



IRELAND'S AUTISM CHARITY

AsIAm Anxiety Resource for Autistic Children/ Young People



#SameChance

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What is Anxiety?

Anxiety is our body and mind's natural reaction to threat or danger. It is a normal response to stressful situations or situations that could be threatening/ dangerous and might have a negative impact on our physical and/or psychological wellbeing. When you are in a challenging situation, your body releases hormones, such as adrenaline, which cause physical reactions in your body. This is known as the fight or flight response; it is your body's way of making sure you are alert and can respond to danger.



Anxiety can be; a feeling of fear, dread or uneasiness. It can affect your body, such as sweating, fast heartbeat, nausea, tensed muscles, feeling restless, feeling jittery, jaw tension, difficulty breathing, and so on. It can affect your thoughts; worrying a lot, being distracted, unable to concentrate, having racing thoughts, avoiding doing things, thoughts being out of control, and so on.

Changes to our bodies help us to prepare to fight and protect ourselves, flee from the threatening situation or can cause us to freeze in response to the threat.

Anxiety can be helpful in many situations, encouraging us to plan and adapt to things in our life, for example if you are preparing for an important exam. Anxiety is a common and non-problematic response in certain situations, like when facing a stressful life situation. Usually, these feelings are manageable, and they go away when the event has passed.

However, anxiety can become a problem if you regularly feel anxious when there is no threat present, or your feelings of anxiety are significantly greater than the situation needs.

Anxiety can become counter-productive; when it stops you being able to prepare for situations and manage your life. Anxiety becomes a clinical condition when it is experienced over a long period of time and when it has a significant impact on a person's well-being.

Common types of anxiety disorders are:

- » Generalised anxiety disorder
- » Social anxiety- relating to of social situations
- » Agoraphobia- relating to open spaces and crowds
- » Phobias- specific fear



You may notice signs of anxiety in your child/ adolescent such as:

- » Finding it hard to concentrate
- » Poor sleep or bad dreams
- » Not eating
- » Crying
- » Tummy aches and feeling sick
- » Being tense or fidgety
- » Anger, irritability or emotional outbursts



Anxiety and Autism

It is very common for Autistic people to experience anxiety. However, there is a myth that part of being Autistic is being anxious. This is not true. Researchers in the area of autism have shown anxiety itself is NOT part of being Autistic but can come from the stress and trauma of being a neurodivergent person in a world that is often built with non-Autistic people in mind.

This means an Autistic person can feel like they must constantly be hypervigilant or on 'high alert' for threats in their environment. Added to this, they may have a brain that is very skilled at hyper focusing on things, and is therefore very skilled at focusing on what's worrying you.

There is a huge variety in how an Autistic person may respond to their anxiety. Often signs of anxiety are internalized and therefore difficult to observe. Despite the resilience Autistic people often develop by living in a world where you are masking or constantly anticipating 'threats', distress can build and build until you **meltdown** or **shutdown**.

What is the difference between shutdown and meltdown?

Generally speaking, a meltdown is described as a loss of your control which shows itself externally (e.g., crying) and a shutdown is described as a more internal experience where it can feel like you are shutting down.

Shutdown

- » "Like a trapdoor closing"
- » "Dead battery"
- » "Self-preservation"
- » "Frozen in a bubble"

Meltdown

- » "Feeling sick"
- » "Total loss of control"
- » "Crying and shaking"
- » "A need to escape whatever way I can"

Here are a few ways someone may try and cope with their anxiety:

- » Seeking reassurance
- » Avoiding objects, situations or settings
- » Overthinking/ getting stuck in patterns of thought
- » Seeking routine and sameness
- » Stimming
- » Self-injury
- » Aggression towards others
- » Increased obsessional thoughts/ "getting stuck" in thinking patterns
- » Trying to control situations

What is Autistic burnout?

