

The Essential Guide to Anxiety and Autism



RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE
IDENTIFICATION INTERVENTION INCLUSION

Introduction



This leaflet provides the key facts about anxiety and people on the autism spectrum.

It examines the research evidence on the types and causes of anxiety in people on the autism spectrum. It also examines the research evidence on some of the treatments and other forms of support designed to overcome those anxieties

It summarises clinical guidance from the National Institute for Health and Care Excellence (NICE). It also provides links to useful organisations and publications.

Key facts

- Anxiety is a feeling of unease, such as worry or fear, and is very common in people on the autism spectrum
- There are several different types of anxiety that are common in people on the autism spectrum including generalised anxiety, fears and phobias, obsessions and compulsions
- There are a number of underlying factors associated with anxiety in people on the autism spectrum including the need for routine and structure, sensory sensitivities, difficulties with emotional regulation etc.
- Someone's anxiety may become worse under certain situations, such as when a stranger enters the room, they are asked to do something new or they experience unpleasant sensations
- Anxiety may cause some people to shut down altogether, preventing them from interacting with or communicating with other people. Anxiety can also cause some people to develop challenging behaviours – such as anger, aggression or self injury
- There are a number of interventions (treatments, services and other forms of support) designed to overcome or reduce anxiety in people on the autism spectrum. These include psychological approaches, medications, and alternative approaches.
- There is some good evidence to support the use of cognitive behavioural therapy to reduce anxiety in some people on the autism spectrum. There is less good evidence to support the use of other interventions although that does not necessarily mean that they do not work.
- Further research is required to determine if anxiety is a core feature of autism or a related condition that just happens to be very common in people on the autism spectrum.
- Further research is required to identify appropriate assessment and outcome measures for anxiety in people on the autism spectrum.
- Further research is required to replicate and extend research into those interventions which appear to be effective.

What is anxiety?

Anxiety is a feeling of unease, such as worry or fear, that can be mild or severe. Everyone experiences feelings of anxiety at some point in their life. For example, you may feel worried and anxious about sitting an exam or having a medical test. However when you are unable to control your worries and they affect your daily life you may have what doctors call an anxiety disorder.

How many people on the autism spectrum have anxieties?

Research suggests that 40% of people on the autism spectrum have significant levels of anxiety or at least one anxiety disorder, although the percentage may actually be much higher.

What anxieties do people on the autism spectrum have?

Some children on the autism spectrum eventually grow out of their anxieties, just like other children do. Unfortunately many children with autism do not grow out of their anxieties and the problems remain or become worse in adolescence or adulthood.

Specific types of anxiety disorders common in people on the autism spectrum include:

- generalised anxiety disorder: constant feelings of anxiety about everything
- social anxiety disorder: persistent fear about social situations and being around people
- fears and phobias: fears about specific things, such as a fear of dogs or dentists
- obsessions and compulsions: unwanted, unpleasant thoughts / and repetitive behaviours designed to prevent those obsessive thoughts coming true
- other anxiety disorders include panic disorder, separation anxiety disorder and post traumatic stress disorder.

What factors are associated with anxiety in people on the autism spectrum?

There are a number of underlying factors that may be associated with anxiety in some people on the autism spectrum. Those factors include the need for routine and structure, sensory sensitivities (such as hypersensitivity to noise) difficulties with emotional regulation (being able to understand and control their own feelings), physiological difficulties (such as having heightened arousal) and medical issues (such as gastrointestinal problems).

In addition, some people on the autism spectrum may become more anxious under certain circumstances. For example some individuals may become more anxious

- in social situations, such as when they have to meet strangers
- if their daily routine is changed or they are asked to do something new
- they experience unpleasant sensations, such as hearing a dog bark or seeing flashing lights
- if they are traumatised by unpleasant events, such as teasing or bullying.

What effect does anxiety have on people on the autism spectrum?

Anxiety affects each individual on the autism spectrum in a different way. For example some people may

- shut down altogether, preventing them from interacting with or communicating with other people
- become more rigid in their thought processes and in their insistence upon routines. When they are happy and relaxed, they may become less rigid and fixed
- become controlling or oppositional. They may use tantrums, emotional blackmail, and non-compliance to ensure they avoid the circumstances that could increase anxiety
- become angry, aggressive or violent. This aggression may be turned on others or on themselves in the form of self injury.

