

A Resource for schools to support children who have or may have Special Educational Needs

Chapter: Anxiety and Autism

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Understanding and Managing Anxiety in Children and Young People with Autism

This chapter provides information for parents and professionals to support the understanding and management of anxiety in children and young people with autism across the educational sectors. It includes sub sections for strategies on helping to managing anxiety in the current circumstances due to the Covid-19 pandemic. *Please see the general autism chapter in the SEN resource with regards to the identity/person first terminology used regarding autism.*

Chapter Sections:

1. Autism and Anxiety
2. Social Communication Differences & Anxiety
3. Sensory Processing Differences & Anxiety
4. Difficulties in Flexible Thinking & Anxiety

Section 1: Autism and Anxiety

Anxiety is often closely associated with autism and one of the most frequently reported difficulties by both families and professionals supporting pupils with autism, with up to 84% experiencing anxiety at some time (Ozsivadjian & Knott, 2011).

Anxiety is a feeling of worry or fear usually triggered by negative thoughts about something which is happening or anticipation of an event with a negative consequence. This feeling is often accompanied by strong internal sensations of tension and symptoms such as racing heart, sweating, stomach ache and shortness of breath.

It is essential that anxiety is addressed as its impact on school age children with autism is significant; if not managed effectively it can negatively affect future outcomes for the child or young person. Anxiety can erode confidence and self-esteem, can lead to increased social isolation, academic underachievement, lack of skill development across all areas, and places the student at a greater risk of developing long-term mental health problems.

It also adversely impacts the family supporting the child or young person, affecting participation in social events, sleeping, eating and general health; all of which reduce family quality of life and increase parental stress (Carter et al, 2013; Dabrowska and Pisula, 2010).

This section explains anxiety within the context of autism, the aim is to support a greater awareness of the key characteristics of autism and their role in escalating anxiety. It outlines key information in relation to anxiety triggers and the behavioural presentation of anxiety to support early detection and recognition by parents and professionals. It will explore anxiety management techniques suitable for school aged children.

How Common is Anxiety in Children and Young People with Autism?

Anxiety is cited as one of the main co-existing difficulties for children and young people with autism (Smith Myles, 2003; White et al, 2009; Kent & Simonoff, 2017) with approximately 40% diagnosed with at least one anxiety disorder in comparison to

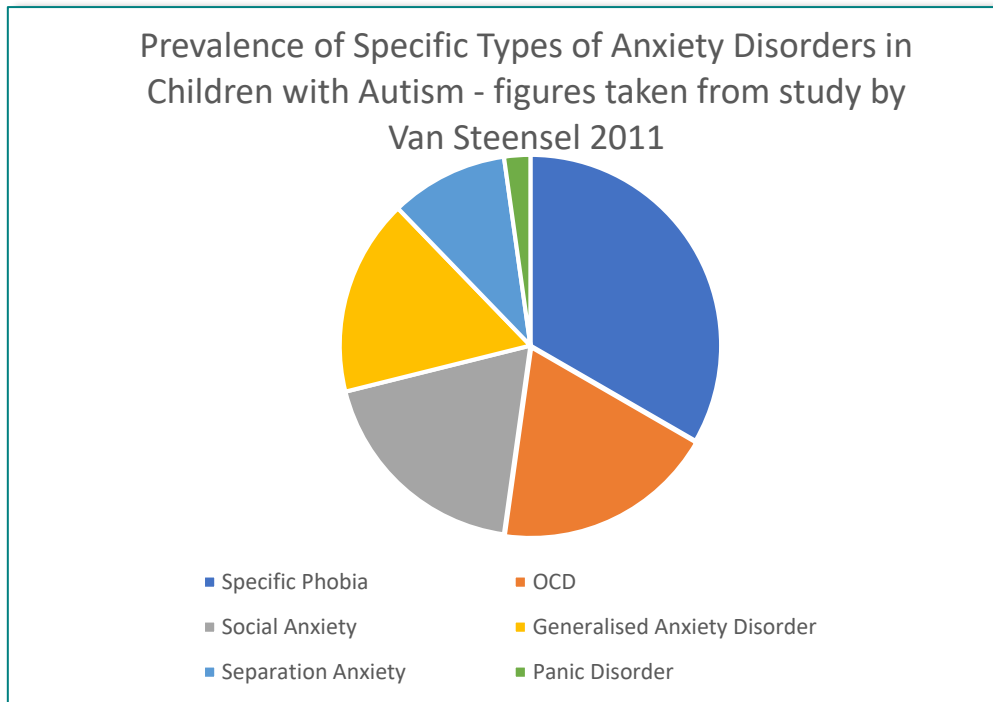
typically developing children with prevalence rates up to 27% (cited in Van Steensel et al 2017).

It has been known for quite some time that mental health difficulties in autism including anxiety starts in early childhood. The *You Need to Know* campaign by the National Autistic Society (NAS) in 2010 suggested 45% of children first experienced problems under age 5 with 37% aged 5-11.

A more recent study indicates 67% of 3-7 year olds have two or more clinically significant signs of anxiety (Sukhodolsky et al 2019). These results help us to understand the importance of early intervention and the significance of teaching anxiety management strategies at an early age to pre-school and primary aged children.

Primary and Post Primary school aged children can experience a broad range of anxiety disorders co-occurring with their diagnosis of autism including

- social anxiety disorder
- separation anxiety
- specific phobia
- panic disorder
- generalised anxiety disorder



Common Triggers for Anxiety in Autism

A trigger is something that causes the child to feel uncomfortable within their environment and is the first stage of anxiety. Common triggers usually come from something unexpected or unpredictable for the child, such as a change in their routine. Poorly managed transitions in school or home where the child is unprepared for starting or stopping an activity, moving to a new activity or area can be triggers.

Life or personal events like adolescence, illness and more serious events such as death of a loved one can trigger anxiety. Sensory stimuli such as smells, tastes and noises can often act as triggers for children with autism especially if the child does not like them or does not expect them.

Triggers for anxiety are important to note and pay attention to. This will help build up a profile of the person which can be shared by parents, teachers and professionals who work with the child.

- Transitions: children and young people transition continually throughout the day from the moment they wake up until bedtime. These including moving from

room to room at home, from activity to activity, from home to school and movement with the school environment (horizontal transitions). These are often stressful for autistic children especially if the child is not prepared or the transition is not communicated appropriately.

- Unexpected changes to routine: change and unpredictability is anxiety provoking for many with autism. Unexpected changes include different caregiver leaving or collecting from school, a substitute teacher in the classroom, the bus arriving late, or an activity being cancelled.
- Unstructured times: When there is no structure in an activity or environment, it feels chaotic and confusing to an autistic child. It can be difficult for them to make sense of the expectations and to know how to respond or react appropriately. Unstructured times include waiting in shops or for medical appointments, break-times and lunch-times in school, school yard or free time within the classroom and at home.
- Unfamiliar places and people: autistic children will often become fearful when going to a new place or meeting new people. Other new or novel events such as new toys, clothes and household objects can even cause upset, as there is usually a strong preference for sameness and for familiar objects and places.
- Sensory stimuli: for many children and young people with autism anxiety can be triggered by environmental stimuli which the child dislikes or finds intolerable, or anxiety may be triggered by multiple overwhelming sensory stimuli, which can be experienced in busy and crowded environments. Sensory input can cause even more stress when sudden and unpredictable (e.g. a car horn, a fire alarm).
- Social demands: challenges with social communication means that many social interactions and situations can provoke anxiety in autistic children. Social rules and expectations can be confusing and overwhelming with many young people experiencing heightened social anxiety about interacting with others. Needing to respond and process social information happens across multiple scenarios in the day, including a teacher asking a question in the classroom, participating in a group discussion in school, chatting with friends at a youth club or asking for an item in a shop.

- School specific anxieties: The busy school day presents specific challenges for autistic children. Alongside the typical stressors of exams and homework, there are triggers such as getting to the correct classroom on time, bringing the correct books and submitting homework to a deadline. These demands are particularly challenging for those with autism if they have executive functioning difficulties as any task which requires planning and organisation is stressful.

Recognising Anxiety in Autistic Children and Young People

If a child is not assisted to deal with a trigger the anxiety response can escalate. At this point you will normally see an increase in certain mannerisms or repetitive behaviours, these may be vocal or physical. Children will experience unpleasant physiological symptoms such as increased heart rate, nausea, sweaty palms and shortness of breath. It is important to remember that when a child is anxious their senses are heightened, so they may be less tolerant of what they perceive as unpleasant sensory input at this stage.

Children may react to anxiety with anger. Alternatively, sometimes the opposite happens, a withdrawal is common for passive children and for girls with autism who can appear to retreat into themselves. It is important that we recognise and understand their anxiety escalation either through their demeanour or physical state so as we can employ an appropriate strategy.

Adults living and working with autistic children need to be alert to the signs of anxiety, particularly as many will not recognise the signs in themselves or have the intent and language to communicate feelings to others.

Physiological responses to include:

- Dry mouth
- Increased heart rate
- Shortness of breath
- Chest pain
- Muscle tension
- Sweating

- Dizziness
- Palpitations
- Blurred vision
- Nausea
- Change in pallor, either becoming pale or flushed
- Dilated pupils
- Shivering

The activation of the sympathetic nervous system and the release of hormones support the brain and body in executing a fight, flight or freeze response to the perceived stress. These behavioural responses are self-protective mechanisms designed to reduce or eliminate the source of anxiety.

- **Fight:** Behaviours may include shouting, hitting out or destroying property. The child may be judged as being intentionally disruptive and aggressive towards others, but when in a high state of anxiety, the child is acting on impulse to self-protect. It may also be the child's means of communicating distress, as functional communication often deteriorates when the child is in a heightened state of stress.
- **Flight:** Behaviours may include running away, withdrawal or refusing to participate in events and activities. These behaviours can be misinterpreted by others as deliberately oppositional, but they are again the child's means of protecting themselves against perceived stressors. If an activity or an event is creating negative emotions, it is natural that the child will try to remove themselves from the situation or refuse to engage.
- **Freeze:** Behaviours may include not moving or interacting and not engaging in surrounding activity. The child seems to shut down and does not respond to surrounding activity and people. This often happens when feeling overwhelmed by sensory input, social interaction and other demands.

The fight/flight/freeze responses will be explored in further details in the section on Sensory Processing Differences (Behavioural Responses to Sensory-Based Anxiety).

Pathways to Anxiety in Autism

Many of the core characteristics of autism such as social communication difficulties, unusual sensory responses and difficulty with flexible thinking may predispose a child or young person to develop anxiety. In addition, biological changes in brain structure and functioning may mean that autistic pupils are more prone to experiencing anxiety.

The remainder of this resource will be separated into sections which will further explore the relationship between anxiety and

- social communication differences
- sensory processing differences
- difficulty with flexible thinking

Section 2: Social Communication Differences & Anxiety

This section will reflect on how social communication features in autism may contribute to and maintain anxiety. It will overview the main aspects of communication and their potential impact on anxiety with practical strategies to prevent and address anxiety.

In order to receive a diagnosis of autism there must be evidence of persistent difficulties in social communication across multiple contexts (American Psychiatric Association, 2013). However, there is a wide range of communication profiles across the Spectrum, with some children acquiring little or no speech while others have high level language abilities. Despite this there are shared difficulties around key areas of communication such as communicative intent, understanding non-verbal communication, and the ability to analyse all the relevant information in order to tailor communication to the specific context.

Research into the impact of social communication difficulties on the increased prevalence of anxiety in children and young people with autism is ongoing. There appears to be consensus that those who have an intellectual disability or communication deficits experience less anxiety within the autism population (Davis et al. 2011). Caution must be taken, however, that those with limited language abilities may not be able to identify and communicate their levels of anxiety. More information on how to help children and young people stay emotionally regulated and understand expectations is available later in this section.

Receptive language skills and non-verbal communication

Receptive language skills refer to the understanding of verbal and non-verbal language. It is estimated that around 50% of the autistic population have difficulties understanding language (Bogdashina 2004). Having a receptive language difficulty is associated with increased anxiety as the young person may feel confused about expectations or routines which can result in feelings of uncertainty. Intolerance of uncertainty is strongly linked to high levels of anxiety in young people with autism (Boulter et al 2014).

Autistic children and young people, and in particular girls with autism (Kreiser & White, 2014) may try to mask their confusion by attempting to follow or imitate others. Those who are unable to do this may engage in behaviours that are challenging, or sensory seeking behaviour in an attempt to lower their anxiety levels. Ros Blackburn (an autistic adult) reported that when she experiences anxiety about the “mayhem” around her she engages in finger flicking in front of her eyes, and when her anxiety escalates, she bites the backs of her hand (Blackburn, 2010).

