowan training. Even so, not every professional will know you are autistic or understand what it means for you, so it is reasonable to tell them and to explain what helps.

PART 4

# Your mental health

IN THIS PART

- Anxiety and depression
- Talking therapies and how they can be adapted
- Medication
- Finding the right professional
- Thoughts of suicide and self-harm

## Anxiety and depression

Anxiety and depression are common among autistic adults. Research that pooled many studies estimated that at any one time about 27 in every 100 autistic adults are living with an anxiety disorder and about 23 in every 100 with depression, and that over a lifetime these figures rise to about 42 and 37 in every 100. Many of these studies involved people already in contact with services, so the figures may be higher than in the wider autistic population, but it is clear that these difficulties are common.

There are understandable reasons for this, including the daily effort of living in environments that do not suit you, experiences of being misunderstood, excluded or bullied, uncertainty and change, sensory overload and loneliness. Being autistic does not mean you will inevitably become anxious or depressed, and when these difficulties do arise, they can be treated.

Anxiety in autistic people can look different from how it is often described. It might show up as a greater need for routine and control, more meltdowns or shutdowns, avoiding places or people, physical symptoms, or finding it harder to speak. Depression might show up as withdrawal, loss of interest even in special interests, exhaustion, or changes in sleep and appetite.

## Talking therapies and how they can be adapted

Psychological therapies, particularly forms of cognitive behavioural therapy (CBT), can help autistic adults with anxiety and depression. A large review of trials found that some forms of CBT and mindfulness-based therapy may be helpful for autistic people without a learning disability, while also finding that more and better research is needed. One trial found that a mindfulness programme adapted for autistic adults reduced depression, anxiety and repetitive worrying.

UK guidance recommends that therapy for autistic adults is adapted. These adaptations include:

- a more concrete and structured approach, with more written and visual information;
- a greater focus on changing what you do, rather than only on changing how you think;
- making rules and expectations explicit, and explaining the reasons for them;
- using plain English, and avoiding too much metaphor, ambiguity or hypothetical questions;
- involving a family member, partner or supporter, if you would like this; and
- regular breaks, and using your interests in therapy where possible.

At UMID we believe good therapy for autistic adults should be neuroaffirming. By this we mean that it respects autism as part of who you are, does not try to make you appear less autistic, and focuses on your wellbeing, your goals and the difficulties that matter to you.

**NHS TALKING THERAPIES**

In England, you can refer yourself to NHS Talking Therapies for help with anxiety and depression without seeing your GP first. You need to be registered with a GP and usually aged 18 or over (16 or over in some areas). It is free. When you refer yourself, it is reasonable to say that you are autistic and to ask for the adaptations listed above, including how appointments are arranged and whether sessions can be in person, by video or by phone.

## Medication

No medication treats autism itself. Medication can, however, help with conditions that sometimes occur alongside autism, such as depression, anxiety, ADHD or sleep problems, in the same way that it helps other people. UK guidance recommends that these conditions are treated in line with the usual NHS guidance for each condition, with adjustments for autistic people where needed.

UK guidance notes that autistic people may respond to medication in less predictable ways and may be more sensitive to it. For this reason, prescribers often start with a low dose, increase it gradually and review it carefully with you. If you notice unexpected effects, please tell your doctor or pharmacist. Some medicines should not be stopped suddenly, so ask for advice before stopping. If you have a severe reaction, seek urgent medical help.

## Finding the right professional

If you are looking for therapy privately, or through your employer, it helps to know how to check someone's qualifications.

- **Clinical psychologists and counselling psychologists** are regulated by the Health and Care Professions Council (HCPC). These titles are protected by law, and you can check that someone is registered on the HCPC website at www.hcpc-uk.org.
- **Cognitive behavioural therapists** can be accredited by the British Association for Behavioural and Cognitive Psychotherapies (BABCP), which keeps a register of accredited practitioners. Its website is www.babcp.com.
- **Counsellors and psychotherapists** may be members of professional bodies that keep registers of their members.
- **Coaches**, including neurodiversity or autism coaches, can offer practical help with organisation, work and planning, and some people find coaching very useful. Coaching is not a regulated profession in the UK, however, so it is worth asking about a coach's training, experience with autistic adults, and whether they belong to a professional body.

