

For parents, just as we want our children to be physically fit and healthy, their mental well-being is equally important in helping them to be at their best.

Summary

- The unique challenges of living with autism means that people on the autism spectrum and their families can be more susceptible to stressors that lead to emotional and behavioural issues and trigger mental health problems.
- The most common mental health issues experienced by children on the autism spectrum include anxiety, depression, obsessive compulsive disorder, and disorders in eating, sleeping and toileting.
- Autism traits can also make it more difficult for a person on the autism spectrum and especially children and teenagers to seek and obtain help for mental health problems, and can perpetuate a mental illness.
- Autism traits can also mean that diagnosing mental health conditions for people on the autism spectrum can be problematic, and this is especially so for children.
- Being aware of mental health issues, the role of stress and resilience in the lives of people on the autism spectrum and the options available for managing mental well-being can help us to take timely action to monitor, protect and build our children's mental well-being. Maintaining open communication with our child also helps us to know when to seek professional advice.
- As a parent or carer, taking care of your own physical and mental well-being is a vital way that you can help your child cope with stress and anxiety.

Common mental health issues experienced by children on the autism spectrum

Current research indicates that from a young age through to later adult life, people on the autism spectrum tend to experience comparatively higher rates of a range of mental health conditions compared to neuro-typical people.

The most common mental health conditions observed in children on the autism spectrum are anxiety and depression¹. Other mental health conditions commonly associated with a diagnosis of autism for young people include disorders in eating, sleeping, toileting, oppositional defiance, obsessive compulsion (OCD) and substance use/abuse; repetitive and avoidant behaviours; psychosis; and bipolar disorder.

Recent studies report that up to 46% of children on the autism spectrum aged between 3 and 16 years had at least one comorbid disorder²; within the group aged 10 to 14 years, the rate was up to 70%³. Furthermore, the prevalence of co-morbid mental health conditions is higher for those children on the autism spectrum who also have an intellectual disability⁴.

Living on the spectrum and stress

While every person on the autism spectrum experiences life in their own individual way, to a greater or lesser degree the experience of living with one or more of the 'core' traits of the autism spectrum while dealing with neuro-typical physical and social environments means that children on the autism spectrum and their families can be more susceptible to stressors that lead to emotional and behavioural issues and trigger mental health problems⁵.

Social skills Children who are seen by other children as being different, or relate to and mix with others in atypical ways can feel isolated and might be more exposed to bullying. Feelings of rejection can lead to stress, impact on the child's self-esteem and make them more prone to mental health problems such as anxiety, depression and behavioural issues⁶.

Communication The experience of living with your voice being 'unheard' and thus feeling that you are unrecognised can be frustrating, disempowering, stressful and isolating. Children with limited or no language or who are atypical in their use of physical contact, gestures or eye contact can struggle to be understood, to express their opinions, thoughts and feelings and to interpret the verbal and body language of other people.

Change Many children on the autism spectrum show a strong need for certainty⁷. Taking a concrete position by using a fixed style of thinking can provide a sense of control. Unpredictable, changing environments and dealing with uncertain, 'grey' areas of living can be stressful and hurt their self-belief.

Sensory processing Children who experience sensory overload can feel overwhelmed in everyday environments, such as a shopping centre (noise, smell, movement, light, colour, hunger, thirst, taste, human proximity). A child's heightened stress and anxiety can mean they are more vulnerable to other factors that affect their mental well-being.

Executive functioning It is very common for all parents to complain about their children's lack of organisation! However, this is significantly heightened for a child on the spectrum who is not skilled in 'executive functioning', such as planning, attention, working memory, problem-solving, verbal reasoning, inhibition, impulse control and multi-tasking. The disorganisation can create an added sense of chaos, uncertainty and isolation for a child and for their family and these can be triggers for stress and anxiety for the child (and any parent!).

Adolescence can be stressful

It's helpful for parents to recognise that for any young person, whether they are on the autism spectrum or not, adolescence can be a time of significantly increased stress and vulnerability. Adolescence is an extended period of major change in all aspects of a young person's life - physical, emotional, cognitive and environmental, in which the child is transitioning to adult life and responsibilities and establishing an adult identity, purpose and sense of belonging. It is also a time of increased social pressure, particularly in peer relationships. Results from numerous studies across the world show that across all young people, the onset and prevalence of mental health problems is highest during adolescence and young adulthood, with half of all lifetime case-level mental disorders starting by age 14 and three quarters by age 24⁸. For teenagers on the autism spectrum, not only can times of change and transition be particularly difficult, but their atypical modes of communication, language and social interaction can also heighten their vulnerability to social isolation and bullying. On a positive note, those children on the spectrum who prefer to conform to rule-bound behaviours or tend not to be influenced by social cues can display a strong resilience to negative peer pressure.