What interventions are available?

Most of the interventions (treatments, services and other forms of support) designed to help autistic people deal with anxiety are the same as those designed to help everyone else.

For example, the National Institute for Health and Care Excellence (NICE) recommends that anyone treating a specific type of anxiety in people on the autism spectrum (such as generalised anxiety disorder) should follow existing advice for treating that type of anxiety in other people.

We believe that if you can identify the causes of someone's anxiety (including any underlying risk factors and any specific situations that are likely to make them anxious) you are more likely to be able to help them. We also believe that, whatever you do to prevent or reduce anxiety in an individual, you should do so in a safe, consistent and predictable environment. You should also involve them in any decisions that affect them.

Psychological approaches

There are a number of psychological approaches sometimes used to help people on the autism spectrum with anxiety. These approaches include

- Behavioural tools such as social stories, visual schedules and predictable routines
- Behavioural techniques such as systematic desensitisation towards the cause of the anxiety, modelling of desired behaviours and reinforcement of desired behaviours
- Psychotherapeutic practices such as cognitive behavioural therapy and mindfulness training
- Multi-component programmes (such as social skills groups and vocational skills training) which teach the individual how to deal with specific stressful situations
- Other approaches such as offering a safe, quiet place to go during breaks

Medications

There are a number of medications sometimes used to help people on the autism spectrum with anxiety. These medications include

- Anxiolytics - such as diazepam (Valium) and buspirone (BuSpar)
- Antidepressants - such as citalopram (Celexa) and sertraline (Lustral)
- Anticonvulsants/Mood stabilisers - such as clonazepam (Klonopin) and lamotrigine (Lamictal).

Other approaches

There are numerous other interventions sometimes used to help people on the autism spectrum deal with anxiety. These include acupuncture, assistance dogs, dietary supplements, hypnosis, low arousal techniques, massage, meditation, music therapy, neurofeedback training, physical exercise, relaxation techniques, sensory integrative training, transcranial magnetic stimulation, weighted vests, and yoga.

Please note

Some medications, dietary supplements and other interventions should only be used for a limited period and under the direction of a suitably qualified practitioner, such as a GP or a dietician. Some medications and supplements have significant side effects or interactions with other substances. Some medications and supplements can actually make anxiety worse. (Please see our website for details.)

National Institute for Health and Care Excellence

The National Institute for Health and Care Excellence (NICE) is a UK government body which supports healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money.

NICE guidance on anxiety in adults on the autism spectrum

NICE makes the following recommendations re the treatment of anxiety and other mental health problems in adults on the autism spectrum. 1

'For adults with autism and coexisting mental disorders, offer psychosocial interventions informed by existing NICE guidance for the specific disorder' and 'For adults with autism and coexisting mental disorders, offer pharmacological interventions informed by existing NICE guidance for the specific disorder.'

In practice this means treating the person with autism in the same way as you would anybody else who suffers from anxiety i.e. using a combination of psychological techniques and/or medication.

1 Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (2012). London: National Institute for Health and Clinical Excellence.

NICE guidance on anxiety in children and young people on the autism spectrum

NICE makes the following recommendations re the treatment of anxiety in children and young people on the autism spectrum.

'In the absence of evidence of how coexisting mental health disorders (including ADHD, OCD, PTSD, depression and conduct disorder) should be treated differently in autism, the GDG agreed that management should be in line with existing NICE guidance. There was, however, evidence for clinical efficacy of CBT programmes with autism – specific modifications on coexisting anxiety for children with autism. There was evidence for a positive treatment response to CBT in terms of no longer meeting diagnostic criteria for the anxiety disorder and/or showing global improvement in anxiety symptoms.' (NICE, 2013) 2

In practice this means treating the child or young person with autism in the same way as you would any other child or young person who suffers from anxiety i.e. using a combination of psychological techniques and/or medication, especially cognitive behavioural therapy.

2. The management and support of children and young people on the autism spectrum. (2013). London: National Institute for Health and Clinical Excellence.

NICE guidance on specific types of anxiety

NICE has published the following additional guidance on specific types of anxiety

3. Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults. (2011). London: National Institute for Health and Clinical Excellence.