Another source of anxiety may occur when expressive language abilities are misjudged. For example, when a young person presents with limited verbal language skills it could be erroneously assumed that their understanding is also limited, which can be extremely anxiety provoking. An example of this is Carly Fleischmann who had limited means of communicating and was presumed to have a severe intellectual disability until she started typing messages on her laptop when she was ten years old. Alternatively, a young person may have a wide vocabulary but limited understanding of verbal language which may result in communicative partners using language which is too complex for the child with autism to understand.

Case Study

Calum is a 15-year-old boy with a diagnosis of autism. He has a wide vocabulary and talks at length about his special interests in computer games. In class he is often unsure of what he has been asked to do so will spend much of class opting out of work tasks. He also does not copy his homework instructions into his diary and regularly

gets detention for failing to have homework completed. Calum often complains of feeling sick in the mornings and does not want to go to school.

Even those with good receptive language skills may miss the gist of communication due to single channelled attention, increased auditory processing times (Hedvall et al, 2013), literal interpretation of language, or difficulties understanding nonverbal communication. These factors are most apparent in busy chaotic environments with multiple sources of sensory stimuli which will compete with processing language. Again, this will result in anxiety building in the moment due to an autistic young person struggling to understand what has been asked of them. For these reasons it is important that assessment of language skills extends to real life settings to ascertain what the young person can attend to and understand in the environment in which communication takes place.

Top Tips:

- Consider findings and recommendations from a Speech and Language assessment, where available.
- Consider the sensory environment and how it may impact on processing of language in a young person with single-channelled attention (see the sensory section for more details).
- Provide additional time to process language. It is estimated that around 10 seconds processing time will support understanding.
- Use visual supports to allow greater time to process instructions and information. For example, pocket card instructions, schedules, or activity systems to explain the sequence of tasks. They need to be adapted to suit the ability level of the child or young person. The child described in the case study above would benefit from using a schedule such as this :

Photo from Division TEACCH

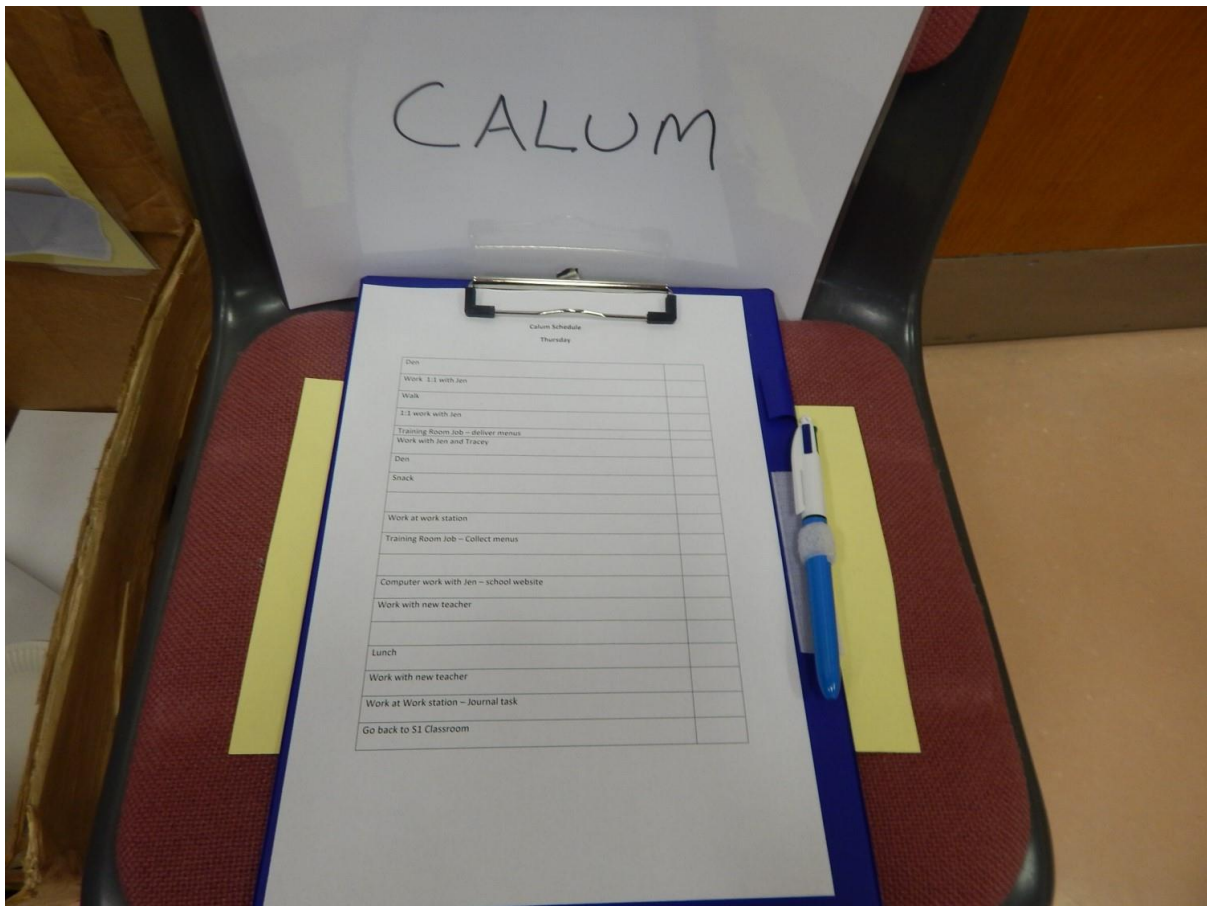


Photo from Division TEACCH

- Information on teaching visual systems can be found on the resource section of Middletown Centre for Autism's website: <http://best-practice.middletownautism.com/approaches-of-intervention/the-teacch-autism-programme/visual-schedules/> An number of examples are detailed below:

Object Schedule Photo from Division TEACCH



Basic symbol schedule

FIRST	THEN	NEXT
		
PLAY PARK	FEED DUCKS	HOME

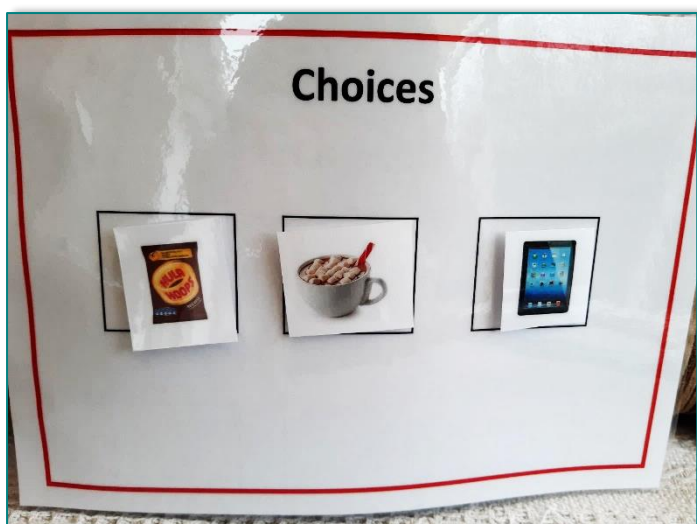


Symbol and Word Schedule Photo
from Division TEACCH

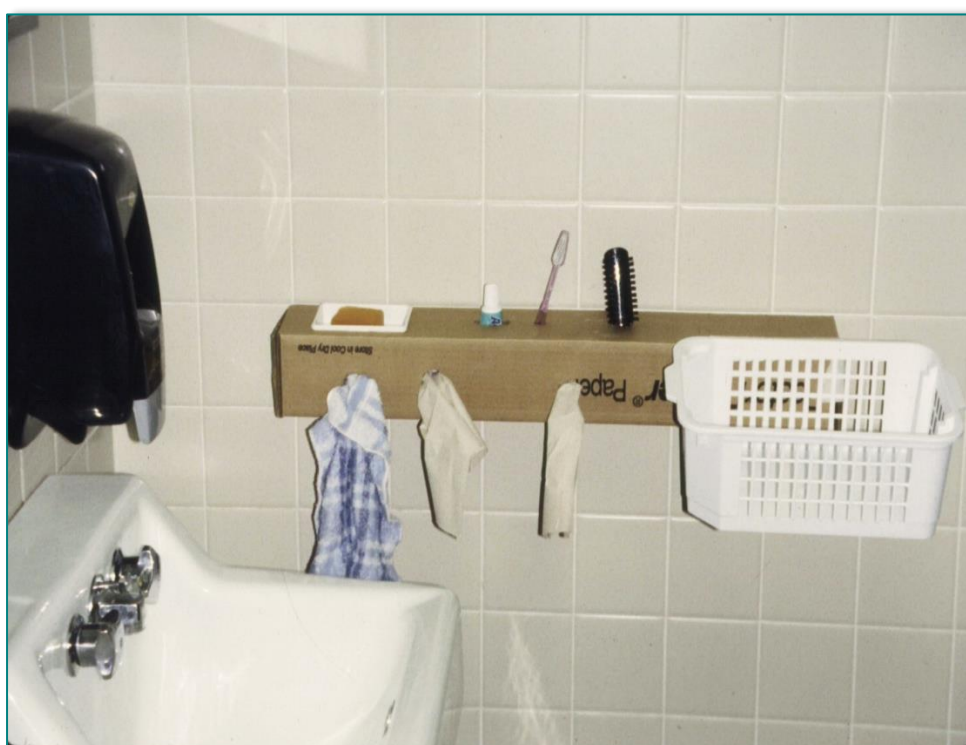
Written Schedule. Photo from Division TEACCH



Choice Board Photo from Division TEACCH



Object activity system for hygiene Photo from Division TEACCH



Object activity system for work Photo from Division TEACCH



Expressive language skills and using non-verbal communication

Expressive language skills refer to our ability to use language to communicate effectively. We use language for many purposes including asking questions, expressing our needs and wants, commenting and expressing our feelings. There are many modes of communication in addition to speech, for example, Picture Exchange Communication (PECS), Makaton (signing), speech output device, motoric communication (taking a person's hand and putting it on a desired item or looking at the desired item). However, with regards to anxiety levels, the young person's ability to communicate functionally is key. This means the young person can use whatever communication system that is most effective for them to express themselves and have their needs and wants met. Often during times of increased anxiety, even those who have high level language skills require a concrete means of communicating, for example, the Incredible Five Point scale or a help card. Having an effective communication system is part of a toolbox of strategies to alleviate anxiety (see sections 1 and 3 for additional strategies including sensory regulation methods).

Case Study

Sarah is 4 and is preverbal. At present she does not have a consistent way to ask for things, meaning she will often become very distressed when she needs something. At times she will bang her head or bite her fingers. This is very stressful for her parents who are trying their best to work out what she needs in the moment.

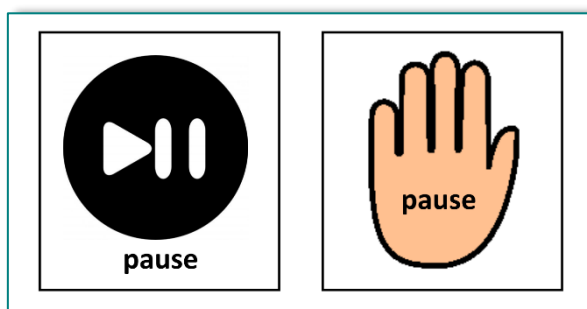
Difficulties engaging in functional dialogue can have far reaching implications. It may contribute to frustration of not having needs or desires met. Moreover, it can result in limited peer relationships and a lack of rapport with teachers (Sciutto et al., 2012; Dillon, Underwood & Freemantle, 2014). There is a risk that if a child or young person experiences repeated failure in interactions with peers they may feel anxious about future interactions resulting in social avoidance and isolation.

Top Tips:

- Consider findings and recommendations from a Speech and Language assessment, where available.
- Consider the sensory environment and how it may impact on processing of language in a young person with single-channelled attention (see the sensory section for more details).
- Consider if the young person can communicate their needs in all contexts, and regardless of their internal state. In other words, can the young person communicate with you effectively on their most difficult day? If not, consider providing consistent alternative ways to communicate such as teaching the use of a communication system at a level they will understand.
- Use visual supports to allow greater time to process instructions and information. For example, pocket card instructions, schedules, or activity systems to explain the sequence of tasks. They need to be adapted to suit the ability level of the child or young person. For a child like Sara, a communication system such as the photo exchange system below may be useful:



- For children who understand symbols a help card, or provide a secret system for communicating something, for example, that they need help or a break.





