



Understanding Chromosome & Gene Disorders

Challenging Behaviour



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Contents

Babies, children and adults	4
Challenging behaviour	4
Why does challenging behaviour happen?	5
Pain and discomfort	6
Golden rules	6
Self injury	7
Biting	7
Anxiety	8
Separation anxiety	9
Pica	9
Faecal smearing	10
Genetic disorders	11
Autism	12
Sensory processing disorder (SPD)	13
Sensory toys, activities, sensory room equipment	14
Stimming	15
Oral motor development	15
What can parents do?	16
ABC chart	16
Cognitive behavioural therapy (CBT)	19
Medication	19
Brushing and joint compressions	20
Weighted therapy	20
Yoga for children and adults with special needs	21
Links	22
Books	25
Coping mechanisms as a parent carer	27

Challenging behaviours

Parents of a child with a chromosome or gene disorder can face many hurdles to find and access the right treatment, support and education for their child. This is in addition to coming to terms with their child's diagnosis and the effect it has on the rest of family life. Parents often judge themselves harshly and feel as if they have failed in some way if their child does not 'behave' like other children. It is important to think about and remember what your child does well, e.g. things like smiling at people, sitting still while watching TV or holding a spoon. It could be any number of achievements. Also, remember to look at and reflect on what you have achieved. You have given your child a loving home where they are cared for, loved, have an education and feel secure. No one else in your child's life will ever know or understand them as well as you do. If you feel positive about yourself and your child, then it will allow you to see when changes to behaviour happen.



Your child might show signs of a behaviour that is either unusual or difficult to manage. Many of these behavioural issues come under the title 'challenging behaviour'. For many children with a particular chromosome or gene disorder some of these behaviours are well documented. But for others, a 'behavioural issue' might be new in that child and could arrive at any age.

Some children with a chromosome or gene disorder may have challenging behaviour in their early years that improves as they get older and are supported to develop better communication skills. For others, it can develop as they get older. Many Unique children have an additional diagnosis of a neurodevelopmental disorder such as autism spectrum disorder (ASD) or they might have autistic traits and their behaviours can be due to sensory issues such as difficulties with noise or social interaction.

In many cases, behaviour that challenges occurs because the person has a limited range of communication strategies to share what they need or want with others.

A famous Chinese proverb states:

“ A journey of a thousand miles begins with a single step. ”

Managing difficult behaviour may be a long journey but you only have to start with that single step.

Babies, children and adults can behave in a certain way because ...

- they learn that their actions will give them a response or a reward
- they have a need, preference or desire to communicate
- they have a medical, emotional or physical need that leads to the behaviour or keeps it going
- they have a sensory sensitivity

Sudden changes in behaviour may indicate that there is an undiagnosed medical, physical or emotional problem. This can happen at any age if the individual has communication difficulties. For example, a child might start to bang their head or cry a lot if they are in pain or having hearing difficulties. An adult may become unusually aggressive with others or towards themselves for a number of very different reasons. They may be anxious, tired or in pain; they may be unsure about how or whether to tell someone or are unable to do so. First and foremost it is important to check that your child does not have any physical or medical problems if you notice a change in their behaviour.

Challenging behaviour: what does this mean?

Generally, it is a description of actions that could be seriously damaging to the person themselves or to others, or to their environment. This could include kicking, biting, throwing objects, smearing contents of a nappy, throwing food or drink about, running off, destroying furniture or property. It might also mean not sleeping or eating properly, taking off clothes, fiddling with parts of the body, self-harming, rocking or shaking and so on. Behaviour may not always be challenging but if it is repeated constantly and for no apparent reason then it can be very difficult and frustrating for parents to manage.

Types of challenging behaviour:

- Aggression - physical (biting, hitting, kicking, pinching, pulling hair, slapping, spitting)
- Aggression - non-physical (screaming, shouting, tantrums, yelling)
- Destruction (damaging or throwing things, ripping clothes, smearing)
- Eating inedible objects (pica)
- Running off or away
- Self-injurious behaviour (biting, pulling hair, head banging, self-hitting, skin picking)

“ Try to use a positive rather than a negative if you can. I find saying NO to my son, he just laughs or ignores me, but if I say STOP! in a firm voice, he takes me more seriously. If your child does something quite aggressively, try saying the word GENTLE or GENTLY in a soft voice, or sing words to them. Singing words often works better than spoken words for some children/ adults. ”

Possible causes

- (1) physical (e.g. illness or discomfort)
- (2) psychological or cognitive (mental/emotional state, thinking and reasoning)
- (3) environmental (e.g. sounds, smells, lights)

Why does challenging behaviour happen?

Certain behaviours happen for an obvious reason. Babies learn to cry loudly when hungry, wet or bored because they have learned that crying gets them what they want or need. As children grow, they learn how to behave appropriately; because they learn that their behaviour gives them access to what they need or what they want through how their behaviour is responded to by others. If a child has difficulty with speech or cannot use sign language, or has very little understanding, then a behaviour becomes the only way a child can show a parent what they need.

