

Managing autism spectrum disorder in adults

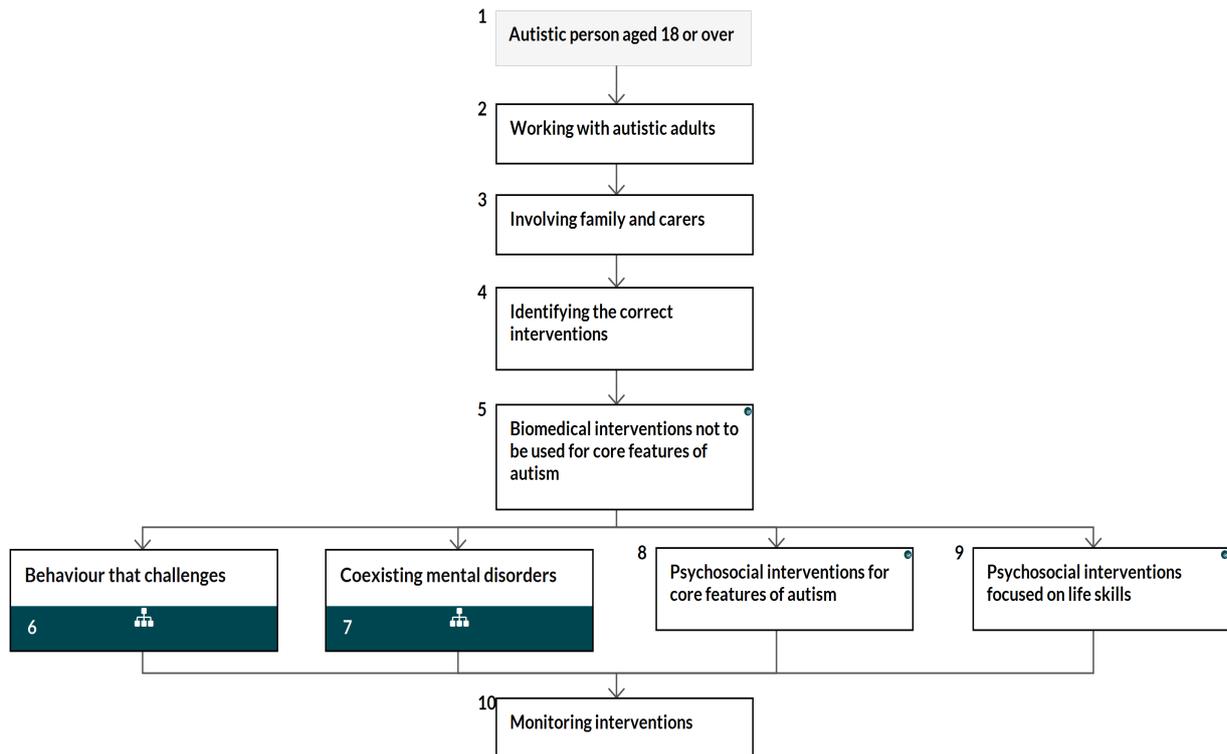
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/autism-spectrum-disorder>

NICE Pathway last updated: 20 August 2021

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Autistic person aged 18 or over

No additional information

2 Working with autistic adults

All staff working with autistic adults should:

- work in partnership with autistic adults and, where appropriate, with their families, partners and carers
- offer support and care respectfully
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

All staff working with autistic adults should have an understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of the social and physical environment.

All staff working with autistic adults should be sensitive to issues of sexuality, including asexuality and the need to develop personal and sexual relationships. In particular, be aware that problems in social interaction and communication may lead to the autistic person misunderstanding another person's behaviour or to their possible exploitation by others.

Health and social care professionals

All health and social care professionals providing care and support for autistic adults should have a broad understanding of the:

- nature, development and course of autism
- impact on personal, social, educational and occupational functioning
- impact of and interaction with the social and physical environment
- impact on and interaction with other coexisting mental and physical disorders and their management
- potential discrepancy between intellectual functioning as measured by IQ and adaptive functioning as reflected, for example, by difficulties in planning and performing activities of daily living including education or employment.

All health and social care professionals providing care and support for autistic adults should:

- aim to foster the person's autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format (including various visual, verbal and aural, easy read and different colour and font formats)
- consider whether the person may benefit from access to a trained advocate.

All health and social care professionals providing care and support for autistic adults and their families, partners and carers should:

- ensure that they are easily identifiable (for example, by producing or wearing appropriate identification) and approachable
- clearly communicate their role and function
- address the person using the name and title they prefer
- clearly explain any clinical language and check that the autistic person understands what is being said
- take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters (someone who does not have a personal relationship with the autistic person) if required.