- Ensure all adults caring for the child or young person are familiar with the child or young person's mode of communication. This could be included in a pupil profile such as the one detailed below.

Pupil Needs Analysis

Name

Address: -

Parents: -

Telephone: _____

Date of birth: -

Class Teacher: -

Class: -

SENCo/SENO: -

Psychological Assessment

Date	Tests administered	See Psychological report for full details.
		Summary

Other Assessment

Speech and Language Assessments

Date	Tests administered	See report for full details Summary

Occupational Therapist Assessments

Date	Assessments	Summary

Other Assessments (please detail)

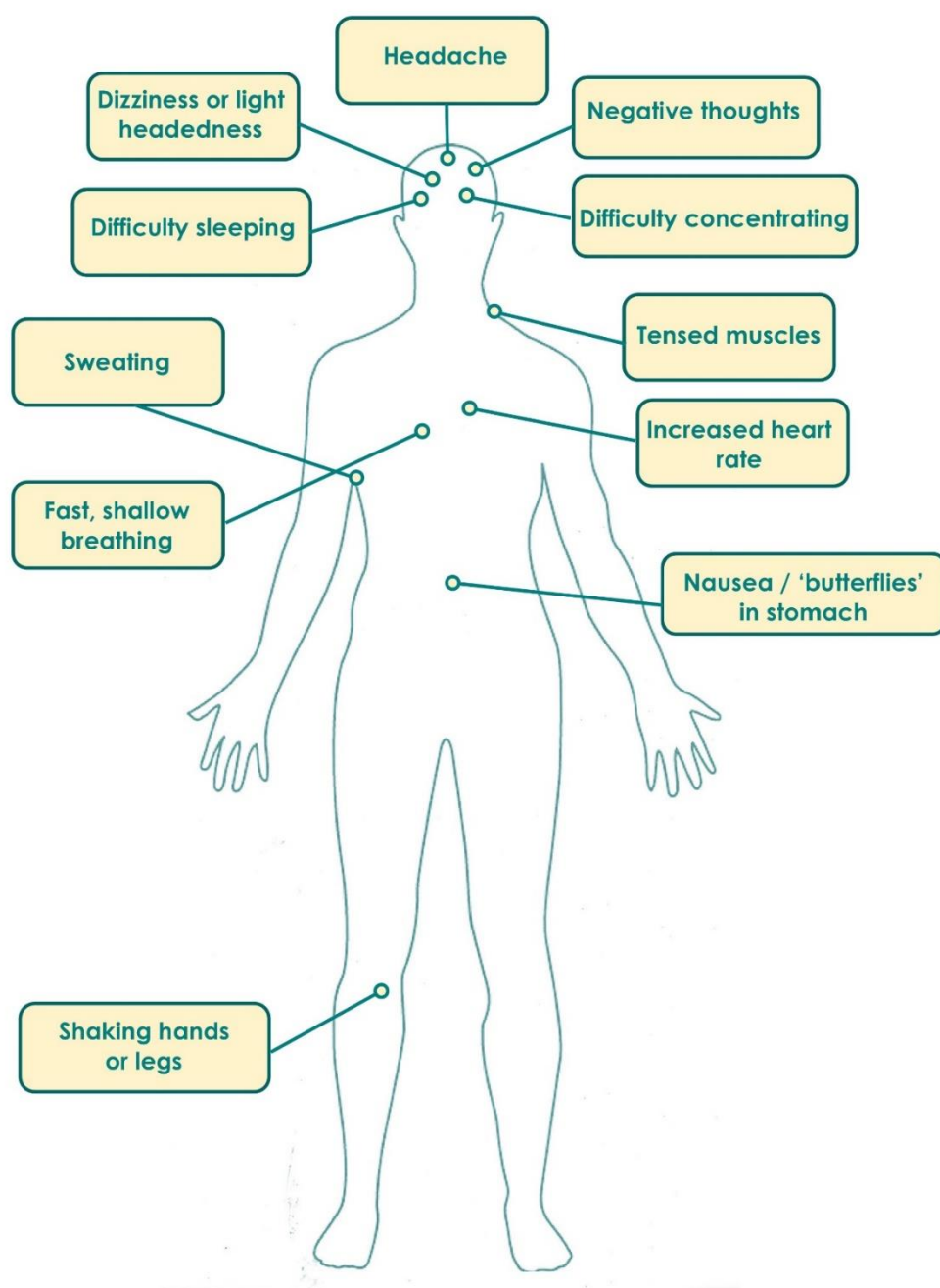
Date	Assessments	Summary

Summary of most Recent School Based Assessments

Date	

- Anxiety levels should not be judged on facial expression alone. Assessment of the child or young person's emotional state must be adapted to suit the developmental level of the child. Those supporting the autistic child or young person should be aware of the young person's signals that suggest the child or young person is experiencing high levels of anxiety. For example, increase in sensory seeking behaviour, opting out of work tasks, talking more or less than usual, or physiological signs such as breathing more quickly or change in skin colour. A body map may be helpful to help discuss the young person's manifestations of anxiety. For those with severe learning difficulties and autism it will be important to pay attention to the signs and offer calming techniques such as those discussed in section 3 and 4.

What Anxiety Does in My Body?



- Build in time to teach the young person to identify and then communicate their internal state, for mainstream pupils, resources such as the Incredible Five-Point scale may support this.

5	 Angry I've lost control. I'm not listening anymore. I could hit, kick or bite. I need a quiet place to calm down.	
4	 Overwhelmed Everything is too hard. I'm losing control and need to leave the environment I'm in. Give me space.	
3	 Frustrated I'm not getting it, I'm showing signs of stress. I should take a break now.	
2	 Anxious Trying to stay focused, but having a hard time staying on task. Use calming strategies now.	
1	 Happy Ready and willing to work	

Social Skills and Social Anxiety

Some children and young people with autism desire social relationships but may not have the skills needed to develop and maintain friendships (Bauminger et al., 2008a; Daniel & Billingsley, 2010). This can result in feelings of loneliness and isolation which impacts on wellbeing. Limited friendships can also result in young people spending more time on their own, which when done in unsupervised areas places them at greater risk of being bullied (Hebron 2012).

Repeated negative social experiences can also in turn place young person with autism at risk of developing social anxiety where there is anticipatory anxiety about future social situations, (Spain et al., 2017). Social anxiety results in the young person wanting to avoid social situations, therefore further limiting opportunities to develop and practice social skills (White et al., 2014) compounding already higher levels of peer rejection.

Case Study

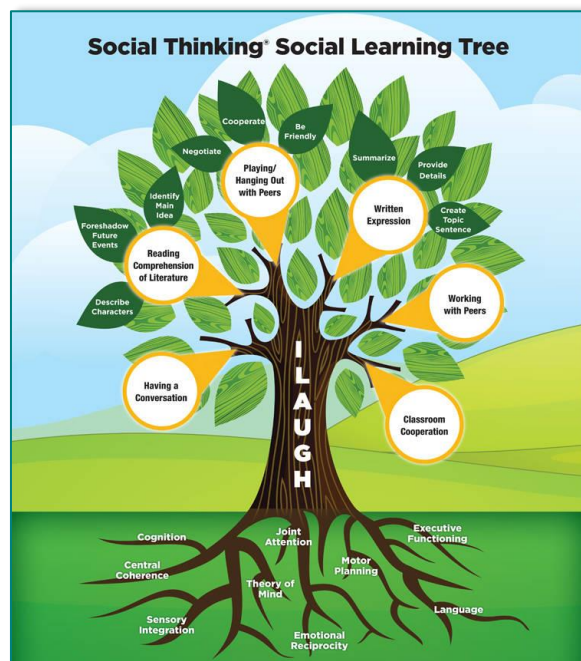
Kate is thirteen and attends a mainstream post primary school. She is shy and usually keeps to herself. Kate developed a friendship with another pupil in her class, who shares her interest in Manga drawing. Recently Kate told a teacher something that her new friend had done, causing a disagreement. Kate is unsure of how to repair the friendship and is now spending all break times on her own again.

Social anxiety can also impact on the young person's ability to access the curriculum in several ways. For example:

- Contributing to class discussions
- Asking a question
- Taking part in group work
- Giving presentations
- Participating in extracurricular activities

As social skill deficits are a key component in the development of social anxiety, supporting the development of social competencies are key to helping young people avoid negative peer interactions which, as noted, can lead to and compound anxiety. Typically, social skills are learned through implicit learning from a young age (Guivarch et al 2017). As outlined in the previous subsection autistic young people learn more effectively through explicit teaching. Therefore, it is essential that these skills are taught in an explicit and visual means.

When teaching social competencies, it is important to focus on foundation skills first rather than observable behaviours which may be targeted as part of behaviour modifications. For example, focusing on co-operation in groups, without first working on prerequisite foundation skills such as joint attention, Theory of Mind or executive functioning.



<https://www.socialthinking.com/Articles?name=social-thinking-social-learning-tree>

Moreover, where possible the language of social competency should extend to all aspects of delivering the curriculum and home life, such as referring to the daily schedule as the 'group plan' or discussing explicitly how behaviour affects thoughts and feelings of the child and those around. Often those who are experiencing social anxiety benefit from working on their observation skills of other people's social behaviour initially by becoming 'social detectives' rather than focusing inward. For more information on why we should teach social thinking please see:

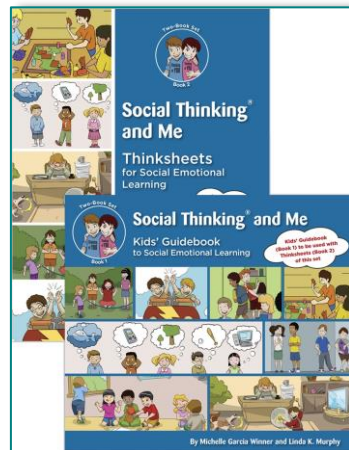
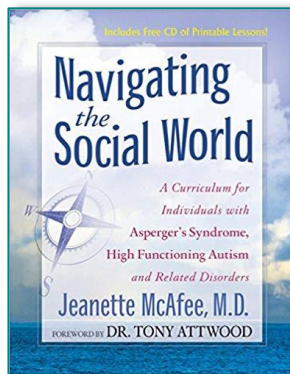
<https://www.socialthinking.com/Articles?name=improve-social-competencies-in-schools>

In addition to supporting the development of social competencies of the student with autism it is also important to empower peers to be accepting and inclusive of autistic young people. Often peers are confused about the autistic young person's behaviour and communication style and are unsure of how to include them. Without a supportive peer group, the student with autism will not have opportunities to practice their social competencies. Peer awareness programmes have been found to improve level of inclusion and attitude towards students with autism, (Campbell et al. 2004, Staniland