Whoever you see, it is reasonable to ask about their experience of working with autistic adults and how they adapt their approach.

## Thoughts of suicide and self-harm

We want to say this clearly because it matters. Research has found that thoughts of suicide and self-harm are more common among autistic adults than in the general population. Researchers have linked this with experiences such as having support needs that are not being met, masking, self-harm, and anxiety and depression. Many of these can change with the right understanding and support.

If you have thoughts of ending your life or harming yourself, please tell someone you trust and seek help. You deserve support, and it is available. The urgent help routes in Part 1 are there at any time of day or night, and your GP can help you get ongoing support. If you are supporting someone who has told you about these thoughts, take them seriously, stay with them if they are in immediate danger, and help them contact one of these services.

PART 5

# Relationships, identity and community

IN THIS PART

- Deciding whether, when and how to share your diagnosis
- Family, friends and partners
- Finding community
- Information for partners and family members

## Deciding whether to share your diagnosis

Whether you tell anyone about your diagnosis, and who, is your choice. There is no single right answer, and you can take as long as you need. Some people tell everyone straight away. Others tell a few trusted people, or no one for a while. Many people share with different people in different ways and at different times.

Sharing can help others understand you and make it easier to ask for what you need. It can also feel risky, because not everyone understands autism, and some people may react with surprise, disbelief or unhelpful assumptions. It may help to think about what you hope will change by telling someone, and what you would like them to do differently.

If you decide to tell someone, some people find it helpful to:

- explain what being autistic means **for you**, rather than describing autism in general;
- give one or two concrete examples of what helps, such as “I find it easier to talk things through by message” or “I need some quiet time after work before I can chat”;
- offer a reliable source of information, such as the National Autistic Society website; and
- choose a calm time and a setting that suits you, or write it down if that is easier.

Information about sharing your diagnosis at work or in education is in Part 6.

## Family, friends and partners

A diagnosis can help the people close to you understand experiences that may have puzzled or frustrated both of you, such as why some social events leave you drained, why changes of plan are hard, or why you need time alone. It can also open up honest conversations about how you each communicate and what you each need.

In close relationships, it often helps to agree practical things together: how you will let each other know when you need space, how plans and changes will be communicated, and how you will handle disagreements in a way that works for both of you. Remember the double empathy idea from Part 2. Misunderstandings between autistic and non-autistic people usually run in both directions, and both people can learn to meet in the middle.

## Finding community

Many autistic adults find that meeting other autistic people, whether online or in person, is one of the most helpful things they do after diagnosis. People often describe feeling understood without having to explain themselves, a sense of belonging, and practical ideas from others who have faced similar situations. UK guidance encourages autistic adults to consider support groups and self-help groups.

Not everyone wants or enjoys groups, and that is perfectly fine. You might prefer a single friendship, an online forum, or a group built around an interest rather than around autism. Options include:

- the National Autistic Society's online community and its local and online branches;
- groups run by local autistic-led organisations, which the National Autistic Society's services directory can help you find; and
- clubs, societies and online communities based on your interests.

## For partners and family members

If you are the partner, parent, adult child or friend of an autistic adult, this section is for you.

Learning about autism can help you understand the person you care about and your relationship. It is worth remembering that the autistic person is the expert on their own experience, and that the most helpful thing is often to ask what they need rather than assume. Respect their choices about who is told and how involved they would like you to be.

Supporting someone can also be tiring, and your own wellbeing matters. UK guidance says that family members, partners and carers of autistic adults should be offered an assessment of their own needs, and in England you can ask your local council for a carer's assessment. The following organisations offer support specifically for families:

- **Autism Central** is a national peer education programme for families and support networks of autistic people of all ages in England, commissioned by the NHS. It offers resources, one-to-one coaching from people with lived or family experience, and online group sessions.
- **The National Autistic Society** offers information for families, and its Parent to Parent service offers emotional support by telephone to parents and carers of autistic children and adults, from trained volunteers who are parents of autistic people themselves.
- **Carers UK** offers advice on carer's assessments, benefits and looking after yourself.