What can help my child develop and maintain mental well-being?

As with our physical health, maintaining mental well-being through healthy habits is an important buffer against illness. Many of the measures you may already have in place for your child can help to build this buffer. This includes measures you can put in place for your child that reduce and manage their exposure to stress and build their ability to recognise and cope with stress, such as strategies to:

- » provide your child with routine, certainty and predictability
- » develop your child's ability to adapt to change
- » build your child's confidence and self-esteem
- » develop your child's social skills and friendships
- » support and equip your child to deal with bullying
- » develop your child's special interests and hobbies
- » help your child to keep their life organised
- » maintain your child's healthy eating and exercise habits.

Staying healthy and supported as a parent

A vital way you can help your child cope with stress and anxiety is for you to look after your own physical and mental well-being. Looking after yourself helps you have the energy and resilience to support and seek help for your child and your family if your child is under extra stress.

A healthy diet, exercise and rest can help you build and maintain your resilience. As a carer, you too may also benefit from professional help to support you through challenging times.

Talking with your child about mental health

Developing an awareness and open dialogue in your family about mental health can make it easier for you and your child to recognise early signs of any mental health problems and to seek more information and help. Some ways to make this easier are*:

- » Keep communication open, be available without being intrusive or 'pushy'
- » Show empathy and don't rush into judgements
- » Take your child's feelings seriously
- » Spend time with your child, take an interest in their activities and encourage them to talk about what's happening in their life
- » Give lots of positive feedback to your child
- » Help them build a support network beyond yourself. Encourage and support any positive friendships and relationships with other family members
- » Let your child know that you love them. They may not always admit it, but this is likely to be very important to them.

If you are concerned about your child:

- » Talk openly and honestly with them and let them know that you are concerned
- » Reassure them that you will always be there for them
- » Ask what they need from you
- » Let them know that there is lots of help available
- » Help find an appropriate service and support them in attending
- » Ask direct questions if you are concerned about suicide. For example, have you been thinking about death? Have you thought about ending your life?

* Source: Headspace <http://headspace.org.au/family/information-for-parents-and-carers/>

How can I recognise if my child might need help with mental health issues?

It can sometimes be difficult as a parent to know the difference between normal behaviour such as occasional moodiness and irritability and an emerging mental health problem, particularly during adolescence. Feeling down, tense, angry, anxious or moody are all normal emotions for young people, but when changes are new, noticeable and last for at least a few weeks, these may be part of a mental health problem. Changes to look out for include:

- » not enjoying or not wanting to be involved in things that they would normally enjoy
- » marked changes in, or withdrawal from their usual level of communication with family and friends
- » marked changes in appetite or sleeping patterns
- » unusual weight gains or losses
- » being more easily irritated or angry for no reason
- » sudden unexplainable changes in mood, both positive and negative
- » when their participation and performance at school, TAFE, university or work is not at their normal level
- » involving themselves in risky behaviour that they would usually avoid, such as taking drugs or drinking too much alcohol
- » changes in their ability to focus
- » withdrawal from their usual relationships or unexplainable breakdown of relationships and friendships; sudden urges to seek solitude from normal social gatherings or family activities
- » seeming to be unusually stressed, worried, down or crying for no reason
- » expressing unusually negative, distressing or bizarre thoughts.

Because a child on the autism spectrum is more likely to be vulnerable to mental health issues, two important ways that you can support your child is to be alert to these signs, and if you are concerned, to seek early help and advice.

A 'symptom checker' provided by a well-credentialed organisation such as Beyond Blue, measures how you may have been affected by depression and anxiety in the past four weeks and can be helpful in deciding if you or your child could benefit from professional help. Your answers and results remain confidential and after you take the test, you can print the results for your records or to give to a health professional such as a doctor or psychologist. <https://www.beyondblue.org.au/the-facts/depression/signs-and-symptoms/anxiety-and-depression-checklist-k10>

Getting help early

Clinicians and researchers experienced in youth mental health emphasise the importance of seeking help early if a young person shows signs of developing a mental health problem. Research shows that if not properly resolved, mental health issues can often persist, escalate and reoccur in later life and can have a profound impact of a person's cognitive skills, their ability to function in education, at work and in social relationships, to make sound lifestyle decisions and develop healthy habits⁹.