This is a state of intense physical, mental or emotional exhaustion that an Autistic person can experience because of the additional load of having to navigate a world that is not built with Autistic people in mind. This can often arise from consistently masking or prolonged periods of sensory overload.

You might have heard the word burnout before, but Autistic burnout is different to general burnout. General burnout is usually associated with working too hard. Autistic burnout can in fact look like depression (loss of appetite, inability to concentrate, trouble sleeping, lack of interest in things, isolation). It can happen when you become completely fatigued by masking and by social interactions that cause you stress.

How can you help your child? When you are in the process of meltdown, shutdown or burnout, explaining to someone what helps can feel absolutely impossible. A group of researchers in Canada¹ decided to ask Autistic young people what they wanted the adults in their lives to do when they were in meltdown.

These young people concluded:

- » Know the things that make me feel out of control
- » Learn the strategies that help me regain control
- » Understand the things that make me feel worse



Did you know?

Autistic people are more likely to experience anxiety than neurotypical people.¹ There are many reasons for this.

Social & Communication Differences

An Autistic person may experience anxiety when navigating social situations and environments. This can be the result of difficulty interpreting facial expressions, tones of voice, body language, and so on- this can lead to a feeling of missing key information in social situations, confusion and uncertainty. Over time, in learning that social situations are difficult to navigate, this can lead to anxiety in expectation of dealing with people. Experiencing social anxiety is valid and very common.² Autistic masking is associated with higher rates of anxiety.

What is masking?

in simple terms, this is basically hiding our Autistic selves and all the things that make us 'us' and learning to behave like Neurotypicals to fit into the world with Neurotypicals.

Due to communication differences, Autistic people may experience difficulties accessing supports, asking for help, explaining what they are experiencing, and so on. Additionally, people who do not communicate verbally experience additional difficulties communicating their needs and wishes.



¹: Find figure

²: <https://musingsofanaspie.com/2013/02/28/my-anxiety-is-not-disordered/>

Sensory Differences

Sensory processing differences are very common in Autistic people. All eight senses can be impacted. Sensory processing differences can lead to sensory overload which can in turn be a cause of anxiety. It is important to keep in mind that anxiety may increase sensitivity to sensory input, which can become a cycle of increasing anxiety. An Autistic person may also experience anxiety in anticipation of sensory input e.g., the school bell, busy streets.