All parents at one time or another have issues with their children, regardless of whether they have a genetic diagnosis or not. There may be difficulties at play, meal, bed, or bath time; with going out, toileting; or their children may hit out, bite or push. Behaviour is sometimes described as 'challenging'.



Behaviour becomes an issue when it:

- hurts the person or someone else
- prevents the person from being included
- stops personal development
- causes major disruption to family life
- is socially unacceptable

Pain and discomfort

One of the first steps in trying to understand a behaviour might be to consider that it could be triggered by pain.

Babies use their mouth to explore objects because it gives them a lot of information. Chewing and biting can also help to develop muscles in the mouth that are used to form sounds. Try a safer alternative to your arm or leg, like a soft toy or teething ring. A child can learn to behave in a 'challenging' way for other reasons. The real difficulty is trying to understand why and what 'message' a child is sending out. Parents find it very hard to deal with difficult behaviour that happens 'out of the blue' and start to think that it is all part of a child's personality and nothing can be done about it.



Often parents have learned to react to these behaviours in a certain way and do not realise that perhaps their reactions are allowing the behaviour to occur again and again, or reinforcing negative behaviour patterns. Your child might have earache, or another pain. In older children or adults acute constipation could be a trigger. Discomfort for those who are less mobile, and might need to be moved more often, could also be a trigger. It is also possible that a medicine that a child is taking is making them feel ill. If you think that your child may be in pain, take them to see their GP or Paediatrician to get them fully checked.

Golden rules

- Children behave in a certain way for a reason. The difficulty is, that we may not understand or know what that reason is and we see the behaviour as a problem.
- Try to think of the behaviour as a 'message' your child is sending.
- Reward behaviour that you want to see more of. Behaviour that is rewarded tends to be repeated, as it may not be obvious that you are giving a reward. Don't forget to reward or praise a child when they are showing desirable behaviour, perhaps just sitting quietly or watching the TV. The key is to identify what your child finds rewarding and then to use that to reinforce desirable behaviours.
- Stop dangerous or harmful behaviour. If behaviour is dangerous or harmful to others or to your child, it must be stopped. You can take precautions to safeguard a room or protect yourself and your child.
- Anticipate problems. If your child likes to bite, offer an alternative object for the child to bite on – a teething toy or rubber tube. If they kick out at everyone, remove their shoes, or let them wear soft slippers. Offer a cushion or large soft toy as an alternative.
- Give children time to process information and time to absorb new information. A visual timetable, where pictures or symbols represent activities at certain times of the day, may help your child to accept change. Give your child enough time to understand your instructions. Sudden change can be very difficult for children. They need enough warning that an activity is about to end. Ten-minute, five-minute, and one-minute warnings for example, are helpful. Egg-timers are ideal for this.
- Offer simple choices. Too many choices can confuse a child. "Would you like orange juice or milk?" is easier to understand than "What do you want to drink?". Offering choices gives children some control over their life, if they feel powerless it can be very frustrating.
- Distraction helps. If your child is having a tantrum, or will not leave the room or listen to you, offer them an interesting alternative to the behaviour or activity that you want to stop. This works well with some younger children. "Look I have just seen a green fairy with red boots dancing up the stairs! Let's go look for it!" will attract their attention and usually stop the behaviour. If your child has communication difficulties then sometimes the distraction will have to be more visual: a glove puppet, silly hats that you can put on, or singing songs in funny voices. Take the child's attention away from the particular activity you want to stop.
- Try to be consistent and persistent. Once you have decided to ignore a behaviour and not reward it, if you give in or lose your temper then your child will continue to use that behaviour – because it works!
- Use simple 'this first, then ...' language, augmented by symbols or object referencing if possible. For example: show your child their coat and say: 'Coat on first, then car.'

Self-injurious behaviour

Self-injurious behaviour, is when someone intentionally harms their own body, such as cutting or biting themselves. It's often a way to cope with emotional pain, intense anger and/or frustration. Or to meet sensory processing needs.

■ Self-injurious behaviour in children with intellectual disability

Website: <https://cerebra.org.uk/download/self-injurious-behaviour-in-children-with-intellectual-disability/>

This is a weblink to a research paper written by Professor Chris Oliver, Dr Louise Davies and Dr Caroline Richards from the University of Birmingham. This paper has been written to help parents and carers of children with an intellectual disability to understand what self-injury is, what the causes are and which interventions are effective. The briefing focuses on children with profound to moderate intellectual disability, who may also have autism spectrum disorder and/or a genetic syndrome.

■ The Challenging Behaviour Foundation

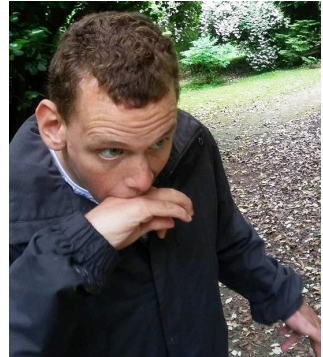
has a useful information sheet about self-injurious behaviour.