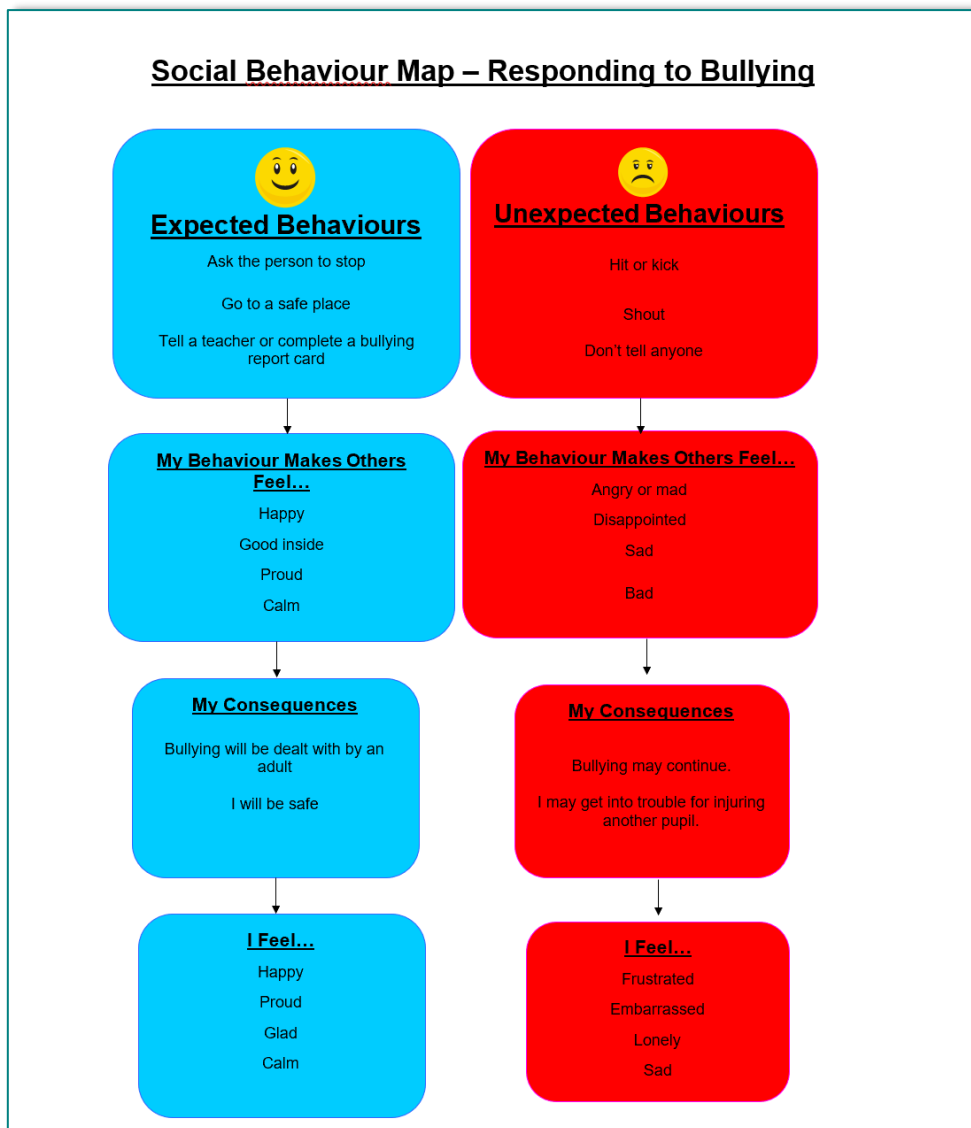
& Byrne 2013). In some schools sixth form students have received training to become mentors at break times, assisting them in being included with their peers.

Top Tips:

- Provide opportunities to teach young people about communication to increase their social understanding. A range of resources are available.



- Some young people may find group work overwhelming and anxiety provoking. Attention Autism helps increase engagement and participation within the group through having shared good times. Information on Attention Autism can be accessed at: <http://ginadavies.co.uk/>. Training can be arranged through Middletown Centre for Autism.



- Provide explicit instruction around social expectations in a positive language, such as “expected and unexpected” behaviour. This should be context specific and discussed ahead of time where possible.
- Young people are often most socially motivated when communicating about their interests. Provide opportunities for young people to spend time with others with similar interests or where possible start a special interest group. Students could also be given opportunities to teach others about their special interest where relevant to the curriculum to build self-esteem.
- Consider ways to support young people during unstructured times of the day, such as lunch clubs, buddy systems or quiet supervised areas.
- Provide peer autism awareness sessions to increase their understanding and awareness to enable them to include autistic peers more effectively.

Social Communication and Anxiety during Covid-19 Pandemic

The implications of the Covid-19 pandemic have far reaching implications for all our lives. New modes of work have been developed and we are all becoming accustomed to our new routines and increased time spent in our homes. For those on this autistic spectrum this may be particularly anxiety provoking and overwhelming. The structure of the school day which provided consistency and familiarity has been taken away. This has been replaced with great uncertainty on all aspects of their lives. Uncertainty on expectations of schoolwork, time spent with loved ones and access to familiar items, activities and foods which may have supported feelings of calm.

With regards to social communication many young people are confused and overwhelmed by the information they hear on the news. They may not understand what is happening and feel overwhelmed by the lack of clarity regarding when things will return to normal. It is important that accessible information is provided with clear overview of what is happening and the Government's advice. This may be done through a social story or other visual method. The visual supports below and others can be found on: <https://www.middletonautism.com/covid19> and www.eani.org.uk/services/pupil-support-services/autism-advisory-intervention-service-aais.



The young person may not have a system in place to communicate their worries about what is happening. Parents may be observing an increase in behaviours that challenge or sensory seeking behaviour as the young person tries to cope. Providing structure and predictability to the day through visual schedules or choice boards, such as a “Bored Board” will help. Including time to complete regulating and relaxing activities is important. The young person may benefit from having a system to express themselves. The University of North Carolina has produced a toolkit which outlines some example of activities for young people to express themselves:

<https://afirm.fpg.unc.edu/offer-opportunities-expression>

Alternatively, other young people may benefit from using a “worry doll” or “wish jar” to talk about what is happening. Some young people may enjoy keeping a schedule while others could start a “positive book” where they record one enjoyable thing from the day. This could be written, a drawing or photograph.





Many young people are experiencing feelings of social isolation from time away from their peers or extended family members. Some young people do not regularly communicate with their classroom peers outside of school time, and so may not have established means of contacting them during this time. Working with parents of peers to establish safe methods of communicating online or a Pen Pal system may help alleviate the feelings of isolation.

Conclusion

As has been highlighted in this section, communication differences in those with autism are likely to contribute to high levels of anxiety. Difficulties understanding the communication of others, expressing oneself or experiencing social mistakes can result in anxiety building in the moment. In turn this can result in anticipatory anxiety about future social situations and in extreme situations can result in social anxiety. Adults and peers can do much to support interactions with those with autism, such as reducing language, providing additional processing times and using visual supports where possible. There is also evidence that increasing awareness of autism amongst school staff and peers can result in higher support and acceptance of autistic peers.

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Section 3: Sensory Processing Differences & Anxiety

Sensory processing difficulties can contribute to feelings of anxiety for children and young people with autism. This section explains the association between sensory over-responsiveness (hypersensitivity) and anxiety. It will highlight sensory triggers which can cause emotional dysregulation and will suggest sensory-based strategies which can be used as part of an anxiety management programme.

Sensory regulation

Sensory regulation is the neurological process that governs which sensory input the brain attends to and which sensory input it ignores. The body and brain are constantly bombarded with sensory input from the environment and from within the body. Environmental input includes surrounding sights, sounds and smells, while internal input includes feelings of hunger, thirst and the need for the toilet.

A student in a classroom will receive multiple simultaneous stimuli, which need to be modulated, integrated and interpreted before an appropriate response can be made. Table 1 illustrates the types of sensory input received in a typical classroom:

Sensory system	Input
Visual	Display boards Worksheets Books and resources on shelves Movement of others around the room Objects outside the window Lighting Colours and patterns on walls, ceiling and floor
Auditory	Teacher's voice Classmates' voices Humming noise from computers, data projector and lighting

	Chairs scraping on the floor Noises from neighbouring classrooms Traffic outside
Tactile (touch)	Clothing Others nudging or brushing past Work materials e.g. pencil, paint, food
Olfactory (smell)	Other people's deodorants and perfumes Food, art materials, chemicals in science Cleaning detergents
Taste (gustatory)	Food or drink
Vestibular (movement)	Pull of gravity Movement of eyes/head/neck when looking between books and whiteboard Moving around the classroom
Proprioception (body position)	Input from muscles, both when sitting still and moving around Handwriting
Interoception	Feelings of hunger and thirst Needing to go to the toilet Tiredness Emotions

A student needs to be in a calm and alert state to learn. There needs to be enough stimulation to engage the brain and sustain attention, but not so much that the student becomes overwhelmed. If students tried to focus on all the stimuli listed in Table 1, they would become overloaded, leading to feelings of stress and anxiety.

Similarly, a child or young person at a birthday party is expected to process large amounts of sensory information. There will be bright colours, balloons and banners, people moving around the room, multiple conversations, music, singing and the smell of different party food items. Many autistic children and young people therefore become overwhelmed at parties, or in settings such as restaurants, soft play centres

and swimming pools. The anticipation of such places and events can trigger anxiety, and the child or young person may then refuse to go. Others may go to these places but become so overwhelmed that anxiety increases when they are there and is likely to result in an emotional incident.

Sensory regulation and autism

When sensory information is successfully regulated, integrated and interpreted the individual is able to respond in an adaptive way, leading to positive engagement in all daily activities. Many children and young people with autism cannot successfully modulate input, which then has a negative impact on their emotional state. At least 85% of people with autism have sensory processing differences (Baum et al, 2015; Tomchek and Dunn, 2007).

These differences are formally recognised in the diagnostic criteria for autism. The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) (American Psychiatric Association, 2013) defines the differences as:

Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects). (American Psychological Association, 2013)

Miller et al (2007) had also identified these sensory modulation patterns, but instead used the terminology over-responsiveness, under-responsiveness and sensory seeking. Sensory over-responsiveness, or hyper-reactivity, describes sensitivity to sensory input, often resulting in sensory overload and negative responses. Sensory under-responsiveness, or hypo-reactivity, refers to individuals who do not register stimuli occurring around them, or do not receive the messages from within their own bodies. Sensory seeking is the term used to explain behaviours in which people crave excessive amounts of certain input, such as movement or visual stimuli.

Sensory over-responsiveness is the category most frequently associated with anxiety in autism (Bitsika et al, 2016; Green et al, 2012; Lane et al, 2012.), with more severe sensory processing difficulties correlated with higher levels of anxiety (Uljarevic et al, 2016). A causal relationship has not yet been established. Sensory sensitivities may

cause anxiety, but the reverse may also be true. Green et al (2012) found that high scores in sensory features predicted anxiety but anxiety was not a predictor of sensory features in children with autism. South and Rodgers (2017), however, found that atypical sensory processing was a predictor of anxiety. Uljarevic et al (2016) suggest that sensory sensitivities and anxiety may simply co-occur due to common dysregulation in neural structures such as the amygdala.

The relationship between sensory over-responsiveness is possibly best viewed as a two-way process in which sensory sensitivity creates anxiety, but anxiety can also make an individual more sensitive to sensory input.

Sensory over-responsiveness, autism and anxiety

Children and young people who are over-responsive to sensory input are processing stimuli at a greater frequency and intensity than other people. They find it difficult to filter out background input, which then leads to feelings of sensory overload. A child or young person may be sensitive to specific stimuli, such as the noise of the data projector, the flickering of fluorescent lights, or the texture of paint and glue. Others may not be sensitive to specific input, but become overwhelmed by multiple stimuli in busy contexts, such as the corridors, the dining hall or the playground.

Another aspect of sensory input which is challenging for the autistic child or young person is its unpredictability. Many sensory stimuli are unexpected. Examples of unpredictable input include fire alarms, a car horn blaring, someone bumping into the child or young person, or the movement of people around the playground or a busy café. This fear of unexpected sensory input can create constant anxiety for autistic children and young people as they wait for the next unexpected noise, touch or smell.

Sensory sensitivity, and the anxiety associated with it, can fluctuate throughout the day. This is because sensory input is cumulative, building as more sensory experiences are added. A child or young person may be calm in the morning and able to cope with various sensory stimuli, but as the day progresses, they may become increasingly agitated and less able to cope with the sensory demands. This can lead to an emotional episode later in the school day, or when returning home from school.

Behavioural responses to sensory-based anxiety

Students who are over-responsive to sensory input and fear the unpredictable will perceive stimuli as threatening and potentially harmful. As Adam Harris (2015) explains:

Every noise, every smell, every texture isn't just something that's unpleasant, it's something that you actually cannot bear.

Many autistic students will be hypervigilant to sensory input which they consider to be potentially harmful, and this then affects their ability to make a reasoned analysis of risk, thus causing heightened anxiety (South and Rodgers, 2017). This then triggers a fight, flight or freeze response.

1. Fight response

Sensory over-responsiveness can result in aggressive behaviours as the child or young person reacts against the sensory input which is causing anxiety. They may hit someone who accidentally nudges them or may break a musical instrument if the noise is causing distress. It should not be viewed as a deliberate intention to cause harm or damage, but rather as a form of self-protection against stimuli which they perceive as harmful. This may also be described as 'sensory defensiveness'.

2. Flight response

In sensory terms, flight behaviours are referred to as sensory avoidance. When sensory input causes extreme anxiety, the child or young person may try to escape from it by running out of a building or hiding under furniture. Some may refuse to engage in activities which they perceive as unpleasant and harmful, and this can then be mistakenly viewed as oppositional or defiant behaviours. A child or young person may refuse to engage in Art due to tactile sensitivities or refuse to go to family events because of auditory over-responsiveness.

