



Community Paediatric Psychology Service

# A guide for parents of neurodiverse children who are experiencing anxiety



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# Introduction to the guide

This booklet has been designed for parents or carers who are supporting a child or young person with a neurodevelopmental condition who is experiencing anxiety. Neurodevelopmental conditions include autism, intellectual disability and attention deficit hyperactivity disorder.

From here on when we mention "child" or "children" we are referring to children and young people of school age.

We are aware that when a child has a neurodevelopment condition they can have a range of skills and strengths which may vary from another child with the same diagnosis.

Remember: You are the expert on your child. As you read through the guide think about the skills your child has and if their skills would allow them to try some of the suggested strategies.

#### This guide will cover:

- 1. What anxiety is
- 2. How anxiety may present in your child
- 3. Why your child may feel anxious
- 4. Strategies that may help your child manage anxiety

## **Section one: What is anxiety**

Anxiety is a normal emotion. We can all worry about things when we are under stress. Anxiety can feel unpleasant for children who might not recognise what it is.

Anxiety triggers what we call the 'fight flight freeze' response in our body. In the past, this response was helpful as it made our body ready to react to threats in our environment. For example, our heart beats faster to pump blood to our muscles so we have the energy to run away or fight off danger. This response can also be triggered when we are not in a life threatening situation. These sensations can feel very unpleasant.

There are many videos on online which explain what the 'fight flight freeze' response does to our body.

It might be helpful to have a look and see if you think your child would enjoy watching any of these videos.

# Section two: How anxiety may present in your child

How anxiety presents in your child may depend on the skills they have and how they communicate. Some children may be able to tell us what makes them feel scared or anxious, others may show us they are anxious through their behaviour. Children may be quiet and withdrawn when feeling anxious. They may report more tummy aches or headaches than usual. Below are some other things you may notice if your child is anxious:

Behaviour that is difficult to manage: All behaviour is communication. For children who struggle to express themselves with words we are more likely to see them communicate with their behaviour. These behaviours might feel difficult to manage or understand. Recognising if this is linked to anxiety may help you and your child think of helpful supports to reduce anxiety and the behaviour that can cause distress for everyone.

If you want to know more about behaviour see our "Understanding behaviour" leaflet on our website.

**Self-injurious behaviour:** Some children may self-harm as a result of anxiety. Self-harming behaviour may be a way of communicating for a child who struggles to say what they are thinking or feeling. Some common examples of self-injurious behaviour may be cutting, biting, or head banging on hard surfaces.

Note: If you have concerns that your child is doing physical harm to themselves then speak to a medical professional.

Not able to focus or being more fixed on particular topics: Some children find it difficult to focus even when they are not feeling anxious. If they are feeling anxious you may notice that your child finds it difficult to focus

on tasks that they were previously able to focus on. They may also become more fixed or repetitive about a particular topic.

Changes in sleep pattern: Sleep difficulties are common in children with neurodevelopmental conditions. If you notice that your child is getting less sleep or that they don't want to be left alone at night, this may be a sign of anxiety.

**Avoidance:** If you find that your child is avoiding situations, places or tasks that they would normally enjoy or not have any trouble with, this may be another sign of anxiety.

**Pacing:** Similar to stimming, pacing might help your child to comfort themselves. It can burn off some of the excess adrenaline which can come from anxiety. Repeating the movement might allow them to regulate their emotions.

**Stimming:** Stimming (or 'self-stimulatory behaviour') may help your child comfort themselves during times of increased anxiety. Stimming can cover lots of different behaviours, but can include things like hand flapping, clapping, rocking, or repeating noises or words.

# Section three: Why might my child be feeling anxious?

Children can feel anxious for many reasons such as:

- Life transitions (for example, starting school or moving to a new house)
- Children who have had a distressing or traumatic experience (for example, a car accident)
- Family arguments and conflict can also make children feel anxious.

Some anxieties are common at different developmental stages in childhood.

Developmental stages are a way of thinking about the skills a child has developed, rather than their chronological age. Keep in mind your child's developmental stage when thinking about the prompts below:

#### **Early childhood: Separation Anxiety**

This is common in early childhood. This is a normal stage in development.
Children may become clingy and cry when separated from their parents/carers



#### Middle Childhood: Social Situations

Some children may feel shy in social situations. These could be things like playtime or being asked to work in a new group at school.