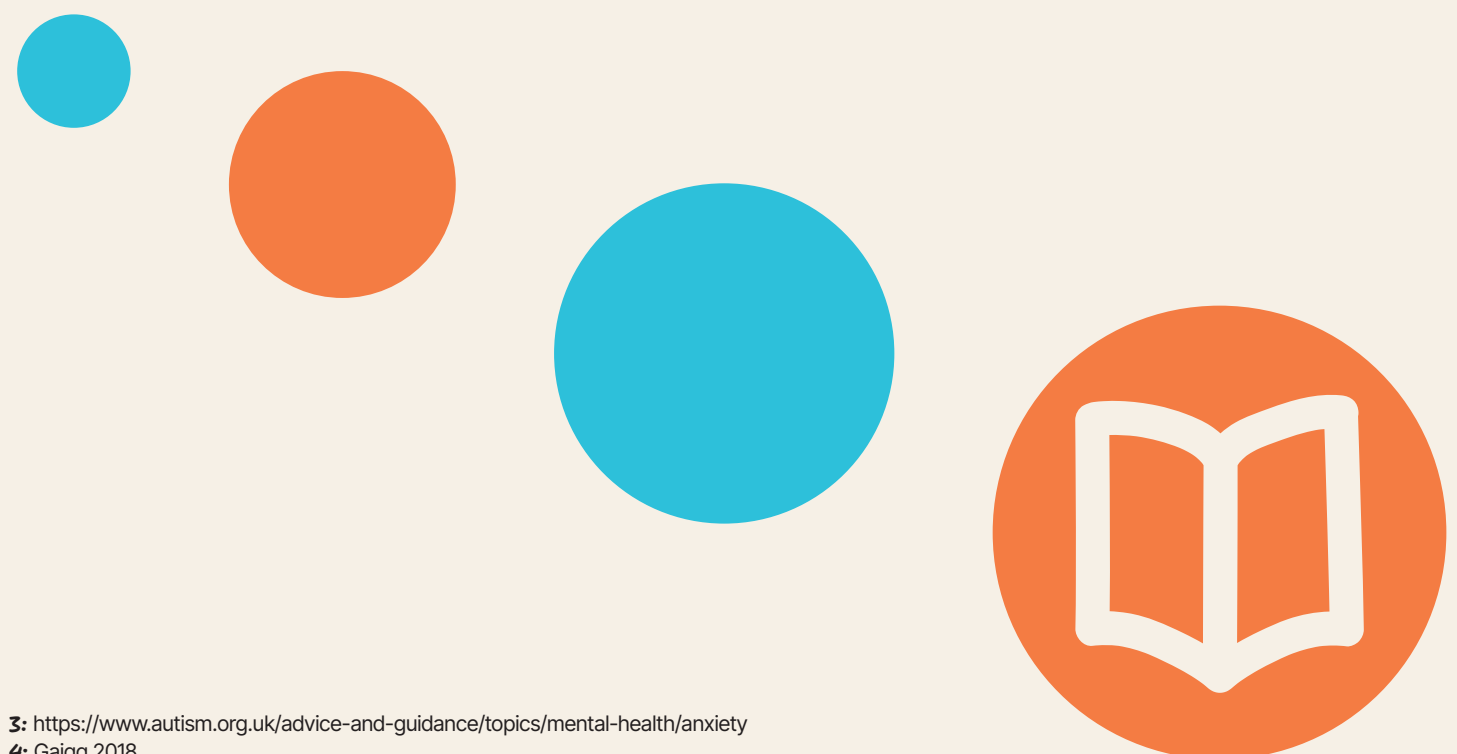
Auditory processing delays can lead to missed information, which can lead to uncertainty and confusion. An Autistic person's sensory difference can also be a real strength to them in managing anxiety as sensory preferences can be used to reduce and manage anxiety e.g., lying under a weighted blanket.

Change & Uncertainty

Many Autistic people experience uncertainty and change as aversive and stressful. They may cope with this difficulty by seeking out sameness and predictability. This can lead some Autistic people to develop rigid ways of thinking- because it gives the predictability and consistency that is needed. Planning and seeking predictability are coping strategies so changes and uncertainty that naturally occur in the world can then lead to anxiety and panic.

Alexithymia

Alexithymia refers to difficulty identifying, understanding and managing emotions.³ Some Autistic people experience alexithymia, and it is considered a factor in higher rates of anxiety in the Autistic community. Difficulty identifying internal signals of anxiety can make the experience of anxiety more confusing and unpredictable.⁴ Difficulty identifying and describing emotions can make it harder to regulate them.



³: <https://www.autism.org.uk/advice-and-guidance/topics/mental-health/anxiety>

⁴: Gaigg 2018

Anxiety Management

Managing anxiety can take time, effort and patience. This is because no single strategy will work for every person or work instantly or consistently. Most strategies work best with time and when used regularly, as well as being practiced when not experiencing anxiety. All anxiety management strategies should be individualized to the unique needs of the person.

Anxiety management strategies can be proactive or reactive. Proactive strategies are preventative measures which aim the anxiety from being experienced. Reactive strategies are used to calm and reduce anxiety.

If you are concerned about your child/ young person's anxiety, you should speak to your GP.

Below are a few suggestions for different strategies to try to support your child/ young person with preventing and managing anxiety.