Some flight responses are less obvious. A child or young person may engage in a disruptive behaviour knowing they will be removed from the setting. If they are feeling anxious in a noisy playground or birthday party, for example, they may hit out at another child, knowing that an adult will then remove them from that setting to a quieter place.

Insistence on sameness can also be a sensory avoidant strategy (Black et al, 2017). A student may feel anxious about the unknown sensory stimulation involved in an unfamiliar activity or place, and so instead follows a rigid routine of familiar activities in which the sensory input is seen as safe and predictable.

3. *Freeze response*

In extreme cases, a child or young person may be so overwhelmed by sensory stimulation that it leads to a freeze or shutdown response. They become completely disengaged from surrounding activity and are unresponsive to other people. There can also be physiological changes, such as sweating and change in pallor.

4. *Repetitive behaviours*

When an autistic child or young person is in a heightened state of anxiety due to sensory hyper-reactivity, there is often an increase in repetitive behaviours, such as pacing, rocking or flicking fingers in front of eyes. Such behaviours help individuals to block out unwanted sensory input as they focus instead on the sensory stimulation they are creating for themselves, and this overrides external stimuli from the surrounding environment. Repetitive behaviours also provide predictable and familiar sensory input which gives the anxious child or young person a feeling of control in overwhelming settings.

Some students will engage in behaviours of an extremely high intensity in order to block out unwanted input and these can sometimes cause harm to themselves e.g. a child who repeatedly bites own hand. This biting causes pain and this then becomes the primary source of sensory stimulation and helps the child to block out overwhelming input. This type of behaviour is a clear indicator that the individual is experiencing very high levels of anxiety.

Sensory-based strategies

Sensory-based strategies are an integral part of any anxiety management programme, given the significant correlation between sensory over-responsiveness and anxiety in autism.

1. Low arousal environment

Many sensory triggers can be managed through the creation of a low arousal environment. Some autistic children and young people will be more regulated in a setting which has reduced stimuli, and this will then facilitate a state of emotional readiness for learning, interaction and play. A low arousal classroom will incorporate some or all of these recommendations:

- Muted colour on walls e.g. pale green, yellow or blue.
- Removal of display boards, or only a minimal number of displays.
- Blinds on the windows.
- Removal of fluorescent lighting; use of reading lamps where required.
- Resources stored out of sight; open shelving covered with a plain fabric.
- Rubber stoppers on chair table legs.
- Carpeted areas and cushions to absorb sound.
- Odour-free resources used where possible; rooms kept well ventilated when using art, science and cooking materials.

At home, it may not be possible to reduce sensory stimuli in every room, but it is useful to have some spaces with minimal sources of sensory input. If the child or young person finds homework and mealtimes stressful, the removal of distracting stimuli can reduce anxiety. This may include switching off the TV, extractor fan, washing machine etc at these times, removing clutter from the desk or dinner table and keeping the window open to dilute the smell of food cooking.

It can be helpful to carry out an assessment of the environment, which will then highlight what adjustments may be required to manage sensory input. The Autism Education Trust has a sensory audit which can be downloaded at this link:

<http://sensory-processing.middletonautism.com/sensory-strategies/sensory-audit-for-school-and-classrooms/>

2. Calm spaces

It may not be possible to create whole rooms as low arousal environments, but calm spaces can be easily established. These are areas in which sensory stimulation is minimised, giving the child or young person a place in which they can emotionally regulate. It can be small room, a corner of a room screened off or pop-up tent. It may be adequate for some to simply have a blank space in which to calm down, while others will need calming resources, such as background music, weighted items, or stress balls. See the sensory section for related information on calm breaks.

Case Study

James is a 6 year old boy with a diagnosis of autism. He lives with his parents, younger brother and sister. He shares a bedroom with his brother. James is overresponsive to noise, touch and visual input, but mum says that the house is always busy and noisy due to his younger siblings. James often came home from school in an agitated state and had emotional outbursts in which he hit out at his siblings. His parents purchased a pop up tent which is set up in a bedroom, with a beanbag and fidget toys inside. James now goes there as soon as he comes home from school and it helps him to calm and regulate before engaging in home activities.

If the calm area is going to be a communal space accessed by several people, such as in the school context, ensure calming resources are stored out of sight and selected by the individual child or young person as required.

The link below describes the establishment of a 'sensory lounge' in a post-primary school:

<https://sensory-processing.middletownautism.com/sensory-strategies/setting-up-a-sensory-lounge/>

3. Removal of trigger

If a sensory stimuli is known to cause stress, consider removal of it where possible. Some input can be removed and replaced. A child or young person who is tactile overresponsive may dislike working with art materials such as paint and clay, so could instead complete projects using pencils. At home, some children and young people may become anxious in personal care activities because they dislike the smell of soaps, shampoos and shower gels. Alternative odour-free products could be used instead.

4. Deep pressure input

Many autistic children and young people report that deep pressure input is calming, and helps them to regulate when feeling overwhelmed by sensory input. Some respond positively to weighted items, such as weighted blankets, lap pads or compression garments. It is essential that the guidelines on such items are closely followed, and where possible advice from an occupational therapist should be sought before use. Others prefer active engagement in proprioceptive activities, such as wall pushes, chair presses or lifting weights.

Case Study

Shay is a 12 year old autistic student in post-primary school. He has always been easily overwhelmed by sensory input and responds positively to proprioceptive activities. In primary school he used a 'calm card' to request breaks and he would then do star jumps and wall pushes at the back of the classroom to regulate himself. He now refuses to use the 'calm card' or to engage in proprioceptive activities as he states he "doesn't want his classmates to notice him doing something different". The SENCo has shown him how to do chair pushes when feeling overwhelmed and squeeze a stress ball as he can do these activities discreetly at his desk. He has also been allocated responsibilities throughout his school day, which provide proprioceptive input, including pulling out the P.E. mats and setting out chairs in the Assembly Hall.

Middletown Centre for Autism provides examples of such activities at this link:

<https://sensory-processing.middletonautism.com/sensory-strategies/strategies-according-to-sense/#proprioceptive>

5. Ear defenders

Ear defenders can be a useful resource for those who become anxious in response to specific noises (e.g. fire bell, washing machine) or overwhelmed in noisy places (e.g. dining hall, shopping centre). They reduce the volume and intensity of surrounding noise, but should only be worn when the noise is present and removed as soon as it ends. They should also be used as part of a desensitisation programme, in which they are removed for gradually longer periods to help the child or young person accommodate to noise. The end goal of the programme would be to remove them completely once the noise can be easily tolerated, and only have them as a fallback strategy on difficult days when anxiety may be more heightened than usual.

Case Study

Alice is 5 year old girl recently diagnosed with autism. She is a pupil in an autism specific class in a special school. Her classroom has been set up to provide a low arousal environment, but Alice was very overwhelmed by the noise when she went to the dining hall and she had become so anxious that she was refusing to transition from the classroom. Her teacher introduced a desensitisation programme in which Alice wore ear defenders in the dining hall, and after 1 week she removed them for the last minute in the dining hall, and this was gradually increased each week until Alice was able to stay in the dining hall for the full dinner without ear defender. Her parents are now going to use the same strategy to reduce her anxiety when in the local shopping centre.

There are alternatives to ear defenders, such as ear plugs or headphones.

6. Desensitisation

It will be beneficial for the child or young person if they can become more tolerant of sensory stimuli as this will help to reduce daily anxieties. Increasing tolerance of stimuli is a long-term process referred to as desensitisation. It

involves the very gradual and controlled exposure to the unwanted input until the child or young person accommodates to it and is more able to cope with it. (Desensitisation will be further explored towards the end of this chapter.)

Case Study

Sam is a 14 year old autistic boy who is overresponsive to tactile input. He has always preferred a bath and refused to take a shower. His family have recently moved house in which there is only a shower. Sam became extremely anxious when asked to shower, stating that the water hurts his skin. His dad has set up a digital timer showing him how long he is to stay in the shower. They have agreed to start with 20 seconds and increase the time in 10 second increments every week. If Sam becomes overwhelmed, he can turn off the shower or step out of the shower.

It can take a considerable length of time for desensitisation to be effective, and so in the immediate term, it is essential to continue with other strategies such as calm breaks and removal of sensory triggers.

Conclusion

Many autistic students are over-responsive to sensory input and experience overload in the school setting. This sensory overload increases anxiety and can lead to fight, flight or freeze responses as the student tries to reduce anxiety by managing the surrounding sensory stimuli. Strategies to support students in regulating sensory input will be discussed in a later section.

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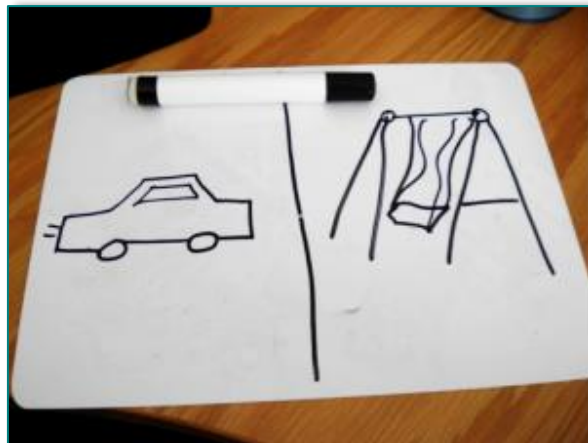
Section 4: Difficulties in Flexible Thinking & Anxiety

Children and young people with autism lack flexibility in their thoughts and perceptions. This means that they often find it difficult to manage unexpected change and cope with unpredictability within their day. This often presents as an insistence on sameness within routines, activities, people and places. Even minor changes to these routines can escalate anxiety for a student with autism. Similarly, the introduction of new people, places or unfamiliar social situations can increase anxiety, which in turn creates a greater drive for routine and sameness by the student.

Difficulties within flexibility of thought can also impact social interactions, children and young people may find it difficult to understand and accept others viewpoint. It can also be challenging to understand the feelings of others or see things from their perspective which adds confusion to social situations.

Strategies to Support Flexible Thinking

- Prepare students for changes within the school day – for example if there is going to be change in teaching staff. Communicate this to the student as soon as possible, preferably the day before the change happens, show a photo of the substitute teacher to the students. A social story can also be used to help the student understand what to expect.
- Help the student understand any changes to the daily routine or activities by using a visual schedule, timetable or first and then board. This should be presented at a level the students easily understands.



- Use a visual change symbol on the visual support to help the student understand what part of the routine or activity is changing and visually present what is happening instead.



- For Post Primary students a visual change card can also be used to communicate change in routine, activity or change in teaching staff. This is a powerful tool which can help children and young people to understand and more readily accept a change in their normal schedule.

There is a Change



_____ will be changed on _____

this change is because _____

Now _____ is happening on _____

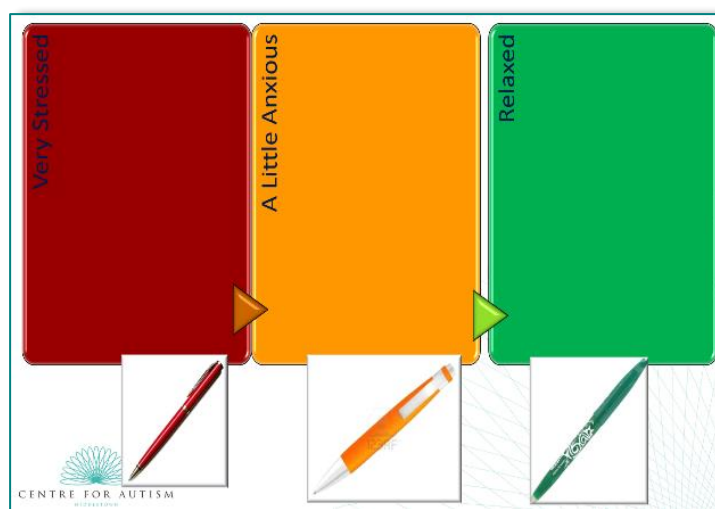
- Use comic strip conversations to visually draw social situations and conversations with others. This intervention tool allows you to draw the thoughts, comments and intentions of other people building the students awareness of how others may be thinking or feeling.
- When students experience difficulties work with them to problem solve by discussing possible solutions. Present these visually to support the students understanding.
- Cue or prompt cards for common problems can be created for the child or young person, for example; what to do when I miss the bus, what to do if I lose my dinner money, what to do if I forget a school book or homework.

