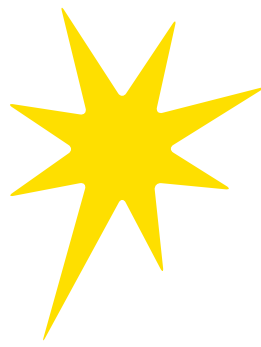




Anxiety

A Guide for Parents



Working wonders for children with brain conditions

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Introduction

This three-part guide has been developed to give up-to-date information on how to spot the signs of anxiety and anxiety disorders and what can be done. Part one describes the common signs of anxiety and specific anxiety disorders. Part two describes the ways professionals assess anxiety in children with intellectual disability, and Part three gives guidance on helping your child reduce feelings of anxiety and gives some examples of specific disorders associated with anxiety.

Part I

What is anxiety?

Anxiety and fear are our body's built-in response to danger – our alarm system. When we are anxious or fearful our hearts beat faster and blood is directed to our muscles so that we are ready to protect ourselves from the danger by either 'fighting', 'fleeing' or 'freezing'. We experience 'fear' when we have to tackle an immediate threat (e.g. getting out of a burning house); however, anxiety is experienced when we anticipate that something threatening might happen in the future (e.g. moving to a new home).

Signs of anxiety

There are many different signs that someone may be feeling anxious or fearful. These can be changes in the person's body, thoughts, emotions and behaviour, and may differ between people. Some examples of possible signs are outlined in Box 1:

BOX 1: Signs of anxiety and fear

Changes to the body	Changes to thoughts/ thinking patterns	Changes to emotions	Changes to behaviour
<ul style="list-style-type: none">● fast and irregular heartbeat● sweating● tiredness● muscle tension● dizziness● trembling● pale complexion● stomach aches● nausea● difficulty falling asleep or staying asleep● startles more easily	<ul style="list-style-type: none">● inability to concentrate● repetitive thoughts about perceived threat● concerns about losing control● inability to relax	<ul style="list-style-type: none">● irritability● feeling worried● distress● crying/negative vocalisations	<ul style="list-style-type: none">● avoiding or hiding from objects or situations● fidgeting/moving more than usual/restlessness● fixed or 'frozen' to the spot● increased preference for routine● pacing● on the look out for danger

Children and individuals with mild communication impairments often have difficulty describing their emotions despite having some speech, so they may describe physical symptoms such as stomach aches or feeling sick. Part 2 of this guide gives some examples of signs of anxiety in individuals with more severe communication difficulties.

As many of the signs of anxiety overlap with signs of physical health difficulties, it is very important to always ensure that a health problem is not underpinning your child's behaviour and emotions and if you are in any doubt, contact your GP or paediatrician. Further information about assessing whether your child may be experiencing pain can be found in Cerebra's Pain guide, which is referenced at the end of this guide.

When does anxiety become an issue?

Everyone experiences anxiety from time to time, particularly in response to difficult or stressful situations. However, this anxiety usually reduces with time or once the stressful situation is over. For example, children may experience anxiety when starting a new school but this gets better once they are used to their new surroundings. Anxiety starts to become problematic when it gets in the way of everyday life, when there is no obvious reason for the anxiety, when it is out of proportion to the threat of a situation, or when it continues for a long time.

Anxiety Disorders

When anxiety is identified as being problematic, a professional may diagnose an anxiety disorder. In the general population, anxiety disorders are known to affect around 7 in 100 children aged 5-16 years¹. A recent systematic review and meta-analysis reported a prevalence of 7-34% in children and adolescents with intellectual disability³¹ and those affected by anxiety is higher in specific genetic syndromes (9% in Down syndrome to 73% in Rett syndrome)³². Researchers are still trying to agree on these

estimates, however, it is generally believed that individuals with intellectual disability are more likely to experience anxiety.

There are a number of different types of anxiety disorders; however, it is important to remember that every person is different and there are often cases where a person's symptoms do not fit exactly with a specified disorder category, particularly when they have an intellectual disability. Therefore, a professional will sometimes diagnose an anxiety disorder without assigning a specific category. Some of the anxiety disorders are described below:

Specific Phobias

The person has a very specific fear, such as a fear of objects, events or situations. This could be a fear of animals, doctors or heights, for example. A person with a specific phobia will be anxious about situations where they may encounter the feared object or situation and they will try and avoid these situations or endure them while experiencing distress.