Website <https://tinyurl.com/2p9b3uf8>

■ Video – Self-injurious behavior

Website: <https://tinyurl.com/2wn5kf4d>

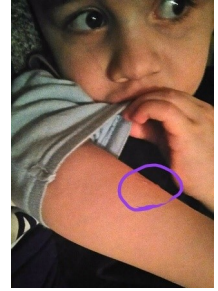
A video created by Professors Chris Oliver and Glynis Murphy, the UK's leading authorities on self-injurious behaviour, join together to offer clear and practical information and advice to families caring for individuals with severe learning disabilities.



Biting

Like other behaviours, biting is often a child trying to communicate a need. Biting is a form of communication for children who are frustrated or angry but can find no other way to express it. If you can figure out what's bothering your child and change that, the biting may go away on its own. Think about what happens after a child has just bitten someone. There are often screams, loud noises, lots of jumping up and down, people rushing about to see what has happened. The child who showed the behaviour might even be picked up and talked to for a few minutes. This can act as a rewarding experience for the child that displayed this behaviour; so much activity and noise. Through this cycle, a child can quickly learn that if they are bored, biting someone will produce a very interesting result. If they bite themselves, it is likely that someone will check for damage, maybe bathe any wounds, and bandage it, so that child is rewarded with more attention. It is important to communicate that biting is not acceptable and to give attention to the person that was bitten. If it is safe to do so, limit the amount of attention you give to the person who has done the biting and work to

understand what the function or purpose of the biting was (see ABC chart on page 10). If they really feel the need to bite and there is an indication from the ABC analysis that the biting is driven by sensory needs, offer them something like a teething or chewy toy. Children with developmental delay are more likely to have sensory issues and are less likely to understand that they are hurting someone.



Anxiety

Anxiety is something we all experience from time to time. It is a normal response to situations that we see as threatening to us, for example, sitting an exam, it would be natural to feel anxious. However, anxiety can be unhelpful as ...

- the symptoms can be uncomfortable
- the symptoms can be frightening if someone doesn't know that these are signs of anxiety or what it is
- it can lead people to worry that there is something wrong with them

When anxiety goes on for a long time, specialist help may be needed. People with a learning disability may become anxious at various points in their life. Stressful life events and times of transition, e.g. changing schools or leaving school, starting at college or a day-care centre, changes in staff support, moving home or a change in family dynamics are some possible causes, but anxiety may also occur for no obvious reason.



■ Anxiety UK

Website: <https://www.anxietyuk.org.uk/>

Helpline: 03444 775 774

Email: support@anxietyuk.org.uk

Anxiety UK is a national registered charity for those affected by anxiety disorders

■ Cerebra has a guide on anxiety

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

■ Young minds has information on how to help with anxiety

Website: <https://www.youngminds.org.uk/parent/parents-a-z-mental-health-guide/anxiety/>

Unique has a guide on Mental Health and Wellbeing which might also be helpful:

<https://rarechromo.org/practical-guides-for-families/>

Separation anxiety

Separation anxiety and fear of strangers is very common in most children when they are babies/toddlers. Babies and toddlers often get clingy and cry if you leave them, even for a short time. It is a normal part of your child's development and they usually grow out of it. However, for some children and adults with a chromosome or gene disorder they don't grow out of it. As they get older and their awareness of the world around them increases, they can feel unsafe or upset in new situations. Children with separation anxiety may try to avoid attending school or family events. They might be reluctant to go to sleep, have nightmares or feel sick, have a headache or tummy ache.

■ NHS link on how to help children with separation anxiety

Website: <https://www.nhs.uk/conditions/baby/babys-development/behaviour/separation-anxiety/>

Obsessive compulsive disorder (OCD)

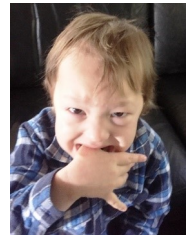
(OCD) is a common mental health condition which can cause behaviour difficulties both in thoughts and actions. More information about OCD can be found in our guide on Mental health and wellbeing (see link on page 8).

PICA

Pica is the eating of non-food inedible items, for example stones, faeces, clothing, sand, snails or dirt. Most young children go through a stage of picking up things they shouldn't, to put in their mouths, for them it is just a way of finding out about the world around them by 'mouthing' everything. But there are many children and adults with a chromosome or gene disorder that carry on eating things they shouldn't. This behaviour may be a sign that the child has a developmental, behavioural, emotional, nutritional or health problem. Some children who have pica have low levels of iron or zinc in their bodies. The risks of pica include choking, vomiting, infections, blockages and poisoning. PICA could be related to a sensory or attention need. It is advisable to discuss your concerns with your GP and request that your child is checked for a possible health related problem. If you are really concerned your local walk-in or urgent treatment centre may be able to offer advice.

■ The Challenging Behaviour Foundation

has a useful information sheet on Pica.
Website: <https://tinyurl.com/3rn7mw5b>



Tourette syndrome

Some children and adults have Tourette syndrome. The main symptoms are tics and usually begin when a child is 5 to 10 years of age. Tics usually are worse during times that are stressful or the person is over-stimulated. Tics tend to improve when the person is calm or focused on an activity. Each individual might have their own way of dealing with their tics.