4. Social anxiety disorder. (2013). London: National Institute for Health and Clinical Excellence.

5. Obsessive-compulsive disorder: Core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder. (2005). London: National Institute for Health and Clinical Excellence.

Literature review

In order to write this factsheet, we carried out a systematic search for research reviews, and clinical guidance, on the topic of anxiety in people on the autism spectrum. We searched a range of databases (such as CINAHL, Medline, Psychinfo) and identified 21 scientific reviews on this topic. We also examined the clinical guidance published by NICE.

Summary of evidence

- Anxiety is very common in people on the autism spectrum. However it is unclear from the research evidence if anxiety is a core feature of autism or a related condition that just happens to be very common in people on the autism spectrum.
- There is a lack of appropriate tools to measure anxiety in people on the autism spectrum. This makes it difficult to judge the true level and nature of anxiety in people on the autism spectrum.
- There is very strong research evidence to suggest that cognitive behavioural therapy may be effective in reducing anxiety in some children and young people on the autism spectrum without learning disabilities, provided it has been adapted to meet their particular needs.
- According to NICE this could mean using 'a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and "tool boxes")' and 'placing greater emphasis on changing behaviour, rather than [thoughts], and using the behaviour as the starting point for intervention'
- Determining the benefits of other interventions to treat anxiety in for individuals on the autism spectrum is not currently possible. We must wait for further research of sufficiently high quality to be completed. The fact that there is little or no research evidence to show that some interventions are effective doesn't mean that they do not work. It may simply mean that more research is required to find out if they do.
- There is some evidence to suggest that some interventions used to treat anxiety, such as some antidepressants, may cause significant side effects. Because of this they should only be used with extreme care and under the supervision of an appropriately qualified practitioner.

Future research

There is a need for further research into the anxieties faced by people on the autism spectrum and the most effective interventions to overcome those anxieties. Specifically there is a need for studies which

- Identify the most appropriate assessment and outcome measures for anxiety in people on the autism spectrum.
- Determine if anxiety is a core feature of some forms of autism or a related condition that just happens to be very common in people on the autism spectrum.
- Identify which groups of people on the autism spectrum with anxiety might benefit most from which interventions.
- Involve people on the autism spectrum to review the efficacy and ethical basis of interventions in this area

You can see details of our search strategy and the reviews we identified at <http://researchautism.net/anxiety-and-autism>

Other reading

- Mind (2012) About anxiety and panic attacks. London: Mind.
- National Autistic Society [201?] Anxiety in adults with an autism spectrum disorder. London: National Autistic Society.
- National Autistic Society [201?]. Understanding anxiety at school. London: National Autistic Society.
- NHS Choices(2012) Generalised anxiety disorder. London: National Health Service.
- Royal College of Psychiatrists (2013) Anxiety, panic and phobias. London: Royal College of Psychiatrists.

Organisations

- Anxiety Alliance. UK organisation which aims to help people overcome anxiety problems. Helpline. 0845 296 78 77. Website. www.anxietyalliance.org.uk
- BACP - British Association for Counselling and Psychotherapy. UK professional body which represents counsellors and psychotherapists. Tel. 01455 88 33 00. Website. www.bacp.co.uk/
- No Panic. UK organisation which provides support for people with variety of anxiety disorders. Helpline. 0800 138 88 89. Website. www.nopanic.org.uk

Further information

You can find more information on this topic (including sources of evidence, glossary of terms used etc.) on Research Autism's website at <http://researchautism.net/anxiety-and-autism>

Essential Guides

'Essential guides' are designed to summarise and explain sometimes complex scientific research findings on a particular topic to a non-scientific audience. They are not designed to provide specific advice for individual cases. However they do provide guidance on how to think through what may help.

Research Autism

We are the only UK charity exclusively dedicated to research into interventions in autism. We commission, carry out and support high quality, independent research into new and existing health, education, social and other interventions.

Disclaimer

The information published in this guide has been written by non-medically qualified individuals. Any such information should be therefore be treated with care. The fact that we mention an intervention does not necessarily mean that we think it is effective. The fact that we list a publication or organisation does not necessarily mean that we agree with its findings or position on this issue.



www.theinformationstandard.org

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