Contact details are in Part 7.

PART 6

# Work, study, money and your rights

IN THIS PART

- Your rights under the Equality Act 2010
- Adjustments and support at work
- Support in further and higher education
- Benefits and practical support
- Driving
- Getting around and being understood in public places
- National policy on autism

## Your rights under the Equality Act 2010

In most cases, autism meets the legal definition of disability in the Equality Act 2010, whether or not you think of yourself as disabled. This means you are protected from discrimination at work, in education, and when using services such as shops, banks, transport and health care.

It also means that employers, education providers and service providers have a duty to make reasonable adjustments. These are changes that remove or reduce a disadvantage you face because you are autistic. What counts as reasonable depends on the situation, including the cost and practicality of the change and the size and resources of the organisation.

You do not need to use the word “disabled” to be protected. You also do not have to tell anyone that you are autistic. However, an employer is only required to make adjustments if it knows, or could reasonably be expected to know, that you are disabled, so sharing your diagnosis is often the first step to getting adjustments in place.

## Adjustments and support at work

Adjustments that many autistic adults find helpful at work include:

- written instructions, clear priorities and agreed deadlines;
- advance notice of changes, meetings and agendas;
- a quieter workspace, noise-reducing headphones, or a desk away from busy areas;
- flexibility over working hours, working from home or breaks;
- adjustments to interviews, such as questions in advance or a practical task instead of a conversation;
- a named person to go to with questions; and
- communication by email or message instead of unplanned phone calls.

If you would like adjustments, it usually helps to make the request in writing, explain briefly what you find difficult, and suggest what would help. Your report from UMID may help, but you do not have to share the whole report. The advisory service Acas and the National Autistic Society both publish clear guidance on reasonable adjustments.

FLEXIBLE WORKING

All employees in Great Britain have the legal right to request flexible working from their first day in a job. This can include changes to your hours, start and finish times, working days or where you

work. Your employer must deal with the request in a reasonable way and can refuse only if it has a good business reason.

**Access to Work** is a government scheme that can help if you have a disability or health condition that affects your work. It can provide a grant towards practical support, such as specialist equipment or software, a job coach or support worker, and help with travel to work if you cannot use public transport. It also offers support with managing your mental health at work. An Access to Work grant does not affect other benefits and does not have to be paid back. It does not pay for the reasonable adjustments your employer is already required to make. Access to Work covers people who live and work in England, Scotland or Wales, and self-employed people can apply too, subject to the scheme's conditions. Northern Ireland has its own scheme. You can find out more and apply at www.gov.uk/access-to-work.

## Support in further and higher education

Colleges and universities must also make reasonable adjustments. These might include extra time or a separate room for exams, recorded lectures, a named contact, flexibility with deadlines, or help with organisation and planning. Contact your college or university's disability or student support service as early as possible.

If you live in England and are studying for a higher education course in the UK, you may be able to get **Disabled Students' Allowance (DSA)** through Student Finance England. Students from Scotland, Wales and Northern Ireland apply through their own student finance body. This helps with study-related costs you have because of a disability, including autism and mental health conditions. It is based on your individual needs rather than your household income, and it does not have to be paid back. Details are at www.gov.uk/disabled-students-allowance-dsa.

## Benefits and practical support

Whether you are entitled to financial or practical support depends on how autism and any other conditions affect your daily life, rather than on the diagnosis itself.