A GP can provide a referral to a psychologist or psychiatrist for a formal diagnosis of any mental health condition. As outlined above, because diagnosing mental health issues in children on the autism spectrum can be problematic, a psychologist or psychiatrist who specialises in helping children with conditions such as autism is well-equipped to provide expert diagnosis and advice for your child.

Another important first step is to have support for yourself as a carer, such as getting information and advice from a service that specialises in helping young people with mental health issues and their families (see the listing below). Well-informed support and understanding from family and friends can be of significant therapeutic benefit for any person with mental health issues, and this is particularly so for a person on the autism spectrum who is likely to rely on a close circle of people whom they take into their trust and confidence. Resources about mental health and young people on the autism spectrum are listed below.

Diagnosing mental health conditions for children on the autism spectrum

A number of factors make diagnosis of mental health conditions in children on the autism spectrum more complex than for neuro-typical children, which can lead to misdiagnosis and missed diagnoses¹⁰.

- » Children on the autism spectrum vary greatly in their experience of autism and their abilities.
- » The nature of autism means that thoughts, feelings and behaviours for a neuro-typical child that might be indicative of a mental health issue can be normal for a child on the autism spectrum.
- » The symptoms of autism and the symptoms of anxiety, depression and other common mood and behavioural disorders in children share common traits, so autism symptoms can mask symptoms of mental illness, and vice versa.

- » The many factors that influence and determine the behaviour of a child on the autism spectrum - biological, social, psychological and environmental - do not operate in isolation but each can influence the other. This means that determining the true source of symptoms can be complex.
- » The process of understanding and analysing mental well-being can be more complex where a child does not or readily 'self-reflect' or express their thoughts and emotions.

As an example of these challenges, a child may present in diagnostic tests as showing a limited range of emotions. In some cases this could be masking signs of depression. In other cases, behaviour such as a lack of facial expression could be misinterpreted as the sign of a mood disorder when in fact it is an inherent part of the child's autism.

For all of these reasons, a sound understanding of both the nature of autism and the normal behaviour of the individual child are essential for diagnosis. This can be achieved by combining the knowledge and experience of a professional who has expertise in children on the autism spectrum with the lay expertise of family members and carers who best understand the child's regular behaviour patterns.

What evidence-based interventions and treatments are available to help children on the autism spectrum who have a mental health problem?

Evidence indicates that with modification, a number of approaches that are effective in helping neuro-typical young people deal with mental health issues can also be effective for young people on the autism spectrum. Examples of modifications may include alternative content and formats to aid communication and engagement; visual supports; concrete techniques such as role plays; increased repetition and homework; and involving family members, friends and buddies (with the agreement of the young person). A number of individual and environmental factors influence the usefulness of any therapy for a child on the autism spectrum, including the child's insight (whether they think they have a problem) and their motivation to change¹¹.

Cognitive Behaviour Therapy (CBT) is a structured talking therapy that helps individuals understand the links between thoughts, emotions, physical sensations and behaviour and apply this understanding to self-regulate their mental state and behaviours. CBT has been found to be effective for neuro-typical young people, and there is some early evidence that with modifications to account for autism traits, CBT can benefit young people on the autism spectrum, particularly those with sufficient verbal skills and intellectual capacity, to manage and reduce their anxiety¹².

Attributional retraining is another form of psychotherapy suggested as possibly useful for people on the autism spectrum, particularly those with Asperger's syndrome¹³. This therapy aims to teach individuals to replace certain behaviours such as learned helplessness and catastrophizing that can trigger and magnify mental health problems with more adaptive and positive approaches to deal with environmental stressors¹⁴.

Music, play and art therapies are three non-talking therapies commonly used for children on the autism spectrum. While there is limited research of the efficacy of these therapies as treatments for comorbid mental health problems for children on the autism spectrum, these activities can be useful by offering alternative settings and formats in which your child can express their emotions in a non-threatening environment, and this may help with greater self-awareness and regulation of their emotional states.

Medication In some cases, health professionals recommend medication as a sole or complementary intervention to treat more serious mental health issues. Medication is generally considered an essential part of the treatment for psychosis, bipolar disorder and obsessive compulsive disorder and also for chronic and persistent cases of depression and anxiety (Karim et al. 2014).

Getting help and more information

Your doctor is a good place to start if you're concerned that your child may need help with mental health issues. A GP can then make a referral to a psychologist, psychiatrist or other service for your child and to get support for you.