Generalised Anxiety Disorder

Unlike a specific phobia, this is a non-specific anxiety about a variety of situations, including events that occur on a daily basis. People may find it difficult to control their anxiety and switch it off. In generalised anxiety disorder, the focus of anxiety can change frequently and be quite fleeting.

Social Phobia

A person is fearful when faced with everyday social situations and settings, and experiences anticipatory anxiety about being in these situations. Often individuals will try to avoid social situations completely or may withdraw if they find themselves in these situations. This disorder can cause people to feel extremely self-conscious in the presence of others and may lead to difficulties with making friendships. Social anxiety can occur across a range of social situations, or when faced with one particular social situation such as public speaking.

Separation Anxiety Disorder

A person experiences significant distress and anxiety when separated from a primary caregiver or when away from home. The person may avoid situations where they are separated from their caregiver.

Panic Disorder

A person experiences attacks of extreme anxiety which occur unpredictably. During an attack, a person's heart rate may increase and they may feel as if they are struggling to breathe. This is often accompanied by anxiety about dying or losing control. A person who has panic attacks may experience anxiety about having another attack and avoid situations in which they have previously occurred. Panic attacks are fairly uncommon in children.

Agoraphobia

A person experiences fear of open or public places that occurs across at least two settings. It is usually an anxiety of situations where escape would be difficult or embarrassing. Therefore, the person may avoid these places.

Other disorders associated with anxiety

Obsessive Compulsive Disorder (OCD)

The person is anxious about causing harm to themselves or others which leads to obsessive thoughts and compulsive rituals that they believe will reduce this threat (e.g. repeatedly washing hands or counting in specific patterns). These compulsions and rituals reduce anxiety in the short-term but means the person avoids being exposed to the perceived threat (e.g. germs) so their anxiety does not reduce in the long-term. It is important to remember that ritualistic/repetitive behaviours are often characteristic of people with an intellectual disability and/or genetic syndrome. This may mean that behaviours that look like symptoms of OCD may have other causes.

Post-Traumatic Stress Disorder (PTSD)

PTSD develops after a distressing or traumatic event. Examples of this include an unexpected death of a loved one or being in a car accident. The person may experience flash-backs to the event and may try and avoid activities or situations that remind them of the trauma due to anxiety about experiencing these memories.

Anxiety Disorders in Intellectual Disability

The most common forms of anxiety disorders in children with intellectual disability are specific phobias and separation anxiety. Prevalence rates for both these disorders range between 2-18%². Social anxiety is slightly less prevalent, with rates ranging between 1-5%². Rates for panic disorder and agoraphobia are reported to be below 2%, and rates for generalised anxiety disorder to be around 2%^{3,2}.