- **Personal Independence Payment (PIP)** helps with extra living costs if you have a long-term condition or disability and have difficulty with everyday tasks or getting around. It is not means-tested, so you can get it while working or having savings. The assessment looks at how your condition affects you, including whether you can do tasks safely, how long they take and whether you need help. PIP is available in England and Wales, and Northern Ireland has its own PIP service. If you live in Scotland, the equivalent benefit is Adult Disability Payment (www.mygov.scot/adult-disability-payment). The rules for benefits can change, so please check www.gov.uk/pip for current information.
- **A needs assessment from your local council** looks at the difficulties you are having with everyday life and what support or help you might be able to get. You can ask your council for one directly.
- **Advice on benefits** is available free from Citizens Advice, and the National Autistic Society has detailed guidance on money and benefits for autistic people.

## Driving

Being autistic does not in itself stop you driving. You must tell the Driver and Vehicle Licensing Agency (DVLA) if you have autism and it affects your ability to drive safely. If it does not affect your driving, you do not need to tell the DVLA. If you are unsure, ask your doctor. You can be fined up to £1,000 if you do not tell the DVLA about a condition that affects your ability to drive safely, and you may be prosecuted if you are involved in an accident as a result. Details are at www.gov.uk/autism-and-driving.

## Getting around and being understood in public places

- **Blue Badge.** Some people with non-visible conditions, including some autistic people, are eligible for a Blue Badge for parking. In England, the criteria include struggling severely to plan or follow a journey, or frequently becoming extremely anxious or fearful of public or open spaces. Blue Badges are issued by local councils.
- **The Hidden Disabilities Sunflower.** Some autistic people choose to wear a sunflower lanyard, badge or card to let staff know discreetly that they have a non-visible disability and may need more time, help or understanding. Many shops, transport providers and airports recognise it. Wearing it is entirely your choice.

## National policy on autism

The Autism Act 2009 requires the government to have a strategy for improving the lives of autistic adults in England, supported by statutory guidance for councils and the NHS. The national strategy that covered 2021 to 2026 came to an end in July 2026. A new strategy is expected, but it had not been published when this guide was written. You do not need to know the detail of national policy to get support, but it explains why councils and NHS services are expected to plan services for autistic people.

PART 7

# Further help and reading

IN THIS PART

- UK organisations for autistic adults and their families
- UK autistic-led organisations
- International autistic-led organisations
- Books we recommend
- Official information

All the organisations below were checked as active in September 2026. Addresses can change, so if a link does not work, please search for the organisation's name.

## UK organisations

- **National Autistic Society**, a UK charity for autistic people and their families. Its website has detailed advice on almost every topic in this guide, an online community, local and online branches, and a services directory for finding support near you. www.autism.org.uk
- **Autistica**, a UK autism research charity. It publishes research-based information on autism and mental health, a tips hub for everyday life, and Molehill Mountain, an app developed with King's College London to help autistic people understand and manage anxiety. www.autistica.org.uk
- **Autism Central**, the national peer education programme for families and support networks of autistic people of all ages in England, commissioned by the NHS and delivered by Anna Freud. www.autismcentral.nhs.uk
- **Mind**, the mental health charity, which offers information on mental health, crisis planning and local support. www.mind.org.uk
- **Carers UK**, which offers advice for partners and family members on carer's assessments, benefits, working while caring and looking after yourself. www.carersuk.org
- **Citizens Advice**, which offers free, confidential advice on benefits, work, money and legal rights. www.citizensadvice.org.uk
- **Acas**, which gives free, impartial advice on workplace rights, including reasonable adjustments. www.acas.org.uk

## UK autistic-led organisations

These organisations are run by and for autistic people and work across the UK.

- **Autistic UK**, an organisation led by autistic people for autistic people, which campaigns for autistic people's rights and equal access to services. www.autisticuk.org
- **National Autistic Taskforce**, a UK-wide body run by autistic people, which works to give autistic adults more say over their own lives and support, particularly those with the highest support needs. It publishes An Independent Guide to Quality Care for Autistic People, written by autistic people, which describes what good care and support look like. nationalautistictaskforce.org.uk
- **Autistic Parents UK**, a national charity led by autistic people for autistic parents. It offers peer support, including online groups and one-to-one support from trained autistic peer supporters, as well as events, webinars and training. www.autisticparentsuk.org

## International autistic-led organisations

These organisations are based in the United States. Their information about services and law does not apply in the UK, but their writing on autistic identity and experience may still be helpful.