If your child is at a special education school, the school may provide psychological or counselling services. In mainstream government and independent schools, a school counsellor can be a helpful source of information about mental health services in your local area. In Australia, mental health services are generally available at local family and youth health centres operated by State governments.

Headspace provides assistance to young people aged 12 to 25 years and their families to cope with mental illness, drugs or alcohol, getting an education and finding a job. Headspace also helps people to discuss their sexual preference, bullying and harassment, stress due to lack of money, problems with concentration, concerns about work or study, sexual health and problems with friends. *eHeadspace* provides online support and telephone counselling for young people and families. *Headspace centres* provide face-to-face services including doctors, psychiatrists, psychologists, social workers, occupational therapists, nurses, youth workers, alcohol workers, drug workers and vocational workers.
www.headspace.org.au/
tel 1800 650 890

Beyond Blue provides support, information and counselling to help people deal with anxiety, depression and other mental health problems.

www.beyondblue.org.au/

tel 1300 22 4636

The symptom checker can help you determine if you should seek assistance from a health professional
<https://www.beyondblue.org.au/the-facts/depression/signs-and-symptoms/anxiety-and-depression-checklist-k10>

The Black Dog Institute provides information and support for all people of all ages to cope with mental illness, particularly mood disorders such as depression and bipolar disorder.

<http://www.blackdoginstitute.org.au/>

tel (02) 9382 4530

Reachout provides online mental health help and support for young Australians aged under 25, with information, videos and fact sheets.

<http://au.reachout.com/>

Kids Helpline provides telephone and online counselling services to support young people aged 5 to 25 years.

www.kidshelp.com.au/

tel 1800 55 1800

Lifeline provides 24/7 crisis support telephone and online counselling, including suicide prevention.

<https://www.lifeline.org.au/>

tel 13 11 14

Mental Health First Aid Australia is a national not-for-profit organisation that develops, evaluates and provides evidence-based courses, including teaching mental health first aid strategies to members of the public. Mental health first aid (MHFA) is the help provided to a person who is developing a mental health problem, or in a mental health-related crisis, until appropriate professional treatment is received or the crisis resolves.

<https://mhfa.com.au/cms/home>

tel 03 9079 0200

Books

A practical guide to mental health problems in children with autism spectrum disorders. It's not just their autism by Khalid Karim, Alvina Ali and Michelle O'Reilly. 2014. Jessica Kingsley Publishers, London.

A clear, practical and informative guide written for both parents and professionals. This book gives the reader a sound understanding of the interaction between the experience of living with autism and mental health for children on the autism spectrum and practical advice about managing these conditions. Both parents and practitioners will find this guide highly accessible, as it draws on real-life examples from the authors' combined clinical and personal experience of living with a child on the autism spectrum.

Asperger syndrome and anxiety: A guide to successful stress management by Nick Dubin. 2009. Jessica Kingsley Publishers.

CBT for Children and Adolescents with High-Functioning Autism Spectrum Disorders, edited by Angela Scarpa, Susan Williams White and Tony Attwood. 2013. Guildford Press.

Other resources

Dealing with Bullying Aspect's information sheet on bullying has comprehensive information and resources for help.

<https://www.autismspectrum.org.au/sites/default/files/Aspect-Practice-Preventing-Bullying-Factsheet-July2015-Final1.pdf>

Positive Partnerships is an Australian Government funded consortium of autism organisations that provides support for school age children on the autism spectrum, including workshops, webinars, online learning, information and resources for parents, carers and educators. Aspect is the lead agency in the consortium.

<http://www.positivepartnerships.com.au/>

The NSW Council for Intellectual Disabilities has a plain language, non-technical fact sheet on mental health that's very readable for young people and people with an intellectual disability.

http://www.nswcid.org.au/images/factsheets/ER6_MentalHealth.pdf

Launchpad, Aspect's website specifically for young people with autism who are about to leave school has information, tips and resources, both for young people and their parents, about mental health and related topics such as health and social life.

<http://www.autismlaunchpad.org.au/health/>

ASteen Social Club is a social group for young people on the autism spectrum aged 13 and over.

<https://www.autismspectrum.org.au/content/asteen-social-club>

Secret Agent Society, The Secret Agent Society (SAS) is an evidence-based social skills program designed for children who find it difficult to understand their own emotions, and those of others. The program helps children develop the skills needed to express their feelings in appropriate ways, using role playing missions and computer games to teach children how to make friends, manage bullies and ask for help when needed.

<http://www.sst-institute.net/>

tel 07 3720 8740

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