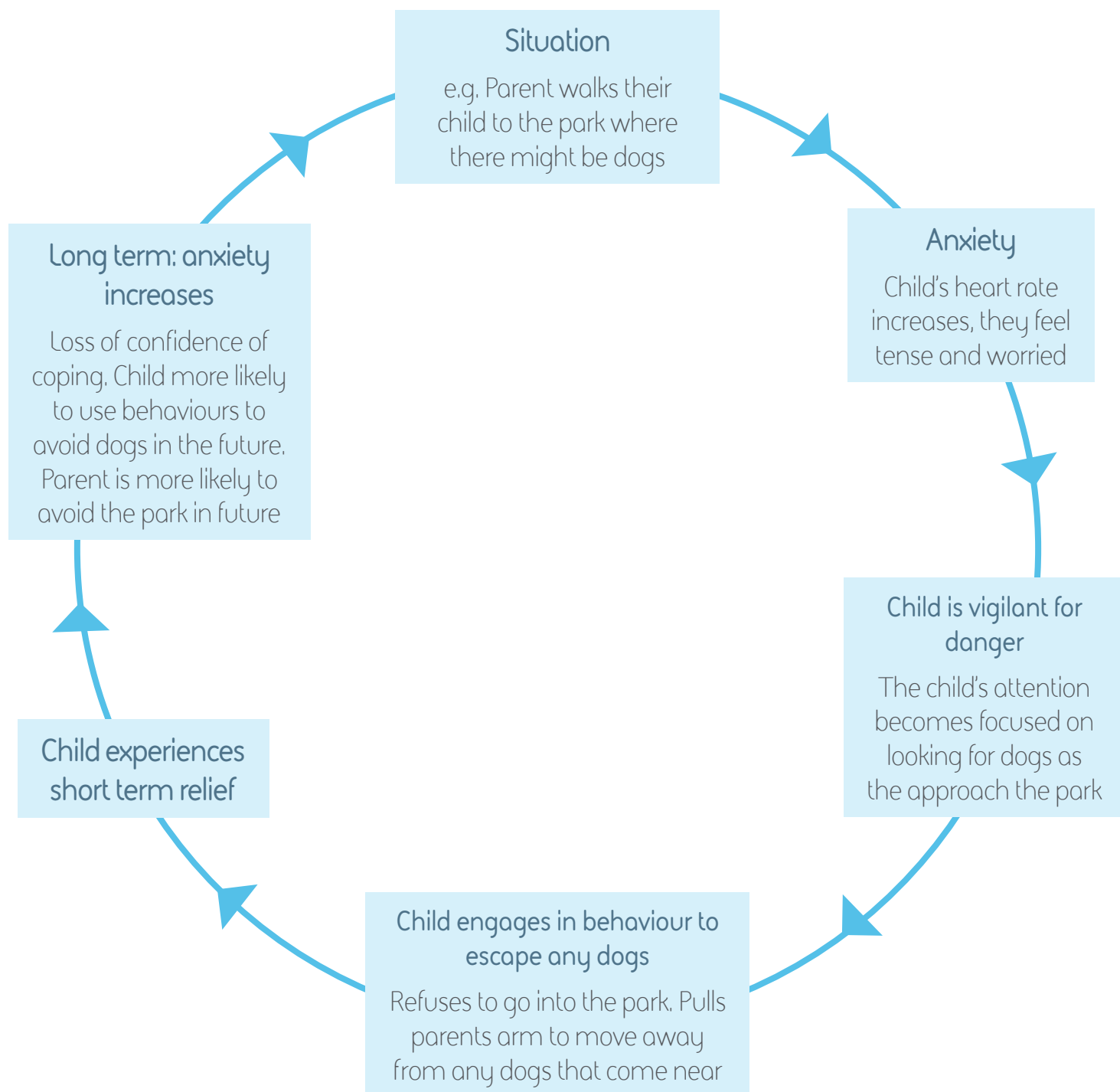
Around half of children who have an anxiety disorder are also diagnosed with a mood or other disorder³. However, it is not yet fully understood how anxiety and other disorders are related and whether having one type of disorder increases the likelihood of another.

The Vicious Cycle of Avoidance

While each anxiety disorder is distinct, a common process that keeps anxiety going is the vicious cycle of avoidance (see Box 2). One example of this is when a person has a specific phobia (e.g. a fear of dogs). A person who is anxious about dogs is more likely to be on the lookout (be hyper-vigilant) for danger, for example, scanning the park for dogs. The person may then engage in behaviours to reduce their anxiety (avoid all dogs or the park). This brings short-term relief (an immediate drop in anxiety) but keeps anxiety going in the long run as the person does not learn a new way of coping with the situation, or learn that most dogs are friendly and approachable. The behaviours that people engage in to escape or avoid anxiety can be complex and difficult to

spot. When considering the anxiety disorders listed above, it can be helpful to have a professional with mental health experience, such as a Clinical Psychologist, explore which avoidance behaviours might be keeping anxiety going for your child. In addition, as we will discuss later on in this guide, it is not always appropriate or necessary to tackle anxiety head on (i.e. exposing the person immediately to the feared situation).

BOX 2: Avoidance cycle



Part 2

Assessment and Diagnosis

There are a variety of different assessment methods that can be used to measure anxiety. Often, checklists and rating scales are used and these can be filled out by parents/carers or, if appropriate, by the person themselves. These measures indicate which symptoms a person may be experiencing; however, they do not provide enough information to diagnose an anxiety disorder. In order to obtain a diagnosis, interviews by professionals that adhere to standardised criteria are needed. However, the majority of these interviews have been designed for the general population, and people with an intellectual disability (ID) may have different symptoms and behaviours that indicate they are experiencing anxiety. Individuals with ID may not be given an anxiety diagnosis when one is needed because the scoring criteria is not tailored for people with ID³⁴. Individuals with ID may also have difficulties communicating feelings in the same way that others can and this can affect whether or not someone receives a diagnosis and which diagnosis they are given.