If I forget my homework

- I will tell my form tutor
- I will tell the subject teacher when I get to the lesson
- The teacher will tell me where to put my homework when I bring it in tomorrow

- Teach children and young people the importance of asking for help, agree with the student a method of requesting help which works for them. Ensure the system allows the student to access help immediately. Asking for help can be facilitated in many ways, some students may prefer to use a help card rather than verbally communicate help. See section 2 for an example of a 'help card' visual support.

Post Primary students may prefer a more discrete method of asking for help by using coloured pens to indicate whether they are managing, for example green represents “I am doing ok” and red to indicate “I need help”.



- Prepare students for new activities, events, school trips or visiting new places by using social stories to clarify the expectations. Social stories communicate information about a context, skill or concept in a clear and meaningful way to autistic students. Include photographs of new people or new places to further familiarise the student. Providing this information can reduce anxiety and improve the person’s ability to cope with new experiences as it provides clarity and predictability.

Flexibility of Thought During Covid-19 Pandemic

Structure and routine are often essential for many children and young people to successfully navigate their day. Structure and sameness can add predictability in a

world that can be overwhelming, confusing and anxiety provoking. Please note that the examples of changes to daily life used below are relevant at the time of writing but are subject to change.

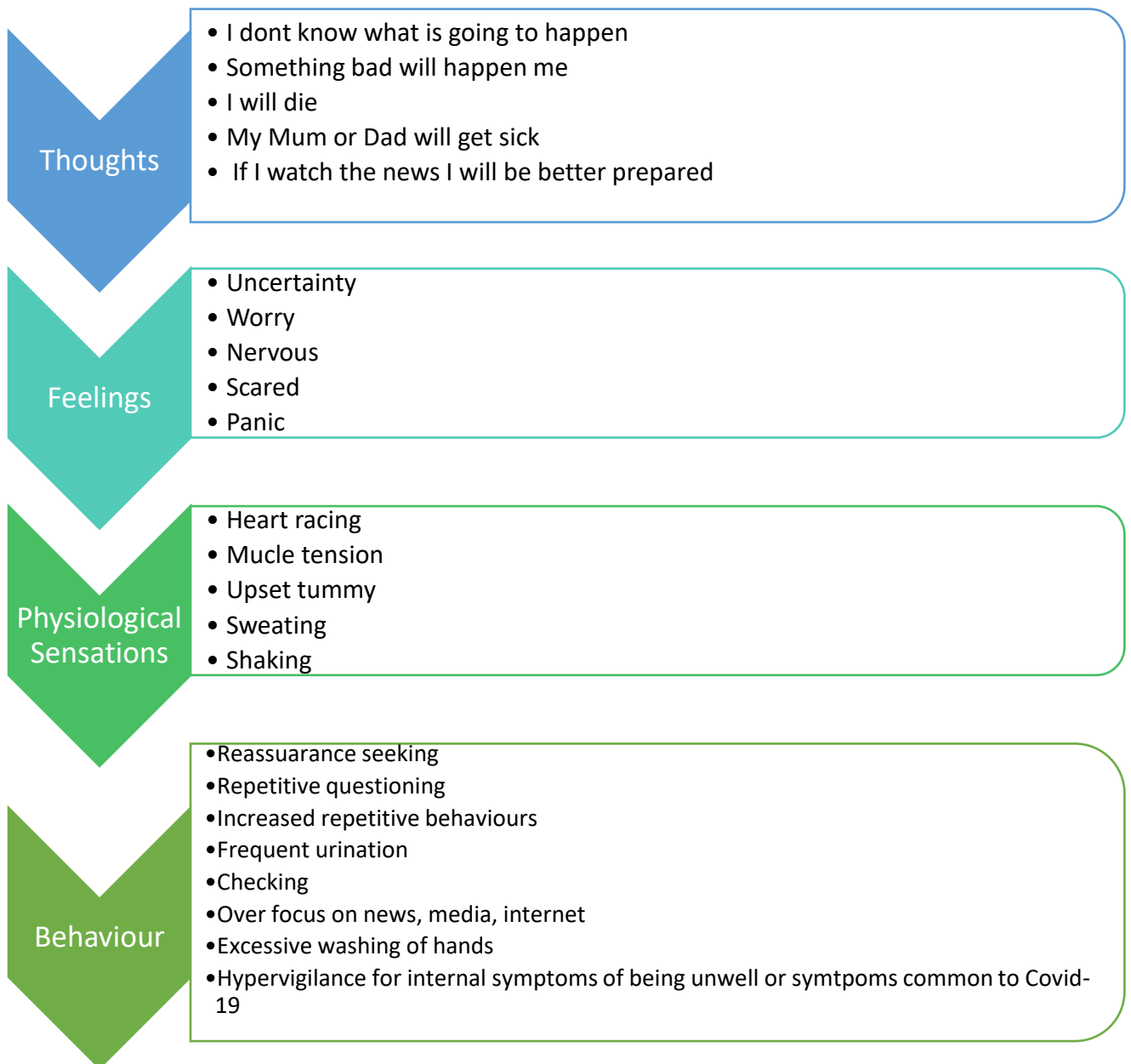
As a result of Covid-19 the Government has introduced restrictions on travel, recreation activities and school attendance. Not being able to attend school as normal may cause high levels of stress and anxiety to many students with autism and going back to school is likely to be challenging too. Other disruptions to routine such as not being able to go to their favourite park, being unable to attend leisure activities such as swimming, or visit close family members such as grandparents will significantly alter many routines. In addition, restrictions may have impacted on autistic students accessing preferred food, this may be because they cannot visit local food outlets or as a result of panic buying preferred brands may be not be available. This sudden change in routine and lack of certainty about the near future will be difficult for many children and young people to understand and cope with.

It may be difficult for some children and young people to understand the confusing emotions and feelings they are experiencing as a result of Covid-19. It will also be difficult for them to understand and interpret the emotions of other family members such as parents and siblings at this stressful time. This can be particularly confusing and overwhelming and will likely further exacerbate anxiety or other pre-existing mental health conditions.

It is known that autistic children and young people can respond to bereavement differently than their typically developing peers. Although many people who are diagnosed with Covid-19 will display mild symptoms and go on to make a full recovery unfortunately some will not. It is important that we recognise that some families will experience a bereavement either within their immediate family or within their school or wider family network. A sudden and unexpected loss is likely to add further confusion and anxiety.

An unprecedented degree of uncertainty will be experienced by many children and young people with autism. Research shows that intolerance to uncertainty (IU) seems to play a significant role in the development and maintenance of anxiety in individuals with autism (Boulter 2014; Maisel et al 2016). In addition, IU is associated with anxiety and repetitive behaviours in adolescents with autism (Joyce 2017); so, parents may see an increase in repetitive motor movements, speech and other stereotypical behaviours. The behaviours may become more frequent and intense, and the child may be completely preoccupied by them. Examples include blinking, flicking fingers close to eyes, pacing, rocking, teeth grinding and repeating a favourite phrase or sound. Repetitive behaviours escalate at times of anxiety because the child is attempting to regulate emotions by focusing on familiar input in order to block out sources of stress. The repetition is also comforting because it tends to be rhythmic and offers predictability when everything else around the child seems unpredictable.

The current heightened levels of anxiety and uncertainty will affect how children think and feel, and change how they behave, and is usually accompanied by unpleasant physiological sensations. The diagram below gives some examples of anxious thoughts or images; examples of common emotions or feelings that may be experienced alongside a range of unpleasant somatic sensations; and lists possible behaviours which may increase during this time. This is not an exhaustive list.



Case Study

Ben is 15 years old and has a diagnosis of autism and severe learning disability. Ben attends a specialist school setting but has been off school and social isolating at home with his family for 3 weeks. Ben enjoys the structure and predictability of the school day and has found this unexpected change in routine distressing.

Ben's parent reports an increase in repetitive behaviours particularly in the evening time; he paces up and down the living floor, tapping his chest repetitively, pausing and rewinding video clips from his favourite children's show and checking all the clocks are in sync. His Mum reports more frequent urination and has observed that he becomes hot, sweaty and his voice is hoarse from repetitive talking and questioning. Ben is finding it difficult to settle to sleep at night and seeking reassurance from his parent beside him until he falls asleep which can take 2-3 hours. His sleep is disrupted with him often getting up during the night to carry out repetitive behaviours such as pacing around the rooms and checking the clocks again.

Ben is teary and says he misses his friends and wants to go to his Granny's house. He is trying to make sense of this confusing time and frequently uses delayed echolalia in the same intonation as his favourite tv characters along with scripting. Ben repeats "it's not meant to be like this", "I feel really sad" and "the germs have gone away".

Strategies to Support

- Limit the amount of exposure primary and post primary children have to news, media and social media channels. Some young people may want to access as much as information as they can to try to reduce their feelings of uncertainty. However, rumination and overfocus are part of a vicious cycle which in fact maintains anxiety.
- When children do hear or read something upsetting, talk about it to help ease fears. Try to be honest and give simple answer to the questions they have, avoid telling the child to not worry, their feelings need to be validated. Encourage the child or young person to draw, write down or ask you questions they may have. Thinking about their learning style and considering using visual

supports to help them process your answers such as a white board or simply a piece of paper and pen.

- Psycho-educate the child or young person about Covid-19 as confusion and uncertainty can fuel fear. Information and language used should be clear and adapted to the person's cognitive ability. Support this with the use of a visual support or a social story (please see Covid-19 resources from Middletown Centre for Autism). When children or young people are highly anxious, they often engage in reassurance seeking, asking the same questions over and over. Take care when responding to reassurance seeking as this can often perpetuate the problem. Write down or draw your answer to help the child process the information if this is suitable, if they continue to repeat the same question direct their attention to the visual support. The following link provides more information on managing reassurance-seeking in children.
<https://www.anxietycanada.com/articles/addressing-excessive-reassurance-seeking/>
- Where possible continue to adhere to familiar routines; although many routines will have been disrupted there are some which can be kept the same, such as morning routine, mealtimes, bath times and bedtime. It may help to replace the activities which are no longer possible with alternative home activities in order to maintain routine. Continue to use visual supports such as weekly or daily planners so the child or young person understands what is happening and when. Activities which include exercise are beneficial in managing anxiety and promoting emotional regulation.

Executive Dysfunction

Executive functions are a set of processes including planning, focusing, shifting attention, initiating activity, self-regulation and impulse control. Some autistic children have difficulty with executive functions and demonstrate behaviours including impulsivity, disinhibition and difficulty controlling emotions (Ozonoff et al 1991; Ozonoff and Jensen 1999; Leung 2016). Executive functioning is a complex system which is involved in everything we do in a day.

Poor executive dysfunction affects children and young people's ability to organise themselves and their belongings. This can limit success in daily activities, such as getting dressed or catching a bus, which can fuel negative thinking patterns and contribute to anxieties. Difficulties in executive functioning also impact on the ability to select and utilise emotionally regulating strategies in stressful situations

Strategies to support

- Checklists - being able to picture and visualise each part of a specific routine or task helps us plan, organise, and execute larger, more complex tasks. Visual supports can also aid organisation and sequencing to support the completion of self-care tasks. Each sequential step is not always obvious to children with executive dysfunction. Visual checklists can show the necessary steps in sequential order which reduces the mental strain and makes the task more achievable. Successful completion of tasks improves children's self-esteem and confidence.
- Daily Planners and visual schedules – children and young people who experience executive dysfunction often have poor working memory. This means it can be difficult to remember school related tasks such as homework, assignments, upcoming projects. Not being able to remember homework tasks can increase anxiety for autistic students. Visual planners and a strategy for recording homework can reduce some of the stress associated with school-work and homework.

These key characteristics of autism create a world which is confusing and chaotic for an autistic child, and this is further compounded by difficulties in recognising and communicating when they feel anxious or knowing how to ask for help. The factors listed above predispose an autistic child to developing anxiety, but then there are certain events which can trigger anxiety at any time.

Proactive and Preventative Anxiety Management Strategies

Anxiety management programmes usually integrate both proactive and reactive strategies.

Proactive strategies are designed to reduce the risk of anxiety occurring or escalating; they include strategies to equip the child with appropriate communication, emotional regulation and life skills.

Reactive strategies are more 'on the spot' strategies which are used to help the autistic individual manage their anxious response, the aim is to keep the child and those around them safe from harm during anxious meltdowns. These strategies are necessary because the supportive adult cannot prevent all anxiety provoking situations in the autistic student's day, therefore at times, reactive strategies to help the autistic individual manage anxiety will be needed. Like proactive strategies, reactive strategies need to be individualised to meet the needs of the autistic person. A good anxiety plan should have more proactive than reactive strategies.