- **Autistic Self Advocacy Network (ASAN)**, an organisation run by and for autistic people, which publishes accessible resources on self-advocacy and neurodiversity. autisticadvocacy.org
- **Autistic Women and Nonbinary Network (AWN)**, which supports autistic women, girls and non-binary people through resources, personal stories and community. awnnetwork.org
- **Monotropism**, a website explaining the monotropism theory of autistic attention and housing the work of Dr Dinah Murray, one of its originators. monotropism.org

## Books

These books are suggestions rather than endorsements. Different books suit different readers, and you may find some ideas helpful and others less so.

- **Autism in Adults** by Luke Beardon (2021). A short, readable and affirming introduction for adults who have recently been diagnosed and the people close to them.
- **Avoiding Anxiety in Autistic Adults** by Luke Beardon (2021). Practical ideas for understanding and reducing anxiety, with guidance for family, friends and colleagues.
- **Unmasking Autism: Discovering the New Faces of Neurodiversity** by Devon Price (2022). Combines personal experience and research to explore masking and how to live more authentically, particularly suited to adults diagnosed later in life.
- **Women and Girls on the Autism Spectrum** by Sarah Hendrickx (second edition, 2024). Explores how autism is experienced by women and girls across the lifespan, useful for autistic women and those who support them.
- **Is This Autism? A Guide for Clinicians and Everyone Else** by Donna Henderson, Sarah Wayland and Jamell White (2023). Explains the many ways autism can present, particularly in people who camouflage, with quotes from over 100 autistic contributors. Helpful for readers and partners who want a deeper understanding.
- **NeuroTribes: The Legacy of Autism and the Future of Neurodiversity** by Steve Silberman (2015). A detailed history of how autism has been understood, suited to readers who enjoy longer non-fiction.

## Official information

- **NHS: Autism**, including pages on adult life and where to get support. www.nhs.uk/conditions/autism
- **GOV.UK: Access to Work.** www.gov.uk/access-to-work
- **GOV.UK: Personal Independence Payment.** www.gov.uk/pip
- **GOV.UK: Autism spectrum disorder and driving.** www.gov.uk/autism-and-driving
- **GOV.UK: Find your local council**, for needs assessments, carer's assessments and the Blue Badge. www.gov.uk/find-local-council

# Words used in this guide

| Word | What it means |
|---|---|
| Alexithymia | Difficulty recognising, naming or describing your own emotions, or telling emotions apart from physical sensations. |
| Autistic burnout | A term used by autistic people and researchers for a period of deep exhaustion, loss of usual skills and increased sensitivity, often after a long period of stress or masking. It is not a formal diagnosis. |
| Carer's assessment | An assessment by your local council of the needs of someone who cares for another person, to see what support might help them. |
| Co-occurring condition | A condition that a person has as well as autism, such as ADHD or anxiety. |
| Cognitive behavioural therapy (CBT) | A talking therapy that looks at the links between thoughts, feelings and actions, and uses practical steps to make changes. |
| Double empathy problem | The idea that misunderstandings between people with very different communication styles, such as autistic and non-autistic people, run in both directions. |
| Equality Act 2010 | The law in Great Britain that protects people from discrimination, including because of disability. |
| Identity-first language | Describing someone as an "autistic person" rather than a "person with autism". |
| Interoception | The sense that tells you what is happening inside your body, such as hunger, thirst, pain or temperature. |
| Masking (or camouflaging) | Hiding or compensating for autistic traits in order to fit in or avoid negative reactions. |
| Meltdown | An intense response to overwhelm, during which a person temporarily loses control of how they are behaving. |
| Monotropism | A theory that autistic attention tends to focus deeply on a small number of things at once. |
| Needs assessment | An assessment by your local council of the support an adult may need in everyday life. |
| Neuroaffirming | An approach that respects autism as part of who a person is and does not try to make them appear less autistic. |