Currently, there is no 'gold-standard' measure used to diagnose anxiety in individuals who are unable to report their own symptoms. However, certain behaviours have been identified that may indicate the presence of anxiety. For example, reduced eye contact with others, reduced length of speech or vocalisations, signs of physical discomfort, freezing, and clinging to a familiar person are thought to be indicative of social anxiety⁴. In addition, there is some evidence that heightened repetitive behaviour may be associated with anxiety in some autistic children⁵.

It is important to bear in mind that the anxiety symptoms and behaviours of children with ID may not fit exactly with the specified categories defined for each anxiety disorder. Yet, even though these categories may not be entirely appropriate for children with ID, receiving a

diagnosis of an anxiety disorder can be helpful for some individuals by increasing support and access to treatment services.

Vulnerabilities to Anxiety

There are some specific factors that may put some individuals with ID at greater risk of experiencing anxiety than individuals within the general population:

- Children on the autism spectrum often experience anxiety. Anxiety may be related to characteristics associated with having a diagnosis of autism, such as differences in social skills and lower tolerance of uncertainty. The world can be a very unpredictable place and so are the people who inhabit it. As a way of managing uncertainty, autistic children may prefer to maintain routines to reduce anxiety^{6,33}.
- Hypersensitivity to sensory stimuli. Some people, including some people with Autism Spectrum Condition (ASC), can experience sensitivity to sensory stimuli. This means that loud noises may appear louder and bright lights may appear brighter for these individuals, which can cause them some discomfort and may contribute to anxiety. For example, people with sensitive hearing may experience anxiety when going somewhere where there may be loud noises⁷.
- Difficulty problem solving. There is some research that individuals are more likely to feel anxious when they feel that the situations they face are outside their skill set and capabilities. If a person is uncertain of how they will manage a situation, this is likely to lead to anxiety⁸.

Anxiety: Associations with some genetic syndromes

Children and adults with some neurodevelopmental disorders are at increased risk for anxiety compared to the general population. These neurodevelopmental disorders include genetic syndromes such as fragile X syndrome, Williams syndrome and Cornelia de Lange syndrome, among others. As noted above, individuals with Autism Spectrum Condition are also thought to be at increased risk of anxiety.

Fragile X Syndrome (FXS)

Fragile X syndrome is a genetic syndrome associated with moderate ID and occurs in around 1 in 2,500-5,000 males. A 'fragile' X chromosome causes FXS. As females have a back-up X chromosome, large sex differences exist in this syndrome. However, both males and females are reported to experience high levels of anxiety. Compared to other populations, individuals with FXS are more likely to meet criteria for an anxiety disorder. A study reported that approximately 82% of people with FXS met diagnostic criteria for one anxiety disorder and over 60% met criteria for multiple anxiety disorders. Specific phobias (52%) and social phobia (28%) are the most commonly reported anxiety diagnoses in FXS^{9,32}. Physical injury fears (37%) and PTSD (32%) are also reported frequently³².

Williams Syndrome (WS)

Williams syndrome is caused by a loss of 26-28 genes on chromosome 7q 11.23¹⁰. It is associated with mild to moderate ID and affects approximately 1 in 7,500 people¹¹. Approximately 5 out of 10 people with WS have an anxiety disorder¹². The most commonly reported anxiety disorder is specific phobia, particularly related to fears of the natural environment, noise, blood-injury, injections, doctors and animals^{13,14,15}. Compared to many other genetic syndromes, the prevalence of social anxiety is lower in WS^{9,16,17}. This may be

explained by the highly characteristic prosocial personality displayed by people with WS, as well as their heightened social drive, which prevents the emergence of this type of anxiety^{18,19}.

Cornelia de Lange Syndrome (CdLS)

Cornelia de Lange syndrome affects approximately 1 in 40,000 people and is associated with mild to profound ID. It is primarily caused by deletions in the NIPBL gene but can also be caused by mutations on different genes. Anxiety has been reported in between 10 – 64% of individuals with CdLS^{20,21,22,23}. Research suggests that anxiety may increase with age in individuals with CdLS, with heightened anxiety peaking in early adulthood^{20,24,25}. The different types of anxiety have not been extensively explored as yet in CdLS, but research does suggest that separation anxiety²⁶, social anxiety and selective mutism (Box 3) are particularly common. Social anxiety, in particular, is thought to occur during times of high social demand²⁷ or when social situations are unpredictable¹⁶.