Website: <https://www.tourettes-action.org.uk/>

Faecal smearing

It sounds horrible, but for some younger children playing with their 'poo' could mean that they are getting ready for toilet training and they are inquisitive about this stuff that comes out of their bottom! For other children/adults - engaging in smearing faecal matter can be a form of attention seeking or, can serve as a sensory input need, or they might just be feeling unwell. As with many challenging behaviours, it is important not to show too much of a negative reaction, but to reward good behaviour with consistent and positive praise. That way a child will learn which behaviours earn positive attention and/or rewards.



What can I do to stop my child from smearing?

- Clothing: try dressing your child in clothing that makes access to their back area difficult i.e. pyjamas that fasten at the back or a onesie or full body vest that closes underneath their bottom
 - Reading: try a social story that reinforces the routine of toilet hygiene
 - Play: try 'messy play' to help with sensory input
 - Scent: smell strong smelling food or objects like cheese or playdoh
 - Touch: playing with playdoh or theraputty.
 - Visual: finger painting or shaving foam
- **The National Autistic Society** has some useful information on faecal smearing on their website: <https://tinyurl.com/y6tcc9p6>



“ J. went through a stage of smearing; he would smear in his bedroom all over the walls. I was at my wits end. However, when I was advised that it might be sensory and that J. may be seeking sensory overwhelm, I was given advice to give him some cloth with lots of Olbas oil. I just used heavy duty kitchen roll and applied about 5 drops of oil which creates quite a strong scent. J. would hold it to his nose and enjoy the strong aroma. Amazingly it worked and over time I reduced the amount of oil I used. Miraculously the smearing stopped!!! ”

Why is challenging behaviour more common in some genetic disorders?

Particular types of behaviour are known to be more common in some well-known genetic disorders. But in some children and adults, the cause of that behaviour is not simply because they have a chromosome or gene disorder. Pain or discomfort and impaired communication skills that arise from the disorder are much more likely to be at the root of the behaviour. It is important to understand that these behaviours are not inevitable and interventions can be helpful.

An early diagnosis, from a geneticist or paediatrician, should include a description of behaviours that might be associated with a disorder and help to identify the best approach to managing them. This would require a multi-disciplinary team approach involving one or more professionals such as: behaviour, educational or clinical psychologists; social workers; psychiatrist; GP; physiotherapist; speech and language therapist; or occupational therapist.

If your child is in school then the SENCO (special educational needs coordinator) or your child's teacher could also be involved. Parents can seek advice and help from their local Child Development Centre, Portage service, Health Visitor or school.

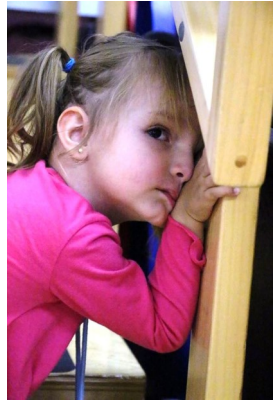


If your child has autism, then that can increase the likelihood of challenging behaviour. If you suspect that your child might have autism then it is important to have an assessment done, because there are specific ways to help a child with autism manage their behaviour and helpful strategies for parents to use too.

“ My son has problems with noise, often putting his hands over his ears to block out sounds. We bought him some noise-cancelling headphones, which have helped him cope in ‘difficult’ situations. ”

Autism

People with autism often have their senses enhanced. A typically functioning person would be able to shut out background sounds and just hear one sound. For those with autism, they find it difficult to shut out these additional sounds and often cup their hands over their ears in an effort to block out lots of noise. People with autism often have difficulty understanding what's happening around them and communicating with other people. Children can have a sensory processing disorder without an ASD diagnosis.



■ NICE pathways

Website: <https://www.nice.org.uk/guidance/cg128>

The autism diagnostic assessment for children and young people.

■ PDA (Pathological Demand Avoidance)

Website: <https://www.pdasociety.org.uk/resources/what-is-pda-booklet/>

Pathological demand avoidance (PDA) is increasingly accepted as a behaviour profile that is seen in some individuals on the autism spectrum. People with a PDA behaviour profile share difficulties with others on the autism spectrum in social communication, social interaction and restricted and repetitive patterns of behaviours, activities or interests. The main characteristic of a PDA behaviour profile is a high level of anxiety when demands are placed on that person. Demand avoidance can be seen in the development of children, including those on the autism spectrum. It's the extent and extreme nature of this avoidance, together with displays of socially shocking behaviour that leads to it being described as 'pathological'.

Severe behavioural difficulties - A large proportion of people with PDA can have real problems controlling and regulating their emotions, particularly anger. As children, this can take the form of prolonged meltdowns as well as less dramatic avoidance strategies like distraction and giving excuses. It is essential to see this as extreme anxiety or 'panic attacks' and to treat them as such. Try using reassurance, calming strategies and de-escalation techniques. As PDA is considered to be a behaviour profile within the autism spectrum, it is usually identified following a diagnostic assessment for autism.