# Older Children & Teenagers: School & Friendships

Older children and teenagers tend to worry more about school or friendships.



#### **Early Childhood: Specific Fears & Phobias**



Specific fears and phobias in early childhood are common. These include fears of animals, insects, storms, heights, water, blood and the dark. Sometimes children need extra support from parents to manage these but they can go away gradually on their own.

#### Middle Childhood: Stressful Situations

Children may feel anxiety in stressful situations. These might be going to a new school or dealing with difficult schoolwork.



We know that children with neurodevelopmental conditions are more likely to experience anxiety.

Some reasons they may experience anxiety may be:

#### Change and uncertainty

Children who prefer routine and who like to know what is happening in advance can have some difficulty coping with change.

As they grow up, children will encounter change on a daily basis. Change can come in many forms such as changes in plans due to the weather or being taught by a new teacher in school. Thinking of ways to help children cope with change could be helpful.

#### **Sensory experiences**

Some children have a heighted or reduced response to sensory experiences. These children may feel anxious if they can't access something they like, or if there is too much of something they don't like. For example, the smells and tastes in the canteen at school might be difficult for some children. The sights and sounds of the playground may be overwhelming.











#### Social and emotional understanding

Some children find it difficult to understand social relationships. They might find it difficult to know how others think or feel. This could mean they find it difficult to guess how others will respond to things. They may become frustrated when people do things that they don't agree with. They may also find it difficult to understand their own emotions. This means it can be difficult to develop the skills that help us regulate when we feel difficult feelings.

### Difficulties with planning and problem solving

Some children who have difficulties with planning or who respond quickly to things may struggle to tolerate uncomfortable feelings. This may be because it is difficult for them to make a plan that will help them to feel better.

Some children may find it more difficult to connect the feelings in their body with the thing that is making them stressed. Again, this can make it difficult to come up with a plan to help them feel better.

# Section four: What could you try that may help your child manage their anxiety?

If you notice some strategies are particularly helpful when your child feels anxious it could be worth keeping a note of these. This may help you and others think about what support they may need in the future if they are presented with a new or stressful situation.

#### Try to remain calm

All children can pick up on the emotions of others. One of the first things to try is for those around your child to remain calm when they are showing signs of distress or anxiety. This can also be one of the most difficult things to do! It could be helpful to remember to take deep breathes, keep a calm tone of voice and to plan some self-care for yourself later in the day.

#### Spotting the pattern

If we know when children are feeling anxious then we can start to identify what might be making them feel anxious. This helps us to plan appropriate supports. It can help to keep a diary of times when they have told you that they are scared or worried or maybe you noticed a change in their behaviour. It can be helpful to note down:

- What your child does. What did they say or do?
- What do others around them do?
- Does this help or make things worse?

If you notice patterns in your child's behaviour it can be helpful to think if there are additional supports you could add in to help them manage. For example, if your child struggles around transitions it could be helpful to use the social story or timetable strategies which are discussed later on.

Your child may not be able to recognise that something is causing them anxiety. They may say that they don't want to do things that make them feel anxious. They may be angry that things that make them feel anxious are around them. If this happens it could be important to talk to your child about the benefits of being able to manage their anxiety and highlight that we can't take away all things that cause anxiety. For example, your child may be anxious about dogs in the park and they may refuse to go to the park. They may say "there shouldn't be dogs in the park". Helping your child to see that the dogs might be making them feel anxious and that there are things we can do to help with those feelings of anxiety. If you work together to reduce feelings of anxiety there may be lots of fun things you child can do in the park.

#### Calming techniques

Some children benefit from calming or soothing activities when they are feeling worried. For some children this may be engaging in repetitive behaviours such as pacing or lining things up.

For some, practising taking deep breaths can be helpful. There are lots of videos and tips online about how to teach children deep breathing skills. When picking one for your child it may be helpful to think about one that

will appeal to their interests to help them engage with the practice.