- » **Investigate the cause, trigger or factors that influence the anxiety:** Note times of day, days of week, situations, settings, people, demands and so on that came before and after the anxiety. You can use a diary, phone notes, app or whatever is most convenient. This can take time to start to see patterns. It can be helpful to note what the child/ young person did to manage their anxiety, and did it reduce their anxiety (helpful coping strategy) or appear to make it worse. You may note how others responded and did this help or worsen the anxiety. The more information the better to gather information on what is triggering the anxiety.
- » **Support the child/ young person to communicate:** Provide the necessary supports to the child/ young person to allow them to communicate their needs, this will depend on the individual's communication style. Use short simple questions, pointing, or visuals to reduce demands and avoid increasing anxiety. Visual supports could include a wellbeing choice board, or visual guide of calming strategies. In some circumstances, it can be helpful for an individual to name/ identify how they're feeling (e.g., ask 'does your tummy feel sick/ tense?') but in many cases it's more effective to support the individual to regulate themselves first. When the child/ young person is feeling regulated again, and the anxiety has lessened it can be helpful to explore, where possible and appropriate, what they were thinking about, how their body felt, what was causing the anxiety, and what helped them feel better.



- » **Remove the source of anxiety:** If it is in the best interests of the individual and where it is possible, simply remove the source of anxiety.⁵ Consider the aims of an activity that is causing anxiety and whether these can be achieved in an alternative way. If the source of anxiety cannot be removed; reduce it or put supports in place to help the individual cope better.

For example: If the playground at lunchtime is causing anxiety but it is not possible for them to spend lunch in another location, reduce the amount of time they are expected to be there and gradually increase it over a number of weeks. Provide the child/ young person with ear-defenders and other supports needed.⁶

- » **Adapt the sensory environment:** Complete a sensory audit of environments. Collaborate with the individual to explore the sensory environment and adapt it to be less triggering and more pleasant for them. Being in an environment that feels safe will reduce anxiety.
- » **Explore and engage with special interests:** Schedule time to allow them to become consumed in hyper-focus. This can provide a feeling of control, certainty, regulate the nervous system and facilitate the experience of a happy and calm 'flow' state.
- » **Practice regulation activities regularly:** Squeezing a ball, taking a big breath, shaking out the body, deep pressure, and using a weighted blanket are just a few examples. This means that when a child is feeling anxious, it is a familiar and practiced activity that can be used.
- » **Reduce uncertainty:** As unpredictability and uncertainty can be sources of anxiety or aggravate feelings of anxiety consider using visual schedules, first-then visual supports, transition supports and social guides to allow the child/ young person to predict and prepare for situations, settings and events.
- » **Create a regulation space in the home:** This is an area that is a buffer for the child/ young person against environmental stressors and triggers. If the individual is sensory defensive, it might be a blackout tent with a beanbag, blankets and noise reduction headphones. For a sensory seeker, it might be a pod swing, trampoline and/ or crashmat. It should be a predictable place where they can retreat to self-regulate.
- » **Relaxation and calming activities:** Different activities can be used to reduce and prevent anxiety, for example box breathing, mindfulness activities, progressive muscle relaxation, physical exercise, and many more. Anxiety changes our breathing to short, shallow breaths. Calm breathing is a technique that teaches how to slow breathing when feeling stressed or anxious. See graphics below for some example activities.

⁵: <https://best-practice.middletownautism.com/approaches-of-intervention/anxiety-management/anxiety-management-strategies/>

⁶: <https://best-practice.middletownautism.com/approaches-of-intervention/anxiety-management/anxiety-management-strategies/>