References:

■ Website:

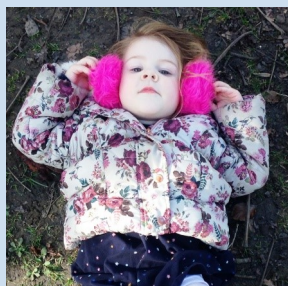
<https://limpsfieldgrange.co.uk/wp-content/uploads/2016/01/PDA-booklet.pdf>

■ Website:

<https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pda>

Sensory processing disorder (SPD)

A Sensory Processing Disorder is a condition in which the brain has trouble receiving and responding to information that comes in through the senses. It was formerly referred to as sensory integration dysfunction. Children with sensory processing difficulties can be oversensitive to sights, sounds, noise, textures, flavours, smells and other sensory input. SPDs can also be associated with balance, body awareness and internal body senses.



For many children with a chromosome or gene disorder 'sensory difficulties' can be a problem and cause behaviour which challenges. For example:

- they might hate the labels or seams in their clothes; they might find them itchy or unbearable
- they might hate to be touched in any way, i.e. having their face and hands or their hair washed, or even dislike the shampoo and/or water running down their face, shoulders or back
- they cannot touch or eat certain foods
- they might be sensitive to certain smells or odours
- they might hate being tickled or cuddled

These types of behaviours can be managed by cutting labels out of clothes or buying seam free clothing, or finding a way of shampooing hair where the water and soap doesn't touch another part of their body.

This is a useful guide explaining sensory processing:

■ **Sensory processing A Guide for Parents**

Website: <https://cerebra.org.uk/wp-content/uploads/2020/04/sensory-processing-low-res.pdf>

Facebook groups for parents.

■ **Sensory Processing Disorder (SPD) Support - Parents**

Website: <https://www.facebook.com/groups/2217476670/>

■ **Sensory Processing Disorder- Parent Support**

Website: <https://sensoryprocessingdisorderparentsupport.com/>

Some really useful information on all different types of sensory behaviour.

Sensory overload occurs when one or more of the body's senses experiences over-stimulation from the environment. There are many environmental elements that impact an individual. Examples of these elements are crowds, noise, media and technology. We have a way of shutting out certain noises, but children and adults with sensory difficulties, can hear lots of noises all at once and have difficulties shutting off the extra noises). For those that find sounds, or noise difficult to cope with, noise reducing headphones can help to minimise what they hear. For some children, more extreme behaviour can be caused by the frustration due to their lack of understanding, or anxiety, or pain and illness.

Sensory toys, activities, sensory room equipment

■ Fledglings

Website: <https://www.fledglings.org.uk/>

Telephone: 0203 319 9772

Email: Fledglings@contact.org.uk

Fledglings (now run by the charity Contact) understand that life with a disabled child can be challenging, and help by providing practical, affordable, good quality products that address everyday problems faced by children with disabilities such as chromosome and gene disorders.

■ Rompa

Website: <https://www.rompa.com/>

Telephone: 01246211777

E-mail: customer.service@rompa.com

Facebook: <https://www.facebook.com/rompaltd>

All types of sensory equipment, sensory environments.

■ Special Needs Toys

Website: <https://specialneedstoys.com/uk/sensory-toys>

Telephone: 01299 827820

Email: info@specialneedstoys.com

Special Needs Toys, from mobile Multi-Sensory, to Swings, Trampolines and other Sensory Integration kits, Switches, Rewards and small Sensory toys.

Also in the USA: <https://specialneedstoys.com/usa/>

■ Sensory Plus

Website: <https://sensoryplus.co.uk/>

■ Sensory toy warehouse

Website: <https://www.sensorytoywarehouse.com/>

■ Sensory Trust garden ideas

Website: <https://tinyurl.com/2jdvavwp>

USA based websites

■ Developmental Pathways For Kids

Website: <https://www.developmentalpathways.com/?s=sensory>

A paediatric clinic, but has lots of useful resources including a checklist on its website.

■ Pathways

Website: <https://pathways.org/topics-of-development/sensory/>

Website with lots of useful information on children's sensory development.

■ SPD Star Website: <https://sensoryhealth.org/>

STAR Institute Treatment Center, customize approaches for specific sensory challenges that you and your child experience.

■ Understood Website: <https://tinyurl.com/2ypts23h>

A free resource for parents and carers

Stimming

Stimming is a self-stimulating behaviour such as flapping, rocking or spinning round and round and can be a harmless way of relaxing. For a child or adult who stims non-stop, it could hold back their learning; because they are so focused on their stimming behaviour.

Other stims can be self-injurious (head banging, repeatedly hitting themselves in the head or face, are extreme forms of stimming). Why many children behave in this way is difficult to understand. Children and adults with a chromosome or gene disorder can have high pain thresholds i.e. they don't always feel pain, like most people would. The sensation they feel from hitting themselves might actually be quite comforting or pleasing, or a tolerable discomfort that distracts them from their anxiety or pain. Vocal (or verbal) stimming – this is when your child uses their mouth to make noises, for example blowing raspberries, humming or repeating the same word or words over and over again.

■ **The National Autistic Society**

Have further information on stimming behaviour.