For some children going into a small dark space or moving to a quiet part of the house may help them feel calm. Listening to calming music or smelling nice smells can help children reduce their level of arousal and feel calmer. Walking or using a trampoline may also help them to calm down.

We all have different sensory likes. We can't assume that what we find relaxing our children will also find relaxing. It may take a bit of experimenting to notice what your child finds helpful.

#### Social stories and visual timetables

Some children become anxious when they don't know what's coming up or if something new is happening. Making things more predictable for children can help to reduce anxiety. Two ways we can do this are by using social stories and timetables.

### 1. Social stories:

A social story is a short story that explains what will happen in a specific situation. Social stories can be very helpful as a way of explaining what will happen. The story can be made with pictures and written words.

You can make up your own social story, or you can use an existing one. There are lots of social stories available on the internet that you could search for. Carol Gray, the creator of social stories, has a website with lots of examples. "NLC Communications Friendly" page on facebook also regularly share social stories.

Once you have a social story it can be helpful to read the story with your child at a time when they are feeling calm. Some children may only need to hear the story once to help them understand. Others may need to hear the story many times.

Some children may have questions about the story or the situation to come. It's important to spend time answering these questions to the best of your ability. If you don't know an answer to a question, you can share with your child that it is a good question. If possible, you could go and search for the answer.

#### 2. Visual timetables:

Visual timetables can be a really good way of helping your child understand what will happen during a day.

You can represent different things that will happen during the day using words, pictures or symbols. Think about your child's speech, language and communication needs and use images and words that they are familiar with.

You can use a timetable that can be kept on the wall at home, or one that you carry with you when you are out and about. Or you can use an electronic version, for example, using an app.

Here is an example of a visual timetable for a morning routine:



# **Labelling emotions**

Labelling or naming emotions can be a helpful way to help your child develop their emotional literacy. This is your child's ability to understand and express their feelings.

At times it may be helpful to say things such as "I wonder if you're feeling anxious", or "you look like you might be worried about something". When you label emotions and suggest how your child may feel, it's important to remember that your child may not know why they are feeling a particular way. It can be tricky for children to tell us why they are feeling worried. Asking "why" can lead to further discomfort and stress at times.

Labelling emotions can help some children start to learn

what they are feeling. We can then add strategies to help them cope. This can be helpful to do for all emotions. Think about the words your child may understand. Some children may understand all the emotions below with the support of images. Others may need support to



Source: NLC Communications

share if they are feeling good or bad, or feeling thumbs up or thumbs down.

# How to help children "have a go"

One of the factors that keeps anxiety going is when we avoid the situation or object. One way that you can help your child to reduce avoidance is to help them to "have a go" at the thing that is making them worried.

Try to spot the pattern of what may be making your child feel anxious and practiced some calming strategies. The next step can be thinking about what they need to learn for them to be able to do this activity? Or go to a place? Or be around particular animals/insects?

If children can tell you why they are anxious, for

#### example,

- they think a friend no longer likes them,
- they are scared a dog may bite them, or
- a teacher will tell them off in school.

# What steps could you take to help your child address these worries?

You and your child can break down the thing that is causing them anxiety into manageable steps. This is sometimes called making a hierarchy. For example, if your child was scared of dogs and won't go to parks because of them, they could:

- Watch videos of dogs online, learn about safe behaviours around dogs
- If a family member has a dog they could send a video of them playing.
- They could visit a familiar dog and practice watching the dog through a window, maybe progressing to being in the same room.
- They could then practice petting a familiar dog.
- They may then take a familiar dog for a walk near home.
- They may then go to the park.

Remember: Your child may need support to

understand that anxiety is causing them to become upset or to feel different.

Using social stories and visual timetables can be helpful to make these practices predictable and helpful.

#### Worry time and the worry tree

Worry time and the worry tree can work well for children who are able to talk about their worries. They can be helpful for children who get stuck or repeatedly talk about their worries

#### Worry time:

If you child has repetitive questions about a worry it may be helpful to plan time to talk about these. It may be helpful to try "worry time". Worry time is a set time in the day when you focus on worries. You should agree with your child what time of day you will have worry time. Your child may need an image on their daily timetable to remind them that you will have time to talk together. We advise that you don't have worry time close to bedtime. It is helpful to try to use distraction following worry time to help your child move on.