All health and social care professionals providing care and support for autistic adults and their families, partners and carers should ensure that they are:

- familiar with recognised local and national sources (organisations and websites) of information and/or support for autistic people
- able to discuss and advise on how to access and engage with these resources.

Encourage autistic adults to participate in self-help or support groups or access one-to-one support and provide support so that they can attend meetings and engage in the activities.

All health and social care professionals providing care and support for autistic adults should:

- be aware of under-reporting and under-recognition of physical disorders in autistic people
- be vigilant for unusual likes and dislikes about food and/or lack of physical activity
- offer advice about the beneficial effects of a healthy diet and exercise taking into account any hyper- and/or hypo-sensory sensitivities; if necessary, support referral to a GP or dietician.

See [the NICE Pathway on people's experience in adult social care services](#).

3 Involving family and carers

Discuss with autistic adults if and how they want their families, partners or carers to be involved in their care. During discussions, take into account any implications of the Mental Capacity Act (2005) and any communication needs the person may have.

If the autistic person wants their family, partner or carer(s) to be involved, encourage this involvement and:

- negotiate between the autistic person and their family, partner or carer(s) about confidentiality and sharing of information on an ongoing basis
- explain how families, partners and carers can help support the autistic person and help with care plans
- make sure that no services are withdrawn because of involvement of the family, partner or carer(s), unless this has been clearly agreed with both the autistic person and their family, partner or carer(s).

Give all families, partners and carer(s) (whether or not the person wants them to be involved in their care) verbal and written information about:

- autism and its management
- local support groups and services specifically for families, partners and carers
- their right to a carer's assessment of their own physical and mental health needs, and how to access this (see [the NICE Pathway on supporting adult carers](#)).

If an autistic person does not want their family, partner or carer(s) to be involved in their care:

- give the family, partner or carer(s) verbal and written information about who they can contact if they are concerned about the person's care
- bear in mind that autistic people may be ambivalent or negative towards their family or partner. This may be for many different reasons, including a coexisting mental disorder or prior experience of violence or abuse.

4 Identifying the correct interventions

When discussing and deciding on interventions with autistic adults, consider:

- their experience of, and response to, previous interventions

- the nature and severity of their autism
- the extent of any associated functional impairment arising from the autism, a learning disability or a mental or physical disorder
- the presence of any social or personal factors that may have a role in the development or maintenance of any identified problem(s)
- the presence, nature, severity and duration, of any coexisting disorders
- the identification of predisposing and possible precipitating factors that could lead to crises if not addressed.

When discussing and deciding on care and interventions with autistic adults, take into account the:

- increased propensity for elevated anxiety about decision-making in autistic people
- greater risk of altered sensitivity and unpredictable responses to medication
- environment, for example whether it is suitably adapted for autistic people, in particular those with hyper- and/or hypo-sensory sensitivities (see [the physical environment](#))
- presence and nature of hyper- and/or hypo-sensory sensitivities and how these might impact on the delivery of the intervention
- importance of predictability, clarity, structure and routine for autistic people
- nature of support needed to access interventions.

When discussing and deciding on interventions with autistic adults, provide information about:

- the nature, content and duration of any proposed intervention
- the acceptability and tolerability of any proposed intervention
- possible interactions with any current interventions and possible side effects
- the implications for the continuing provision of any current interventions.

When deciding on options for pharmacological interventions for behaviour that challenges or coexisting mental disorders in autistic adults:

- be aware of the potential for greater sensitivity to side effects and idiosyncratic responses in autistic people, **and**
- consider starting with a low dose.

5

Biomedical interventions not to be used for core features of autism

Do not use anticonvulsants for the management of core features of autism in adults.

Do not use chelation for the management of core features of autism in adults.

Do not use the following interventions for the management of core features of autism in adults:

- exclusion diets (such as gluten- or casein-free and ketogenic diets)
- vitamins, minerals and dietary supplements (such as vitamin B6 or iron supplementation).

Do not use drugs specifically designed to improve cognitive functioning (for example, cholinesterase inhibitors) for the management of core features of autism or routinely for associated cognitive or behavioural problems in adults.

Do not use oxytocin for the management of core features of autism in adults.

Do not use secretin for the management of core features of autism in adults.

Do not use testosterone regulation for the management of core features of autism in adults.

Do not use hyperbaric oxygen therapy for the management of core features of autism in adults.

Do not use antipsychotic medication for the management of core features of autism in adults.

Do not use antidepressant medication for the routine management of core features of autism in adults.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

6. Treating the core features of autism: medication

6 Behaviour that challenges

[See Autism spectrum disorder / Behaviour that challenges in autistic adults](#)

7 Coexisting mental disorders

[See Autism spectrum disorder / Coexisting mental disorders in autistic adults](#)

8 Psychosocial interventions for core features of autism

For autistic adults without a learning disability or with a mild to moderate learning disability, who have identified problems with social interaction, consider:

- a group-based social learning programme focused on improving social interaction
- an individually delivered social learning programme for people who find group-based activities difficult.