Proactive strategies are essentially preventative measures which aim to stop or reduce the likelihood of an individual getting anxious. This is sometimes referred to in education and schools as creating an autism competent learning environment.

Proactive strategies include:

- Visual Supports - Implementing visual routines and schedules in various forms, depending on the understanding and developmental stage of the autistic individual, is known to be effective in preventing anxiety. Using a visual support, such as a schedule can help clarify what is expected and may reduce the chances of an emotional response. Visual supports strategies include inconspicuous techniques such as iPads, emails, smart phones, images stuck into the cover of a file etc. The type of visual you use, will depend on the age and cognitive ability of the person you are supporting. Other visual supports include change cards - preparation for change in an activity, situation or environment can help reduce or prevent an anxiety response and/or emotional

outburst for an autistic individual. Using visual strategies can be proactive in helping prepare the autistic individual for change.

The type of visual used will depend on who is being supported and what they need support with. For example, for an autistic individual who has anxiety responses with time-based concept such as the passage of time or waiting, using visual supports makes time much more tangible and real. For the passing of time, an alarm or countdown timer on an electronic device could be used. For teaching 'wait', a visual with the word 'wait' or a symbol representing wait along with an electronic timer or a countdown strip could be used. The traffic light colours of green, yellow/amber and red can also be used to teach wait. When using these the autistic individual is shown a yellow/amber coloured object or card to mean get ready to wait, a red object or card is shown to communicate waiting, and a green card or object is used to communicate that waiting is over, it is time to move or to access an item. The autistic individual must be taught what the different colours represent before being expected to use them effectively.

- Special Interest - Utilise the child or young person's special interest. Many students find engaging in their special interest to be calming and relaxing as it is often predictable and familiar.
- Reduce complex information – there are many ways in which an education professional can reduce the amount of information required to process throughout the school day. This can include reducing the amount of verbal information which is given at any one time. Keep instructions short, direct and specific. Provide a visual reminder of multi-step instructions within tasks. Allow enough processing time for the student to understand and comprehend verbal information.
- Manage sensory input – classrooms and other areas within a school can be sensory rich environments. Consider the sensory input within your classroom and reduce or remove unnecessary sensory inputs. Be aware of the student's specific sensory differences. Create a consistent quiet relaxation space either

within your classroom or wider school environment. Considerations for a calm, relaxing space include gentle lighting, calming music, sensory items, and the incorporation of relaxation routines for the student.

- Offer choice – being able to make choices for self is an accepted part of a person's life. Think about the number of choices you make in your day: when you get up you choose what you will eat for breakfast, what clothes to wear and so on throughout the day. Choice does not only apply to home life, you make choices about what you want to do with your life, places you want to visit, people you want to socialise with etc. We often underestimate the amount of choices we make in our lives. For autistic individuals, making choices can be very difficult and cause an anxiety response. Some autistic individuals may not understand what their choices are or recognise times/situations when they have a choice. Some autistic individuals may not be able to communicate their choices to others.



Providing opportunities to make choices supports the autistic individual develop a sense of self, increases autonomy, builds self-esteem and improves problem solving skills. It is important that autistic individuals are provided opportunities to make choices throughout their day. Providing opportunity to communicate and make choices also helps reduce the likelihood of an anxiety response and gives the autistic individual some control over aspects of their life.

- Structure downtime – unstructured downtime can increase anxiety responses for the autistic individual as they may not intrinsically know what to do during these times. Free time should be structured for the autistic individual who finds this difficult. In the school/college or employment environment, peer mentoring can be set up with identified people who can assist the autistic students/employee in the yard, at lunch breaks or during other unstructured times in the day. In the educational setting, Lunch Clubs are a great way for children and young adults with autism to practice their social skills in a structured and safe environment.

Lunch-time Activity Options		
Activity	Rules	Names
	Only 2 students may play this at one time.	
	See instructions inside board game	
		
		
		
		

- Movement breaks – these are essential throughout the day for the autistic individual whether it is in a school or work setting. A clear time limit should be set. Using a visual support such as schedule can help the autistic individual identify when they will get a break. Where possible, the break should take the autistic individual away from their work desk or station. When used as a

proactive strategy, calm breaks should be a consistent part of the child's daily routine and should be given even when the child is having a 'good' day.

Reactive strategies include:

- Remove the source of anxiety - If possible, remove or eliminate the source creating anxiety for the autistic individual. If a specific activity causes anxiety or an anxiety response, and it is not mandatory for the autistic individual, excuse or avoid this particular activity. It is worth considering the aim of the activity and whether it can be achieved through an alternative activity. In the school environment the autistic student may be able to have a differentiated timetable where they are excused from subjects, tasks or events that increase anxiety.
- Reduce the source of anxiety – It is not always possible to completely eliminate the source of anxiety but it is usually possible to alleviate the anxiety provoking triggers or hotspots. The source of the anxiety in certain environments could be removed or changed to alternatives e.g. fluorescent lighting which hums and flickers can trigger an anxiety response for an autistic individual, changing the lightening to LED can eliminate anxiety responses. The noise of an alarm or bell, such as the school/college or workplace bell indicating the end of a class or shift can be anxiety provoking for an individual with autism. Changing the sound of the bell and/or lowering the tone may reduce the anxiety for the autistic individual.

If a specific activity creates anxiety, limit the amount of time the autistic individual is expected to participate in the trigger/hotspot activity and gradually increase exposure time to the activity over a number of weeks. If the autistic individual gets anxious completing certain tasks, such as homework, differentiate the task and reduce the demands placed on the autistic student.

If social interactions such as group work causes anxiety for the autistic individual, limit the amount of group activities the autistic individual is expected to participate.

1-2 paired/group tasks each day may be adequate for an autistic student. If homework/coursework or a work project is causing anxiety, ensure deadlines are spread over a reasonable time. It is also important to remember that if the autistic individual has participated in group work in school or in work, he/she may need quiet alone time during the day or in the evening.

- **Redirection** – The supportive adults should always remember that the autistic individual is likely feeling anxious, therefore the supportive person should depend on visual supports and minimum verbal instruction to redirect the autistic individual to something away from the source causing anxiety. The anxious autistic individual should be redirected to a calming or special interest activity using a gesture or visual support.

More ‘On The Spot’ Strategies

Trembath and colleagues (2012) found withdrawing, removing self, or being guided away from the anxiety-inducing situation to a calm area was the most common strategy across participants in their study.

Brenda Smith-Myles details strategies effective in helping the autistic individual regain control (2005). These are often referred to as ‘On the Spot’ strategies and include movement and calming activities. It is important to remember that when the autistic individual is feeling anxious they are unlikely to be able to coherently think or process what is being said.

- **Movement:** Smith-Myles (2005) identified the ‘Just walk and don’t think’ strategy as being an effective on the spot strategy. This is where the supportive adult just walks with the autistic individual. During the walk, the supportive adult is silent, calm, non-confrontational and shows the least amount of reaction to whatever the autistic

individual verbalises. During the walk the autistic individual can say whatever they want without fear of argument or repercussion.

- **Calming activities** can also be used as on the spot reactive strategies. The calming activities chosen will be personal to each autistic child or young person. It will take the supportive adult time to work out which activities are calming for the autistic individual they are supporting. To do this, the autistic individual should be exposed to a range of activities when regulated and their engagement with/response to the activity observed as well as the autistic individual being asked how the activity made them feel.

Examples of calming activities might be: reading/looking at a special interest book or magazine, listening to music, colouring (for adults and children) rocking/rolling on an exercise ball-the deep pressure input and movement is known to be calming for many autistic individual, jumping on a trampoline, lifting weights or engaging in activities such as hanging out wet towels, stacking chairs, carrying books or groceries, and raking leaves- the proprioceptive input to the muscles is known to be calming for autistic individuals.

Educate child or young person about anxiety – Increase Self-Awareness

There are several steps involved in building a child's 'self-understanding'. This is a person's knowledge of their own internal emotional state and involves being able to identify and label a range of emotions appropriately. It also includes understanding how emotions work and being able to appropriately express and talk about emotions. Because children with autism often present with limited emotional language, they can struggle to identify and label the emotion they are experiencing. Affective education focuses on teaching the 'language' of emotion, this is an essential area of learning for children with autism.

When teaching the language of emotion, explore one emotion at a time. An emotion scrapbook can be created to support understanding of each emotion. This can include

pictures of people, such as family members and characters from a child's special interest expressing the different emotions or different degrees of emotion.

Parents can use a range of games and resources which appeals to the visual learning strength of individuals with autism, to support identifying emotions in not only themselves but other people. A body map can help identify and explain to the child the physical symptoms they may experience with different emotions (see section on “Expressive language skills and using non-verbal communication” for further information).

Emotion Thermometers

Emotion thermometers and the Incredible 5 Point Scale are effective tools for supporting a child with communicating an emotion, such as anxiety. It also provides a means of identifying the level of intensity of their anxiety at any given time. It can help a child build up their language of anxiety and support accurate expression of how they are feeling. These strategies can be adapted to suit the child's special interest, which may promote motivation and engagement. Ensure these strategies are portable, particularly when first teaching the resource. This will help the child generalise the language and skills across situations and environments. The Incredible 5 Point Scale (previously referred to in the section on “Expressive language skills and using non-verbal communication”) provides a visual breakdown of anxiety and includes individualised anxiety strategies for each stage, it directs the child to a strategy based on their reported level of anxiety. Another example is provided below.

	<i>How I feel</i>	<i>What I can do</i>
5	Panic has set in!	See my teacher. Take a 2 minute walk in the room.
4	I know this stuff but I can't remember.	STOP. Put down my pencil. Put head down and breathe for 30-60 seconds.
3	This test is <u>so</u> hard!	Breathe and try to relax.
2	Okay-I have questions I might double check.	Slow down! Read carefully and look for things I know.
1	Calm- I know this	Keep going!

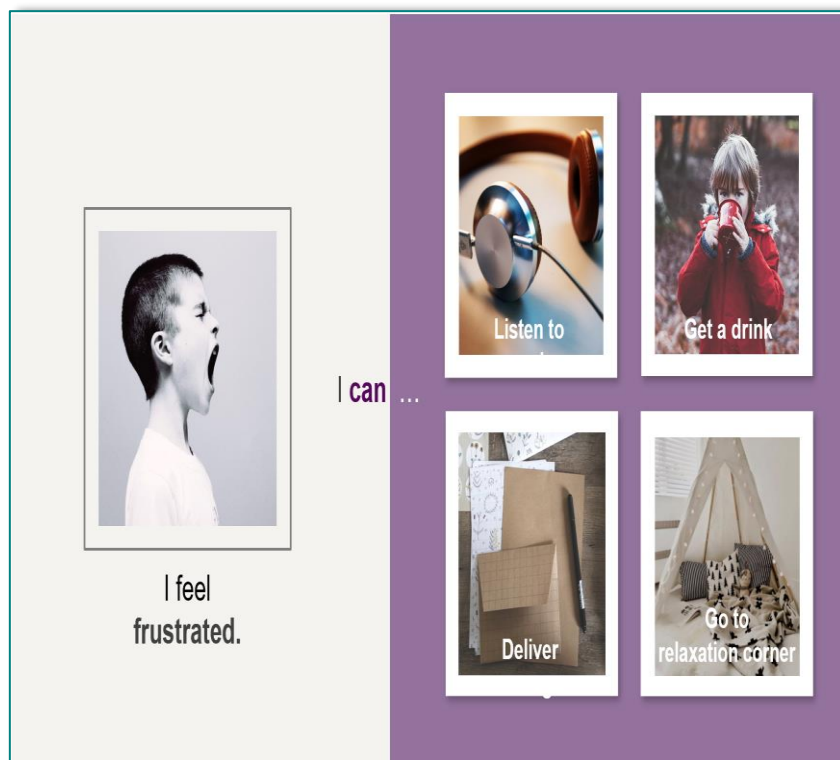
There are many different ways a child can be taught to communicate their anxiety. The strategy you use for your child will depend on their age and developmental ability. Some children like to use emotion cards or break cards to communicate to an adult they are feeling anxious. Other children may not wish to use an obvious prompt in front of others, so you may need to provide a more discrete method. For example, coloured pens to represent anxiety are useful for mainstream pupils, who can hold or flash a red pen to their teacher to indicate that they need a break. The child can effectively communicate their anxiety without drawing attention to him or herself or letting others in the class know what he or she is communicating.