If a child shares worries out of this time you could make a note of their worry in your phone and return to it at worry time. You could ask the child to write it down or record it as a voice memo in their phone, so you are able to discuss it at worry time.

#### The worry tree:



During worry time you could use the worry tree to help think about the different types of thoughts or worries we can have.

#### There can be two kinds of worries:

 'what if...?' thoughts. These are thoughts that we can have about something that might never happen.
 When we have these thoughts, we often imagine what would happen in those worst-case scenarios. This can cause us anxiety yet it could be very unlikely to actually happen.  Current problems are worries that relate to real situations (for example, a difficultly with a friend). We can do something about these and can plan steps to help us cope.

If your child can say what they are worrying about, you can use the worry tree with them to help them to differentiate between these two kinds of worries.

You could ask them what they are worried about and try to decide together whether this a worry that you can both do something about now. If the worry is about a current problem, you can work together to make an action plan: what to do, when to do it and how to do it.

If the worry is a "what if" thought, you can share that you understand that the thought must be causing them to worry. You can support your child to think about something else.

If your child is still worried after doing this, you can encourage them to do something such as play a favourite game or watch a preferred TV show to help distract them. It can be helpful to come up with a list of positive distractions.

#### Repeat these strategies with support

Some children struggle to generalise their skills. For example, they may struggle to think about the skills they have in one part of their life and apply them to other parts of their life. When they overcome things that make

them feel anxious, they may struggle to do the things that helped in a new situation where they feel anxious. They may need to be encouraged and supported to use helpful strategies again in new situations.

It may be helpful to spot times when your child does something they have been scared of and coped well with it. It may be helpful to try and record this. For example, telling them that they have overcome anxiety to do a particular thing, taking photos, writing down what helped (Were they really motivated to do something? Did they use any calming techniques? Did someone support them?). It can be helpful to look back at this record with real life examples of how they have coped if new anxieties present over time.

#### Reassurance: the do's and don'ts

Lots of children seek reassurance when they are feeling worried/anxious. They may stay close to you or want more physical contact. If this reduces anxiety children can seek it more. This might mean they don't learn other skills to help cope with anxiety. This can be particularly tiring for parents and carers.

#### Do:

 Label and acknowledge their feelings when they show signs of worry/anxiety.

- Label what they might find helpful and encourage them to make a choice. Some children benefit from two choices rather than giving them complete free choice it could help to offer option A or option B
- Set time to think together about what they may need to learn, or what support may need to be in place to reduce the worry.

#### Don't:

- Tell them not to worry about it and expect the worry to go away.
- Expect your child to be able to tell you what made them feel anxious.
- Make promises about solutions that may not be possible.

# **Creating a team**

We know that at times it can be tiring looking after a child who is experiencing anxiety. You won't always have solutions to the problems that they are experiencing. It's important to think about your own wellbeing. Some people find it helpful to have a team of people around them who are aware of their child's unique needs.

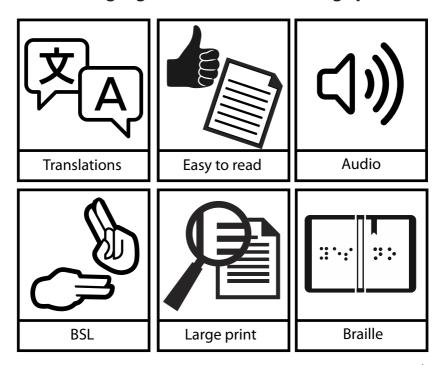
By creating a team around you they can help you solve the problems and celebrate successes with you when they come. Or they can simply be there to listen and understand. Team members could be:

- A friend
- A neighbour
- A partner
- A support worker
- · Anyone else who cares for your child

It might not always be possible to have team members physically present. Connecting with them over the phone or through texts, WhatsApps, or social media can provide positive supporting.

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Tall: 01563 825856

reviewed for plain English

Email: pil@aapct.scot.nhs.uk

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Last reviewed: December 2020 Leaflet reference: MIS20-146-CC PIL code: PIL20-0125