| Word | What it means |
|---|---|
| Neurodivergent | Having a brain that works differently from what is considered typical, for example because of autism or ADHD. |
| NICE | The National Institute for Health and Care Excellence, which publishes guidance on health and care in England. |
| Proprioception | The sense of where your body and limbs are in space. |
| Reasonable adjustment | A change that an employer, college or service must make, where reasonable, so that a disabled person is not put at a substantial disadvantage. |
| Sensory differences | Being more or less sensitive than other people to things such as sound, light, touch, taste, smell, movement or internal body signals. |
| Shutdown | A quieter response to overwhelm, in which a person withdraws and may find it hard to speak or respond. |
| Stimming | Repetitive movements or sounds, such as rocking, tapping or humming, that often help with regulation and focus. |
| Vestibular sense | The sense of balance and movement. |

# Where this information comes from

This guide draws on UK clinical guidance, official government and NHS information, advice from leading UK autism organisations, and published research. Where research is limited or still developing, we have said so. The main sources are listed below. Research articles can be found by searching for their titles online, and many are free to read.

**Guidance and official information**


1. National Institute for Health and Care Excellence (NICE). Autism spectrum disorder in adults: diagnosis and management (CG142). Published 2012, last updated 2021. www.nice.org.uk/guidance/cg142
2. National Institute for Health and Care Excellence (NICE). Autism quality standard (QS51). 2014. www.nice.org.uk/guidance/qs51
3. NHS. Autism, including "What is autism?", "Adult life and autism" and "Help and support". Accessed September 2026. www.nhs.uk/conditions/autism
4. NHS. Where to get urgent help for mental health. Page last reviewed 2023, accessed September 2026. www.nhs.uk/nhs-services/mental-health-services/where-to-get-urgent-help-for-mental-health
5. NHS. NHS Talking Therapies for anxiety and depression. www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies
6. NHS England Digital. Reasonable Adjustment Flag. digital.nhs.uk/services/reasonable-adjustment-flag
7. Department of Health and Social Care. The Oliver McGowan code of practice on statutory training in learning disability and autism. Final version September 2025. www.gov.uk/government/publications/oliver-mcgowan-code-of-practice
8. Department of Health and Social Care and Department for Education. The national strategy for autistic children, young people and adults: 2021 to 2026. 2021. www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026
9. UK Parliament, House of Lords Autism Act 2009 Committee. "Time to deliver: The Autism Act 2009 and the new autism strategy". Report published November 2025, government response January 2026, debated June 2026. committees.parliament.uk/committee/770/autism-act-2009-committee
10. Equality Act 2010, section 20 (duty to make adjustments). www.legislation.gov.uk/ukpga/2010/15/section/20
11. Acas. Reasonable adjustments at work. www.acas.org.uk/reasonable-adjustments
12. GOV.UK. Access to Work: get support if you have a disability or health condition. www.gov.uk/access-to-work
13. GOV.UK. Flexible working. www.gov.uk/flexible-working
14. GOV.UK. Disabled Students' Allowance. www.gov.uk/disabled-students-allowance-dsa
15. GOV.UK. Personal Independence Payment. www.gov.uk/pip; and Scottish Government. Adult Disability Payment. www.mygov.scot/adult-disability-payment
16. Department for Transport. Can I get a Blue Badge? (England). www.gov.uk/government/publications/blue-badge-can-i-get-one
17. Driver and Vehicle Licensing Agency. Autism spectrum disorder and driving. www.gov.uk/autism-and-driving

18. Health and Care Professions Council. The professions we regulate (protected titles). www.hcpc-uk.org/about-us/who-we-regulate/the-professions
19. National Autistic Society. Advice and guidance on masking, sensory processing, autistic fatigue and burnout, meltdowns, and reasonable adjustments at work. www.autism.org.uk/advice-and-guidance
20. Autistica. What is autism?, and Molehill Mountain. www.autistica.org.uk