Self-Regulation Prompt Cards

After teaching the individual about different emotions including anxiety, provide small portable emotion cue cards. Encourage the child or young person to be involved in designing and choosing the strategies included on their prompt card.

Prompt cards should be portable, usually credit card size (if appropriate for that child) so the child can carry them around, they act as a visual reminder of which relaxation or anxiety strategies they can use when they are feeling distressed.

Initially the supporting adult will likely need to prompt the student to look at their cue card when they recognise the person is becoming anxious. However, as you continue to teach about recognising their own anxiety the child or young person will become better at using their cue cards independently.



Desensitisation

As previously explored in the section on Sensory Processing Differences, desensitisation is a process of very gradually introducing the student to the source of their anxiety and increasing their tolerance of it, for example gradually increasing the time the child or young person spends in the environment/activity which causes anxiety e.g. playground, dining hall, assembly, messy play activities. Use a visual timer and very gradually increase the time over several weeks or months.

If a child or young person is hyper reactive to auditory input and becomes anxious as a result of auditory stimuli then consider allowing them to wear ear defenders, headphones or ear plugs in noisy environments, but ensure they remove these for the last minute in the environment, and then the last two minutes, the last three minutes etc, and gradually work backwards until he/she can tolerate the full required time in the noisy environment.

If a child or young person is tactile sensitive and dislikes the feel or touch of certain textures for example paint, clay, wet food items, allow them to work with alternative materials and then very gradually introduce other textures.

When using desensitisation methods, always monitor the child or young person's reaction and stop the activity if he/she is showing signs of distress. Ensure you have provided a strategy or visual support for them to communicate anxiety levels during desensitisation and then follow with a calming activity.

Further desensitization reading and strategies are available on MCA Sensory Resource.

<https://sensory-processing.middletownautism.com/>

Calm Breaks

Calm breaks are a proactive strategy, ensuring the child or young person stays regulated throughout the day. They should be incorporated as part of the daily routine, even on days when anxiety levels seem low. The frequency of calm breaks is individual to each student, however consideration should be given to increased frequency and possibly duration of calm breaks for children with heightened anxiety. It is important that calm breaks are not contingent of behaviour, this means that they should not be removed if or when a child behaviour is challenging. In fact, behaviour that challenges may be an indication that the child requires a break. The break should be provided before the child is in a heightened state of anxiety, therefore plan to have a calm break prior to activities or tasks which escalate stress or anxiety. Pre-empting a rise in anxiety or stress will assist the child to cope more effectively with challenges as they will be in a calmer state when approaching activities.

Children with adequate self-awareness who can self-regulate should be encouraged to request calm breaks when they require them. In order to reach the stage of requesting the individual will need to have insight into what anxiety feels like and relate this to a need for a break. Visual cue cards to communicate or request a break should be encouraged if needed. An example is provided below.



Case Study

Adam is a 10 year old autistic boy, attending his local mainstream primary school. He is noise sensitive, and in the past he used to hide under desks or run out of the classroom during Music, Assembly or in the dining hall. He had started to refuse to go to school as he was so anxious about the noise. His teacher introduced a 'calm token' which Adam could use to request time in the school's calm room. She taught him how to recognise the signs that he was becoming anxious and practised using the token before generalising it to the real settings.

It is important to note that this strategy is dependent upon the child or young person recognising that they are feeling overwhelmed and then linking this to the need for a calm break. Others may not yet be ready to identify emotions and link them to a strategy, and so it is essential that parents or professionals recognise the signs of escalating anxiety and direct the child or young person to a calm break.

Case Study

Sarah is a 7 year old girl with autism and severe learning difficulties. She enjoys going to soft play centres as she loves the ball pools. However, her parents noticed that after a short time, she became very overwhelmed and began to scream and bite her hand. At this point, they removed her and took her home, but then she was upset that she had to leave. Sarah's occupational therapist suggested to the parents that they alternate between 10 minutes of play and a 2 minute calm break several times while at the soft play centre, and use a First/Then schedule to communicate this to Sarah. This was successful and Sarah is now able to play for almost an hour at the soft play centre. Her parents now use the same strategy at the swimming pool and birthday parties, which has prevented Sarah in becoming overwhelmed at these events.

Calm Kits

A calm kit is a practical strategy to help a child self-manage their anxiety. The goal is that the child will feel more relaxed and regulated after engaging with items in the stress kit or calm box. Consider options for making the child's stress kit portable e.g. they can have a mini box in the car or smaller items in their pockets. A calm kit or calm box is a proactive and positive intervention, it is used to help a child calm and increase self-management skills, it should be easily accessible at all times.

- worry beads
- fidget toys such as tangles or spinner
- music
- games
- calming items such as stress balls or bubble wrap.
- Photo album – which has pictures of favourite places or related to special interest



Resources used to help a child or young person to calm down will be dependent on the unique needs and preferences of the individual. Items which reduce one person's

anxiety will not necessarily be effective with another. Particularly in post primary a discussion on what helps me feel calm is helpful with those who can verbalise and understand their feelings. For those individuals who have difficulty with understanding or talking about their feelings, give them a choice of resources to try and allow them to tell you what works. If the person is unable to communicate this, observe reactions to different items and select those which seem to calm the person.

Stress kits for post primary students may include:

- Joke book, word searches
- Sensory items – fidget items, therabands, theraputty
- List of OT activities – cue cards to direct the person to engage in physical activity such as running up the stairs, push ups, wall presses or chair presses
- Special interest objects
- Stress ball
- Music



Relaxation Strategies

Relaxing slows down the systems in the body that speed up when we get anxious. If we can learn to turn on the bodily symptoms of relaxation, we can turn off the symptoms of tension. They are two sides of the same coin – you cannot experience feelings of relaxation and tension at the same time.

Relaxation is a skill that needs to be learnt through practice, so do not expect it to work straight away. With practice, a child or young person will find it easier to relax, so do not be discouraged at first. By using relaxation techniques with a child or young person you are teaching them to learn to recognise how it feels to be tense and how to relax

to ease that tension. With practice, they should be able to put this skill to use in everyday life. When first learning to relax, do not practise when the person is feeling tense or anxious, as it is difficult to learn under these conditions. With time and practice, they will be better equipped to reduce anxiety using relaxation techniques. Practise relaxation at least once a day, remember it is only through practice that you will learn.

Once a child or young person with autism has mastered the skill of relaxation they can use it whenever they feel anxious. However, it is best used as a preventative measure. Encourage them to use their relaxation skills before they go into a situation that they know is going to be stressful.

Calm Breathing

Breathing techniques can be used as a quick relaxation method to control anxiety in stressful situations. It is important to recognise personal tension spots and early warning signs of anxiety. You may need to do some self-awareness of emotions with the child so they are able to identify hotspots for them and their early warning signs of anxiety. Once you are able to do this it will equip you with the skills required to intervene with a relaxed response before the tension and anxiety rise too high.

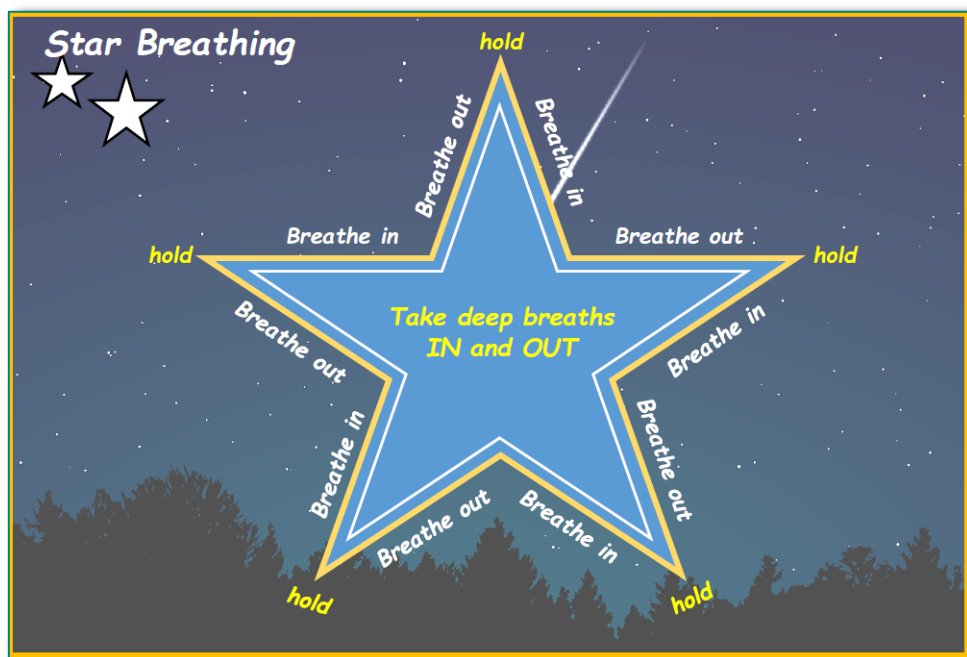
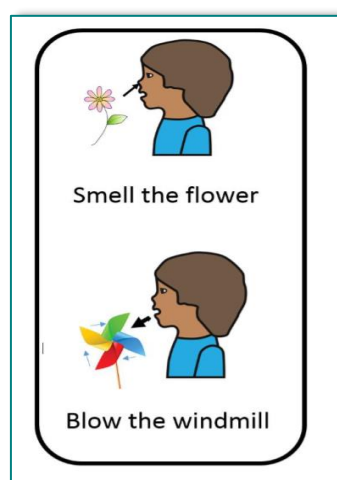
Calm breathing is a technique that teaches a child to slow down their breathing when feeling stressed or anxious. When we are feeling anxious our breathing changes, we start to take short, quick, shallow breaths. This type of anxious breathing can actually make the feeling of anxiety worse and can lead to hyperventilation.

Calm breathing involves taking slow, controlled breaths from the diaphragm. When we slow down the rate of breath it sends a message to the brain and body that there is no emergency. Practicing and encouraging calm breathing with a child or young person can help lower their anxiety, and give him or her a sense of control. Calm breathing is a great portable tool that they can use when feeling anxious, especially in situations when you are not there to help him or her through it.

Until the person is comfortable with this skill, he or she should practice it at least twice a day, doing 10 calm breaths in a row. When you are practicing calm breathing, start when relaxed, before he or she is feeling anxious. They need to be comfortable breathing this way when feeling calm! Once the child or young person is comfortable with this technique, he or she can start using it in situations that cause anxiety.

Use the following link for more information

https://www.youtube.com/watch?time_continue=1&v=p2hRwa8_S5Y&feature=emb_l
[ooo](#)



Progressive Muscle Relaxation

Progressive muscle relaxation provides a framework for children and young people to go through all the main muscle groups in their body and systematically tense and relax them whilst breathing slowly.

Teach the child to tense each of the main muscle groups, holding for several seconds and then releasing. As with calm breathing, muscle relaxation strategies initially need to be taught in a one-to-one setting and at a time when the child is not feeling stressed so skills can be processed and retained. Visual prompts such as written instructions or a video are useful to support these relaxation activities.

Cognitive Based Strategies

Cognitive Behaviour Therapy (CBT) is designed to help people become more aware of and understand the connections between how their thoughts, behaviours and emotions affect each other. Cognitive based strategies support children and young people to learn new ways of thinking about and responding to situations that they find distressing.

When we experience heightened anxiety or worry our negative thoughts occur more often and can seem overwhelming. CBT teaches children strategies to help manage these thoughts and think about anxious situations in an alternative way.

A CBT approach to anxiety includes psychoeducation, that is, teaching the child or young person about their anxious response, how anxiety feels in their body and the behaviours associated with their anxiety. Other core components of CBT include cognitive restructuring, teaching relaxation and the use of gradual exposure to anxiety provoking situations and/or stimuli.

Useful cognitive based resources include:

- Starving the Anxiety Gremlin by Kate Collins
- Think Good Feel Good by Paul Stallard
- Parent Led CBT for Child Anxiety by Cathy Creswell et al
- The CBT Toolbox for Children and Adolescents by Amanda Crowder et al
- CBT for Children and Adolescents with High Functioning Autism Spectrum Disorders by Tony Atwood et al
- The Homunculi Approach to Social and Emotional Wellbeing by Tommy Mackay

Conclusion

Anxiety is a concern for many autistic children and young people and their families at any time but particularly during this pandemic. It is hoped that the information and strategies included in this chapter will help with supports to assist current concerns, and those arising when the transition back to normal life resumes. Middletown Centre staff are working on an online resource to help at the time of this transition and links can be included in this chapter when it is completed.

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