BOX 3: Selective Mutism

Selective mutism is an anxiety disorder in which someone, who is otherwise capable of speaking, demonstrates a lack of speech in particular situations where speaking would usually be expected. Selective mutism is more common in people with some genetic syndromes, such as Cornelia de Lange syndrome. Research has suggested that selective mutism may serve as a coping mechanism to reduce anxiety²⁸.

Autism Spectrum Condition (ASC)

Autism Spectrum Condition is a behaviourally defined neurodevelopmental condition resulting in differences in social communication and restricted or repetitive behaviours. Over half of individuals with ASC are likely to meet criteria for an anxiety disorder²⁹. The most common types of anxiety disorders seen in children on the

autism spectrum include generalised anxiety disorder, social phobia and specific phobias. The presentation of anxiety in children on the autism spectrum is likely to be influenced by age, level of ability and ASC-related impairments such as social impairment and level of arousal³⁰.

The diagnosis of anxiety is likely to be particularly difficult in children on the autism spectrum. A review³⁰ has suggested that this is the case, as children with ASC often do not display age-typical symptoms of anxiety. Furthermore, clinicians are likely to have difficulty determining whether symptoms are part of the ASC itself, or a separate

but co-occurring anxiety disorder. Therefore, professionals should speak with a number of informants and use a range of assessments during the diagnostic process. Due to the overlap of symptoms seen in ASC and social anxiety, assessment is particularly important. As ASC is associated with social differences, anxiety may make these differences more apparent. For example, experiencing social anxiety may result in the avoidance of social situations promoting further isolation and less opportunity for social interaction³⁰.

EXAMPLE 1

James is 19 years old and lives at home with his parents, sisters and two pet dogs. He was diagnosed with an autism spectrum condition at the age of two and is able to communicate using short sentences. Some of his favourite activities include horse riding, swimming and gardening. He also enjoys tasks that he feels confident with, such as reading and completing puzzles.

Background Information

James experiences anxiety when he is in a new setting or unfamiliar situation, especially when in crowded and chaotic places. One thing in particular that James really struggles with is when there are babies crying nearby. When James is feeling anxious, he 'freezes', his muscles tense up, he screws up his face and he closes his eyes. He is unable to overcome these feelings on his own and is more likely to feel anxious when he is tired and less anxious when occupied doing physical activities.

What can be done to help?

- In situations that James finds anxiety inducing, he wears noise-cancelling headphones. These help to make noisy situations more bearable for him.
- It may be helpful to teach James a way to communicate that he is finding the situation anxiety provoking and would like the situation to be removed. This could be achieved by teaching James to respond verbally with a simple sentence, with Picture Exchange Communication System (PECS) symbols or makaton signing, or with a big mac (a red button with a pre-recorded message).
- Whilst avoiding situations that cause anxiety can be useful in the short term, this may maintain the anxiety that James experiences in these situations. Situations that James finds difficult could be introduced for a short period of time and can be gradually increased as James becomes more comfortable with them over time.

Part 3

What can be done to reduce anxiety?

Most evidence-based interventions for anxiety in people with intellectual disabilities (ID) contain similar components that are designed to make the environment more predictable for the person with ID, or increase the person's coping and communication skills. There are very few adapted interventions for people with ID who have a specific diagnosis of an anxiety disorder; however, knowledge of the type of anxiety and triggers associated with anxiety can be important when working out which type of intervention may work best for someone.

For example, if someone has a specific phobia, a Clinical Psychologist may be able to design a plan to gradually increase exposure to the feared situation, and if someone has difficulties coping with uncertainty due to generalised anxiety disorder, consistent predictable routines may be very helpful for managing anxiety if it is not possible to increase a person's ability to cope with uncertainty. The following section describes some of the most frequently used strategies and the checklist in Box 4 summarises some of these. It is important to remember that not all these strategies will work for every child so when trying an intervention, it is essential to carefully monitor your child's anxiety. Seek support if you have any concerns.

BOX 4: Frequently used strategies

	Yes	No
My child has a predictable routine		
Everyone responds consistently to my child		
I use a 'cue' to let my child know when a change is coming		
My child has some strategies to self-calm (even if I need to prompt them to use them).		
My child has a way to communicate 'stop that' or 'I want to go'		

Does your child have a predictable routine?