- » **Use visual communication supports:** These are very important for people who don't typically use words and phrases to communicate their needs and wishes. However, they are also a useful tool to support communication when a child or young person is feeling strong emotions and may find communicating stressful or difficult. Visual supports can include communication cards, emotion thermometers, self-regulation prompt cards and so on. It is essential to practice using visual supports when the child/ young person is calm, rather than waiting until they're in an anxious state.
- » **Movement and sensory input:** Movement breaks can help a child/ young person stay regulated and calm. Proprioceptive and vestibular input can be particularly helpful including bouncing on an exercise ball, jumping on a trampoline, head/ hand squeezes and so on.
- » **Create a calm kit:** This is a set of items that help the child/ young person uses to stay calm and manage their anxiety. This could include photographs, toys, fidgets, etc. These items should be always available and easily accessible.
- » **Increase understanding:** Helping a child/ young person to understand what they are feeling and why can help the feelings to be less intimidating and scary. Using a body mapping activity can be helpful. It can be helpful for children and young people to understand that everyone feels anxious sometimes, and that there is nothing 'wrong' with them. You can help them to identify the bodily sensations associated with anxiety as well as the connected thoughts. This can be helped by being open about your own emotions, and anxiety, as well as how you reacted to and managed those feelings. When a child speaks about their feelings be sure to encourage this by validating their feelings, listening intently and nonjudgmentally, and responding with kindness.



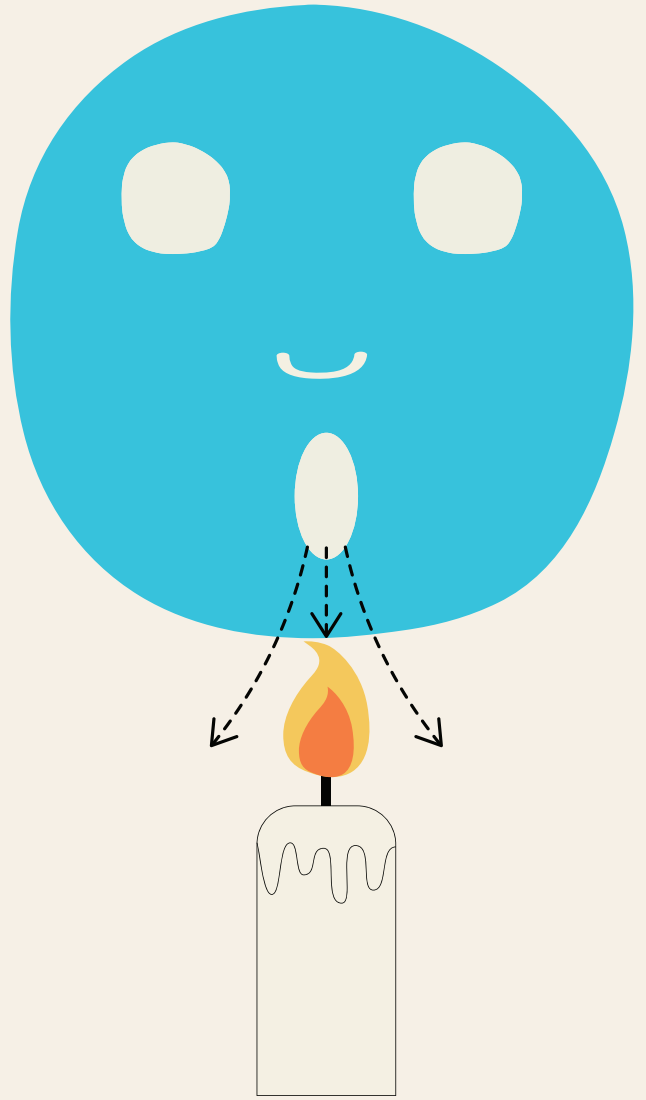
Visuals and Activities

If you have trouble knowing any techniques to help manage your anxiety, here are some activities to get you started.