Social learning programmes to improve social interaction should typically include:

- modelling
- peer feedback (for group-based programmes) or individual feedback (for individually delivered programmes)
- discussion and decision-making
- explicit rules
- suggested strategies for dealing with socially difficult situations.

Do not provide facilitated communication for autistic adults.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

5. Treating the core features of autism: psychosocial interventions

9 Psychosocial interventions focused on life skills

For autistic adults of all ranges of intellectual ability, who need help with activities of daily living, consider a structured and predictable training programme based on behavioural principles.

Structured leisure activity programmes

For autistic adults without a learning disability or with a mild to moderate learning disability, who are socially isolated or have restricted social contact, consider:

- a group-based structured leisure activity programme
- an individually delivered structured leisure activity programme for people who find group-based activities difficult.

A structured leisure activity programme should typically include:

- a focus on the interests and abilities of the participant(s)
- regular meetings for a valued leisure activity
- for group-based programmes, a facilitator with a broad understanding of autism to help integrate the participants
- the provision of structure and support.

Anger management interventions

For autistic adults without a learning disability or with a mild to moderate learning disability, who have problems with anger and aggression, offer an anger management intervention, adjusted to the needs of autistic adults.

Anger management interventions should typically include:

- functional analysis of anger and anger-provoking situations
- coping-skills training and behaviour rehearsal
- relaxation training
- development of problem-solving skills.

Anti-victimisation interventions

For autistic adults without a learning disability or with a mild learning disability, who are at risk of victimisation, consider anti-victimisation interventions based on teaching decision-making and problem-solving skills.

Anti-victimisation interventions should typically include:

- identifying and, where possible, modifying and developing decision-making skills in situations associated with abuse
- developing personal safety skills.

Employment programmes

For autistic adults without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme.

An individual supported employment programme should typically include:

- help with writing CVs and job applications and preparing for interviews
- training for the identified work role and work-related behaviours
- carefully matching the autistic person with the job
- advice to employers about making reasonable adjustments to the workplace
- continuing support for the person after they start work
- support for the employer before and after the person starts work, including autism awareness training.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

5. Treating the core features of autism: psychosocial interventions

10 Monitoring interventions

For any intervention used in autistic adults, there should be a regular review of:

- the benefits of the intervention, where feasible using a formal rating of the target behaviour(s)
- any adverse events
- specific monitoring requirements of pharmacological interventions as highlighted by the summary of product characteristics
- adherence to the intervention.

Glossary

Behavioural principles

(ideas, such as reinforcement and function of behaviour, that underlie behavioural therapies and underpin many interventions teaching adaptive skills for community living for autistic people, including those with challenging behaviour)

Chelation

(a procedure that involves using one or more substances (chelating agents) to remove materials that are toxic, including heavy metals such as mercury, from the body)

Easy read

(an accessible format for written communication designed for people with a learning disability; it uses simple jargon-free language, short sentences and illustrations)

Facilitated communication

(a therapeutic intervention whereby a facilitator supports the hand or arm of an autistic person while using a keyboard or other devices with the aim of helping the person to develop pointing skills and to communicate)

Functional analysis

(a method for understanding the causes and consequences of behaviour and its relationship to particular stimuli, and the function of the behaviour; the function of a particular behaviour can be analysed by typically identifying (1) the precursor or trigger of the behaviour, (2) the behaviour itself, and (3) the consequence of the behaviour)

Hyper- and/or hypo-sensory sensitivities

(being over-sensitive (hyper-sensitive) or under-sensitive (hypo-sensitive) to sound, light, colour, smell or taste, which can cause anxiety or even pain in an autistic person)

Modelling

(a technique used in behavioural therapy that utilises video and other media; the service user observes target behaviour on the video or computer screen, and repeats it)

Learning disability

(lower intellectual ability (usually defined as an IQ of less than 70) that leads to problems in learning, developing new skills, communication and carrying out daily activities. Learning disability severities are defined by the following IQ scores: mild = 50–69, moderate = 35–49 and severe = 20–34; a person with a mild to moderate learning disability may only need support in certain areas; however, a person with a moderate to severe learning disability may have no speech or limited communication, a significantly reduced ability to learn new skills and require support with daily activities such as dressing and eating; learning disabilities are different from 'learning difficulties', like dyslexia, which do not affect intellect. Learning disability is sometimes also called 'intellectual disability')

Sources

Autism spectrum disorder in adults: diagnosis and management (2012 updated 2021) NICE guideline CG142

Your responsibility

Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in

their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.