One way to reduce anxiety, particularly when anxiety is due to anticipated events, is to ensure that there is a predictable pattern to the day. Visual schedules of 'now' and 'next' cards can be very helpful when supporting your child to follow the order of the day. Once a person has a predictable routine it may be important to gradually reintroduce some flexibility into this routine to help the person begin to tolerate a more variable schedule. However, this needs to

be done very slowly at a pace that the person can manage.

Is everyone responding to your child in the same way?

In addition to setting up a visual schedule, it is also important that those supporting the child are consistent. This may mean predictable and consistent responses to all behaviours, not just consistent responses when the person starts to experience anxiety.

Do you let your child know a change is coming?

Even the best schedules do not always run to plan and using a cue to indicate that change is coming can often be effective at reducing this anxiety. This may be a particular picture card. Sometimes families report that telling a person

about a change a long time before it happens can increase anxiety and lead to worrying until the event comes to pass. Therefore, cuing a change closer to the time (5-10 minutes before) may be a helpful middle position as opposed to 'springing' changes on the person, or warning them days in advance. Making sure the person's visual schedule is updated to reflect the change is also important.

EXAMPLE 2

Ben is 11 years old and lives with his younger sister and his parents. He has Cornelia de Lange syndrome and a moderate level of intellectual disability. Ben likes to play on his computer games and goes swimming at the weekend with his family. At the time of writing, Ben was attending a mainstream middle school where he was receiving full-time assistance but was due to move to high school.

Background information

Ben's mother said that Ben shows selective mutism during situations he feels under pressure. This leads to him 'freezing' and not being able to verbally respond. Ben had recently started to ignore his support assistant when she asked him to do something that he didn't want to do, such as answering questions or reading in front of the class.

What can be done to help?

- Alternate between tasks that Ben finds achievable and those that he finds a little more difficult. However, he should only be asked to complete tasks that are suitable for his cognitive ability level. This is to keep Ben interested and engaged in the tasks.
- Give positive feedback and frequent praise when Ben attempts to answer questions or read out loud. This would help to build Ben's confidence so that he may attempt to do this more often.
- Teach Ben to verbalise or communicate when he doesn't know the answer to something or when he needs help and to provide reassurance that it is okay that people sometimes need help. Ben should have help to adopt this new skill through teaching, prompting and praising when he attempts to do this.

Does your child have a way to self-calm?

We all have strategies to calm ourselves down when we are feeling anxious such as talking with a friend, taking a warm bath, or exercising. Often, children and people with ID do not have the skills to manage anxiety and may need support to do so. Strategies for reducing anxiety may be as simple as listening to calming sounds or music, deep breathing, squeezing a ball, chewing on a

chewy tube or self-massage. Depending on a person's level of ability they may need prompting or support to carry out these actions. After lots of practise some individuals may learn to do these actions by themselves, particularly if they have previously been prompted to use them in lots of different places.

When encouraging self-calming strategies, it is important to ensure that these strategies are used to help the people reduce anxiety in difficult situations rather than avoid the situation

completely. The idea is to teach the person new coping skills to help them in stressful situations.

Can your child recognise their emotions?

To give the person the best chance of being able to use self-calming strategies independently, they need to be able to recognise when they are starting to feel anxious. Noticing when the person is starting to feel anxious and naming the emotion out loud, or helping the person keep an anxiety diary can help them build up their emotional literacy. If responding verbally is difficult for the person, using a picture card to point to an 'anxious face' might be one way the person can learn to communicate their feelings.

For some children, modified cognitive-behavioural therapy (CBT) may be appropriate. This is a therapy that teaches a person to think differently about the situations that cause them anxiety. In order to be able to do CBT, a person has to be able to identify their emotions, identify that certain situations lead to these emotions and identify that the way a person thinks about a situation can change their emotions. A lot of people with ID, even when they have good verbal skills, find the last step, linking thoughts to emotions, very hard; however, a Clinical Psychologist may be able to adapt CBT to make it accessible for some children with ID.

Does your child have a way to tell you they do not like something?