Deep Breathing Exercise



Smell the flower



Blow out the candle

5 Grounding Technique

5-4-3-2-1 Grounding Technique

A calming technique that connects you with the present by exploring the five senses



5

Things
you can
see



4

Things
you can
touch



3

Things
you can
hear



2

Things
you can
smell



1

Things
you can
taste

5 Finger Breathing



Worry / Anxiety Scale

5

Freaking out/ Panic



4

Really Worried



3

Worried / Nervous / Anxious



2

A Little Worried



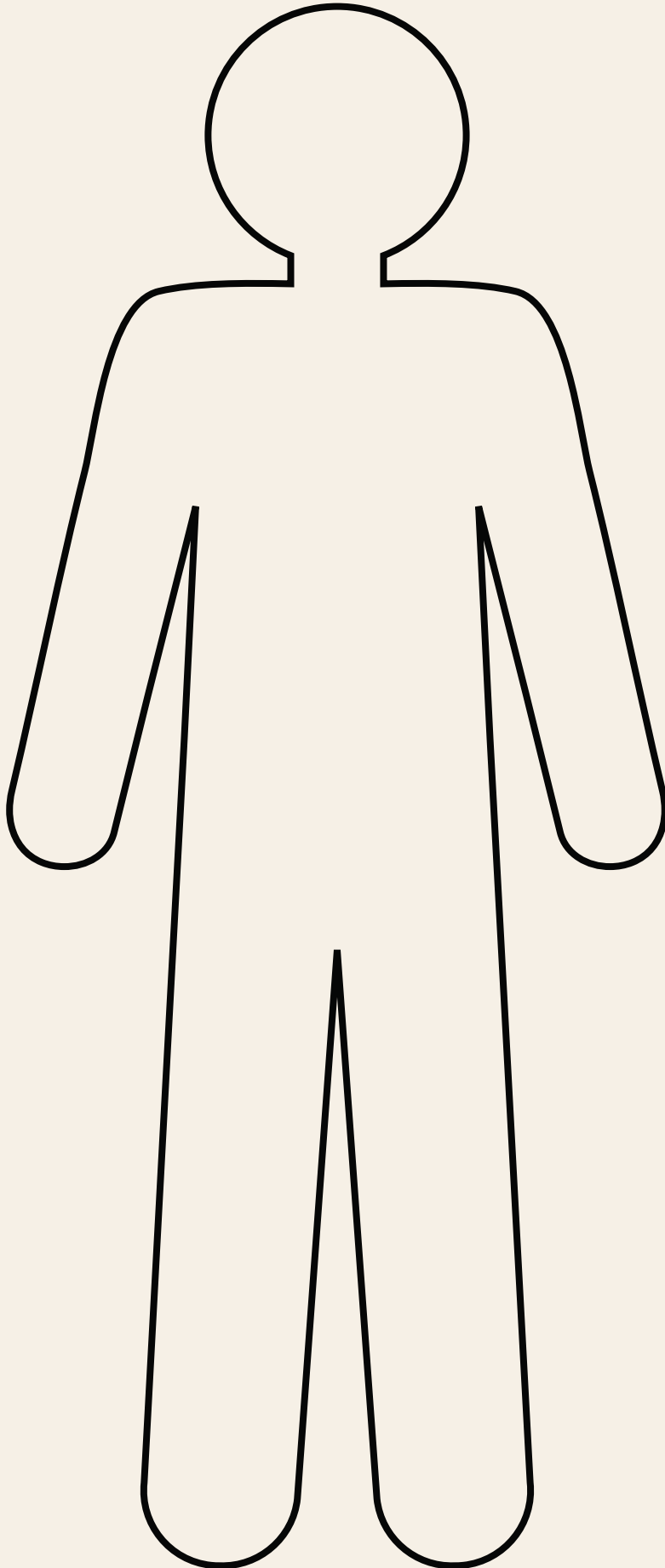
1

Okay



How My Body Feels When I'm Anxious

When you're feeling worried or anxious, you can draw how your body is feeling inside. Maybe you feel like there are bees buzzing in your stomach! Or is there's a thousand worries swirling in your head? Talk to a trusted adult as you draw your feelings in the outline below.





IRELAND'S AUTISM CHARITY

Same Chance

As I Live, Work, Grow, Participate

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