Website: <https://tinyurl.com/4mvwxztr>

■ **Ambitious about Autism**

Have information on stimming. Website:

<https://www.ambitiousaboutautism.org.uk/information-about-autism>

Oral motor development

Oral motor development is the use and function of the mouth, tongue, lips and teeth. The coordination and movement of all of these is very important in speech production, safe swallowing, and eating food. Children can be either hypo-sensitive or hyper-sensitive. Signs that a child is hyper-sensitive typically include dislike of brushing their teeth or having their face wiped, and they are usually very picky eaters especially with a dislike of specific textures. They might dislike certain foods because they look, taste or smell odd.

■ **Maximum Potential**

Website: <https://maximumpotential.org.uk/>

Telephone: 0207 486 4747

Specialising in Sensory Integration and Neurodevelopmental Therapy.

■ **Sensory Direct**

Website: <https://www.sensorydirect.com/>

For all things sensory, including weighted blankets, fidget toys, clothing, body socks etc.

■ **Sensory Integration Network**

Website: <https://www.sensoryintegrationeducation.com/>

Telephone: 0118 207 2773

Email: support@sensoryintegration.org.uk

Facebook: <https://www.facebook.com/SensoryIntegrationNetwork/>

Sensory integration is about how our brain receives and processes information so that we can do the things we need to do everyday.

What can parents/carers do?

There are so many different types of behaviours that can challenge. Depression, extreme social anxiety, trauma related, sensory processing disorder, auditory processing disorder, school refusal, repetitive questioning, excessive reassurance behaviour and the relatively new 'excessive technology use', Autism, ADHD related behaviour. Different types of behaviour will require different therapies/treatment. There are also specialist schools for children that require additional behavioural support. A child may have a number of behavioural difficulties or just one. You have to decide which one of these difficulties needs the most urgent attention. It is impossible to stop everything all at once. It will take time and energy and effort; there is no on/off button or magic wand. You have to choose the one behaviour that causes the most difficulty and start working on that. If you want to change your child's behaviour, then you have to try to find out why a child behaves in a certain way. Usually parents see a Behavioural or Clinical Psychologist to discuss any difficulties, but there are often long waiting lists. Each local authority (in the UK) may have a specialist/intensive behavioural support team but they might be called slightly different names depending on where you live. There are ways to help this process along and parents can look at what a child does immediately before, during and after a particular behaviour. A psychologist will talk to you about the difficult behaviours that most concern you so that they can assess the reasons why the behaviours may be occurring. If there is no obvious reason why the behaviour happens, then they will carry out an assessment, known as a functional analysis. This will involve a detailed interview with you; home and school observations and the recording of the behaviours. You will be asked to record on a sheet of paper when a particular behaviour occurs. You will also be asked to note down what happens just before the behaviour, what exactly the behaviour was, and what your reactions were immediately afterwards. This record is known as the **ABC chart**

Antecedents - what happens directly before the behaviour occurs

Behaviour - what the behaviour was

Consequence - what happened after the behaviour occurred

You observe your child's behaviour for several weeks and look to see if a pattern emerges. It may be something very simple. For example, a child who would not leave an activity to go out would have a chart that looked like this:

DAY, DATE, TIME	WHAT HAPPENED JUST BEFORE?	WHAT WAS THE BEHAVIOUR?	WHAT HAPPENED AFTERWARDS?
17/01/23 Monday 10.00 am	Jay is watching a video.	When Jay is asked to get ready to go out, he screams and has a tantrum.	Mum switched off the TV and yelled at Jay. Jay carried on screaming. Mum gets angry and holds Jay until he stops.

The chart shows there was no 'warning' given to Jay that it was time to go out. Some children need time to absorb change.

Timetables and timers

Timetables help children understand what is going to happen next. The timetable could be a visual picture showing a clock and then the activity – shopping, library, school etc. A small cooking or egg timer set to ten minutes can help a child to understand, that when the buzzer goes off it is time to stop the activity. If you can start recording this information about your child's behaviour before you see a psychologist, it will help the assessment and save time.



After an assessment children/adults are offered a 'behavioural support plan'. After an 'SPD assessment' parent's are offered a 'sensory diet plan', specific to their sensitivities. The 'diet' isn't related to food. It specifies methods/ techniques/activities that can be put in place.

■ NICE (The National Institute for Health and Care Excellence)

Website: <https://www.nice.org.uk/guidance/qs101>

Evidence-based statements to deliver quality improvements in the care of people with a learning disability and behaviour that challenges. On the NICE website there is an interactive flow chart that helps parents to develop a support plan. There are several other flowcharts on the website aimed at children or adults and different types of behaviour. The guidance states that services should carry out a functional assessment of the behaviour and develop a written support plan.

■ Challenging behaviour foundation (CBF)

Website: <https://www.challengingbehaviour.org.uk/>

Family Support Line: 0300 666 0126

Email: support@theCBF.org.uk

CBF is for families caring for, or individuals with, **severe or profound learning disabilities** (both children and adults) who typically display behaviour which may put themselves or others at risk. The Challenging Behaviour Foundation provides a range of factsheets on their website. Their Family Support Service offers a listening ear and provides free information about challenging behaviour to anyone who supports someone with a severe learning disability. The Challenging Behaviour Family Linking Scheme will try to link you with another family who are experiencing or who have experienced some of the same issues as yourself. CBF have lots of useful information on their website including an editable template letter for getting behavioural support and individual funding.