It is important that children have a way to request or to say 'stop that' or 'I want to go'. This could be a picture card, a sign or a word. Simply knowing you have a way to let others know that something is difficult can reduce the anxiety of being in an inescapable and frightening situation. It also increases your child's level of control and choice. The way to teach this is to introduce the picture or sign when your child first starts to show

signs of anxiety in a situation where it would be appropriate to leave or 'take a break' and making sure you respond to the request after it is prompted. However, it is important to remember that while escaping a situation may reduce anxiety in the short term, it may mean that the person is more likely to experience anxiety in the future, so this strategy should be paired with gradually increasing the amount of time the person spends in the feared situation (see below).

Does your child have any exposure to the feared situation, individual or object?

Finally, when a person has a specific anxiety (e.g. phobia of dogs) this can be maintained by avoiding situations that cause it. We all get better at coping with difficult situations the more we are in them, particularly when the person's anxiety is very specific and nothing bad happens when they are in the situation. It is often not appropriate, however, to take an extremely anxious individual straight into the situation they fear as this might cause too much distress and make matters worse. When trying to introduce a person to a feared situation, it is important to take tiny steps (see Example 3 on page 14).

Is the anxiety related to a sensory issue?

Sometimes a person may seem fearful or anxious of a situation because of an underlying physical or sensory issue. For example, a child with a painful ear infection may show signs of anxiety when his little sister reaches to touch his face, or a person with hyper-sensitive hearing may show anxiety when going somewhere associated with loud noises. In these instances, treating the ear infection or using strategies suggested by an Occupational Therapist to reduce the impact of loud noises (see [Cerebro's Sensory Processing Guide](#)) would be the best intervention for these children.

Specific anxiety disorders

If you have concerns that your child is experiencing a specific anxiety disorder described on page 5, or that the person's anxiety is impacting significantly on their quality of life, seek out support from a professional such as a Clinical Psychologist. Clinical Psychologists are usually available through Learning Disability Community Services or through your local Child and Adolescent Mental Health Services (CAMHS).

Medication

There are many different types of medication used to alleviate symptoms of anxiety. Selective serotonin reuptake inhibitors (SSRIs) are one of the most common types of medication that are often prescribed for both depression and most types of anxiety disorders. SSRIs increase levels of serotonin in the brain. Serotonin plays a role in mood and emotion so, it is thought that increasing levels of serotonin may improve

symptoms of anxiety and depression. Although SSRIs are commonly prescribed for adults displaying anxiety, little is currently known about how effective these medications are in children, and in children and adults with a neurodevelopmental disorder. SSRIs are not suitable for everyone, particularly for people with some physical problems. Therefore, it is important to discuss anxiety medication with your GP. If the person you care for is prescribed medication for anxiety, it is important to monitor both their progress, and any side effects they may display. Common side effects of SSRIs include dizziness, blurred vision, feeling nauseous, and feeling shaky. Other medications for anxiety include serotonin and noradrenaline reuptake inhibitors (SNRIs), Pregabalin, and Benzodiazepines. Due to their potentially addictive qualities, Benzodiazepines are used only as a short-term treatment and should not be taken for longer than two to four weeks at a time.

Example 3

Specific Phobia

Rebecca had developed a specific phobia of the doctors after she had been unwell as a young child and had to have a number of medical interventions. She would become very distressed whenever she was in the car with her parents and they pulled into the car park at the doctor's surgery for a routine check-up. Getting Rebecca to go inside the surgery was a battle of wills and was extremely distressing for Rebecca.

Over a period of three months, Rebecca was gradually exposed to the doctor's surgery through a carefully designed programme monitored by a Clinical Psychologist. The first stage was simply to drive by the doctor's surgery with Rebecca in the car. During this time her parents played music that they knew calmed Rebecca and paired this with her favourite food. Once it was clear that Rebecca was perfectly relaxed driving by the surgery, her parents started to stop the car by the surgery gate. Rebecca showed some signs of mild discomfort but was able to tolerate being in this situation.

During each stage, her parents monitored Rebecca's behaviour as they realised that if she became too distressed it would be counter-productive to her learning that she was safe. Her parents also taught her a 'sign' so that she could request to 'leave' a situation if it got too much.

Gradually Rebecca's anxiety decreased, and her parents were able to move Rebecca closer to the surgery until she was able to go inside and meet the reception staff. It took a lot of patience and perseverance for Rebecca to be happier visiting the doctors, but over repeated exposures where nothing scary happened she became much more comfortable.