**Research**

21. Hollocks MJ and colleagues. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. Psychological Medicine, 2019. doi.org/10.1017/S0033291718002283
22. Lai MC and colleagues. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. The Lancet Psychiatry, 2019. doi.org/10.1016/S2215-0366(19)30289-5
23. Cook J, Hull L, Crane L, Mandy W. Camouflaging in autism: a systematic review. Clinical Psychology Review, 2021. doi.org/10.1016/j.cpr.2021.102080
24. Hull L and colleagues. Is social camouflaging associated with anxiety and depression in autistic adults? Molecular Autism, 2021. doi.org/10.1186/s13229-021-00421-1
25. Raymaker DM and colleagues. Defining autistic burnout. Autism in Adulthood, 2020. doi.org/10.1089/aut.2019.0079
26. Ali D and colleagues. Burnout as experienced by autistic people: a systematic review. Clinical Psychology Review, 2025. doi.org/10.1016/j.cpr.2025.102669
27. Crompton CJ and colleagues. Autistic peer-to-peer information transfer is highly effective. Autism, 2020. doi.org/10.1177/1362361320919286
28. Milton D, Gurbuz E, Lopez B. The “double empathy problem”: ten years on. Autism, 2022. doi.org/10.1177/13623613221129123
29. Kenny L and colleagues. Which terms should be used to describe autism? Perspectives from the UK autism community. Autism, 2016. doi.org/10.1177/1362361315588200
30. Kinnaird E, Stewart C, Tchanturia K. Investigating alexithymia in autism: a systematic review and meta-analysis. European Psychiatry, 2019. doi.org/10.1016/j.eurpsy.2018.09.004
31. Murray D, Lesser M, Lawson W. Attention, monotropism and the diagnostic criteria for autism. Autism, 2005. doi.org/10.1177/1362361305051398
32. Linden A and colleagues. Benefits and harms of interventions to improve anxiety, depression, and other mental health outcomes for autistic people: a systematic review and network meta-analysis of randomised controlled trials. Autism, 2023. doi.org/10.1177/13623613221117931
33. Spek AA, van Ham NC, Nyklicek I. Mindfulness-based therapy in adults with an autism spectrum disorder: a randomized controlled trial. Research in Developmental Disabilities, 2013. doi.org/10.1016/j.ridd.2012.08.009
34. Newell V and colleagues. A systematic review and meta-analysis of suicidality in autistic and possibly autistic people without co-occurring intellectual disability. Molecular Autism, 2023. doi.org/10.1186/s13229-023-00544-7
35. French B and colleagues. Adverse outcomes for autistic people: an umbrella review of mental health, physical health, social and lifestyle domains. Frontiers in Psychiatry, 2026. doi.org/10.3389/fpsyt.2026.1702822
36. Fan F and colleagues. Physical exercise therapy for autism spectrum disorder: a scoping review of systematic reviews. Frontiers in Public Health, 2026. doi.org/10.3389/fpubh.2026.1907318
37. Cassidy S and colleagues. Risk markers for suicidality in autistic adults. Molecular Autism, 2018. doi.org/10.1186/s13229-018-0226-4

38. Malik-Soni N and colleagues. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatric Research, 2022. doi.org/10.1038/s41390-021-01465-y

**Services and organisations**

39. Campaign Against Living Miserably (CALM). Suicide prevention helpline. Accessed September 2026. www.thecalmzone.net/suicide-prevention-helpline
40. Autistic UK. Home page ("Led by autistic people for autistic people"). Accessed September 2026. www.autisticuk.org
41. National Autistic Taskforce. Home page, FAQs and An Independent Guide to Quality Care for Autistic People (2019). Accessed September 2026. nationalautistictaskforce.org.uk
42. Autistic Parents UK. Home page and About. Accessed September 2026. www.autisticparentsuk.org

AT THE BACK

# Ownership and use of this guide



Enquiries: umid@umid.co.uk

The latest version of this guide is always available at

**umid.co.uk/resources**



UMID is the trading name of Umid Healthcare Limited, registered in England (14498359). Registered with the Care Quality Commission, provider ID 1-18243073360. Enquiries: umid@umid.co.uk