Website: <https://www.challengingbehaviour.org.uk/information-and-guidance/positive-behaviour-support/getting-behaviour-support/>

■ Cerebra - The Be-Well Checklist

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

The Be-Well Checklist can help parents, carers and professionals to reduce challenging behaviour and improve the wellbeing of people with a severe learning disability and complex needs.



■ Cerebra - Pain

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

The charity Cerebra have a really useful guide on pain, including the FLACC pain scale. Cerebra also offer a range of free services to families of children with brain conditions, including a sleep advice service, legal advice service, a toy and book lending library service and lots of other practical guides, visit: <https://cerebra.org.uk/>



■ Cerebra - Cognitive Inflexibility and impulsivity

Website: <https://cerebra.org.uk/download/cognitive-difference-cognitive-inflexibility-and-impulsivity/>

Many Unique children can have cognitive inflexibility and impulsivity. This refers to their thought process and how they need to do things routinely. Any changes to that routine can make them react impulsively. This guide helps you to understand these differences and strategies to help.



Contacting a medical professional

If you have concerns about your child's behaviour, then there are several ways to get help. Contact your GP who can refer you to an appropriate service. If your child is in school, then most Local Education Authorities (LEAs) will have specialist teams that advise on behaviour management. Your school will have contact information.

The Child and Adolescent Mental Health Service (CAMHS) offers a comprehensive range of services and can provide help and treatment to children and young people who are experiencing emotional or behavioural difficulties, or mental health problems, disorders and illnesses. There can be long waits to see someone at CAMHS and your GP might suggest an alternative service. Some of these services are based in NHS settings, such as Child and Family Consultation Services, in-patient and outpatient departments of hospitals, GP surgeries and health centres. Others are based in educational settings such as schools, colleges, universities, or in youth centres. Although it is usual for a GP to refer young people to this service, it may be accessed through your Health Visitor, Community or School Nurse, your child's school, a social worker or a health professional. It is sometimes possible to contact them directly.

NHS England has worked to bring in a **Family Ambassador** programme

Website: <https://www.e-lfh.org.uk/programmes/family-ambassadors/>

This programme is to improve the quality of care that children and young people receive within mental health inpatient services.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy (CBT) is a talking therapy that can help people manage their problems by changing the way they think and behave. Its most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems. You can ask your GP for a referral.

■ **British Association for Behavioural and Cognitive Psychotherapies**

Website: <https://www.babcp.com/>

Free online therapy websites:

- **Therapy for you** <https://www.therapyforyou.co.uk/courses/online>
- **Better help** <https://www.betterhelp.com/>
- **Beating the blues** <https://www.beatingtheblues.co.uk/>
- **NHS (UK) self help** <https://tinyurl.com/z8ndsufk>

Multisystemic therapy (MST)

UK and Ireland website: <http://www.mstuk.org/>

Email: psychology@nes.scot.nhs.uk

Multisystemic therapy is an intensive family and community-based intervention for children aged 11-17 with severe behaviour problems that aims to break the cycle of antisocial behaviours while remaining safely at home.



Medication

A range of medications have been widely used to treat self-injury in individuals with an intellectual disability, including those typically used to treat anxiety, depression, epilepsy and psychosis. Generally, interventions based on Applied Behaviour Analysis should always be tried before medication. If medication is to be used at all, given the numerous and potentially harmful side effects of such medications, they should be prescribed as a last resort and their effects very carefully monitored with regular reviews. There is a useful video discussing the use of medication on the charity Contact's YouTube channel:

<https://www.youtube.com/watch?v=2NMFrw4-9qI>

Brushing and joint compressions

Many of Unique parents, particularly in the USA, have used this type of therapy for sensory defensiveness. It might not work for everyone but for some it has been helpful. You can find out more about this technique here:

Website: <https://tinyurl.com/4pf4wef7>

As with all therapies, it is best to check with your occupational or physiotherapist before undertaking this therapy.



Weighted therapy - blankets, pads and compression vests

Weighted blankets are a sensory tool that occupational therapists often recommend for children and adults with attention deficit hyperactivity disorder, sensory processing disorder, anxiety and autism spectrum disorders to assist with calming and sleep. There are many makers of these types of items, you can find them using search engines online, but please be careful where you buy from. It is recommended that the weighted blanket should not exceed 10% of the users bodyweight. Please follow guidelines for safety.

You can get weighted blankets, lap pads, compression vests, and pressure clothing online from a variety of different companies and they will vary a lot in price.

■ Sensory direct

Website: <https://www.sensorydirect.com/products/weighted-blankets>

■ Fledglings

Website: <https://www.fledglings.org.uk/>

■ Cerebra have produced a factsheet on the evidence for weighted blankets

Website: <https://tinyurl.com/4rhw7tmn>

Minimum user weight	Blanket weight
25kg	2.5kg
30kg	3.0kg
36kg	3.6kg
45kg	4.5kg
60kg	6.0kg
70kg	7.0kg
80kg	8.0kg

Weighted blankets may be unsuitable for people with certain medical conditions, including chronic respiratory or circulatory issues, sleep apnea, asthma, low blood pressure, type 2 diabetes, epilepsy, and claustrophobia.