Summary

There is some evidence that children with intellectual disabilities (ID) may be more prone to anxiety than typically developing children, and anxiety can be even more common in some genetic syndromes. It can be very difficult for children with ID to report feelings and emotions so often the best indicators of anxiety are a child's behaviour. There are a number of strategies that can be helpful for reducing anxiety in children with ID including establishing routines, ensuring consistency, developing self-calming strategies and improving communication. If your child is experiencing anxiety that is impacting on their quality of life, a referral to a professional with mental health training, such as a Clinical Psychologist, may be appropriate.

TOP SIGNS TO LOOK OUT FOR:

IF your child has a mild ID:	IF your child has a moderate ID:	IF your child has a severe ID:
<ul style="list-style-type: none"> ● Changes in their thought processes ● Reports of stomach aches/nausea, headaches or muscle pain that seem to be unrelated to physical illness ● Behavioural change, e.g. withdrawal or restlessness ● Changes in communication, e.g. increased or decreased chatting ● Physiological signs such as muscle tension 	<ul style="list-style-type: none"> ● Behavioural changes such as withdrawal or restlessness ● Physiological signs such as muscle tension ● Visible distress or discomfort ● Changes in communication ● Reports of stomach aches/nausea, headaches or muscle pain that seem to be unrelated to physical illness 	<ul style="list-style-type: none"> ● Keep an eye out for behavioural signs of anxiety, e.g. repetitive behaviours ● Physiological signs such as muscle tension ● Visible distress or discomfort ● Possible challenging behaviour motivated by wanting to avoid or escape from situations/objects

Who are we?

The Cerebra Network is a collaborative research network consisting researchers from the University of Birmingham, University of Warwick, University of Surrey and Aston University. The work of the Network focuses on the difficulties experienced by children and adults who have intellectual disability, autism spectrum conditions and genetic syndromes that are associated with developmental delay. The Network has strong links with numerous support groups who invite us to attend family conferences and support group meetings. We also have close links with NHS Trusts and schools for children with intellectual disability and autism. Both the family support groups and NHS Trusts commission research from us. To make our research effective, we have a network of national and international research collaborations. At the Network we are able to offer clinical consultancy in specific areas but we do not offer a full clinical service. Clinical and research training are important strands of our work. We offer placements to undergraduate and postgraduate students who want to gain the clinical and research skills necessary to understand and support children and adults with neurodevelopmental disorders. We also invite research colleagues from the UK and abroad to visit the Network to see the work we conduct and teach us about their work.

Further resources

Books

Attacking Anxiety: A Step-by-Step Guide to an Engaging Approach to Treating Anxiety and Phobias in Children with Autism and Other Developmental Disabilities By Naomi Chedd, Karen Levine

Handbook of Autism and Anxiety (Autism and Child Psychopathology Series) Hardcover – 27 Aug 2014 By Thompson E. Davis III (Editor), Susan W. White (Editor), Thomas H. Ollendick (Editor)

The Panicosaurus: Managing Anxiety in Children Including Those with Asperger (K.I. Al-Ghani Children's Colour Story Books) Hardcover – Illustrated, 15 Oct 2012 By K.I. Al-Ghani (Author), Haitham Al-Ghani (Illustrator)

Overcoming Anxiety and Depression on the Autism Spectrum: A Self-Help Guide Using CBT. Paperback – 21 Feb 2015

When My Worries Get Too Big!: A Relaxation Book for Children Who Live with Anxiety Paperback – 15 May 2006 By Kari Dunn Buron

Websites

The Association For Persons With Developmental Disabilities (NADD); This webpage offers a brief overview of treatments and services available for people who have a dual diagnosis

<http://thenadd.org/idd-mi-diagnosis/>

Patient: Has an online forum for discussing anxiety

<https://patient.info/forums/discuss/browse/anxiety-disorders-70>

Hands In Autism: Information on how to create visual schedules

https://handsinautism.iupui.edu/wp-content/uploads/2019/05/How_To_Visual_Schedules.pdf

Guides

Pain in children with severe intellectual disability: A Guide for Parents

<https://cerebra.org.uk/download/pain-a-guide-for-parents/>

The Be-Well Checklist

<https://cerebra.org.uk/download/be-well-checklist/>

Sensory Processing: A Guide for Parents

<https://cerebra.org.uk/download/sensory-processing/>

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