Yoga for children and adults with special needs

Yoga can help children and adults with special needs to relax and de-stress as well as helping to strengthen and tone their muscles. There is a huge variety of different types of yoga, so it might be a case of contacting yoga teachers and talking to them about your needs.

Here are a few links that provide more information:

- **Special Yoga** Website: <https://specialyoga.co.uk/>
- **Gentle Therapeutic Yoga for Children with Special Needs** (Somerset, UK based) Website: <https://tinyurl.com/3ybj8wrđ>
- **Special Yoga (USA)** Website: <https://www.specialyoga.com/>
- **YogaMobility** <https://yogamobility.org/>

“ My son will often scratch at his face, mouth or his hands when he becomes cross and agitated. I found that using white prescription gloves and the scratchesleeves (<https://www.scratchsleeves.co.uk/>) we purchased help a lot during meltdowns. If he scratches at his face whilst he has the scratchesleeves on, due to the mitts being made of silk he will not cut/harm his skin. We particularly use them when going into new surroundings to protect him if he becomes agitated or upset. This technique has worked well for us. ”



“ We use Chewelry a lot. They are silicone chewable shapes on a necklace or keyring, which provide a safe way of gaining comfort when teething. Our little one has a habit of chewing anything she can get her hands on and has even bitten through buttons on her school uniform. You can get Chewelry from several online shops including Amazon and Ebay. ”

Links

■ **ACAMH** (Association for Child and Adolescent Mental Health)

Website: <https://www.acamh.org/>

Telephone: 020 7403 7458

Email: membership@acamh.org

Facebook: <https://www.facebook.com/ACAMH>



■ **The Autism research institute of America**

Website: <https://autism.com/>

■ **Family lives**

Website: <https://www.familylives.org.uk/>

Helpline: 0808 800 2222 (24-hour helpline)

Family Lives offers a confidential helpline service which is free from landlines and most mobiles.

Information, advice, guidance and support on any aspect of parenting and family life, including bullying, cyber bullying, stress and anxiety.

■ **FIND (Further Inform Neurogenetic Disorders)**

Website: <https://www.findresources.co.uk/>

This website summarises findings from high quality research studies into genetic syndromes. This website was built by the Cerebra Centre for Neurodevelopmental Disorders in partnership with Cerebra, Economic and Social Research Council and syndrome support groups to reduce the amount of time it takes research findings to reach parents, carers and professionals – the people who need the information the most. The work of the centre focuses on the difficulties experienced by children and adults who have intellectual disability, autism spectrum disorders and genetic syndromes that are associated with developmental delay.



■ **Living life to the full**

Website: <https://lltff.com/>

Free online life skills course for people feeling distressed and their carers. Helps you understand why you feel as you do and make changes in your thinking, activities, sleep and relationships.

■ **MenCap**

Website: <https://www.mencap.org.uk/advice-and-support>

Helpline: 0808 808 1111 (Mon-Fri 9am-5pm)

Email: help@mencap.org.uk

Northern Ireland: 02890 691351

Wales - Cymru : 02920 747588

■ **Mind**

Website: <https://www.mind.org.uk/>

Telephone: 0300 123 3393

Monday to Friday (except for bank holidays). 9am to 6pm

Email: info@mind.org.uk

MIND is a mental health charity and has a variety of useful leaflets available to download or purchase.

■ **MindEd**

Website: <https://www.minded.org.uk/>

MindEd is a free e-learning resource to help adults to identify and understand children and young people with mental health issues. It is aimed at everyone with a duty of care for children and young people, whether this be through their work or outside it in a voluntary or charitable capacity. This could be as a counsellor, teacher or police officer, an athletics or football coach, or through involvement with the Scouts or Brownies. MindEd has something for everyone.

How does it work?

MindEd offers short (no more than 20-30 minutes) online learning sessions, to help adults identify mental health problems (looking at how problems manifest themselves through particular feelings or behaviours) and demonstrate what action to take in the best interests of the child or young person. These sessions can be completed as a 'one off'. Alternatively, visitors can sign up as MindEd members and complete several sessions which they can record on their personal page and print as a certificate for their learning record.

■ **Mood gym**

Website: <https://moodgym.com.au/>

An Australian website providing free online CBT resources with an interactive programme, that helps you to identify and overcome problem emotions, helping to prevent and decrease depression, using information, quizzes, and skills training.

■ **National autistic society** (UK)

Website: <https://www.autism.org.uk/>

■ **National child and maternal health intelligence network**

Website:

<https://www.chimat.org.uk/mental-health-and-psychological-wellbeing/>

ChiMat do not provide direct services to families but have links on their website to information and support.

■ **PBIS (Positive Behavioural Interventions and Supports)**

Website: <https://www.pbis.org/>

US based organisation.

■ Positive behavioural support (PBS)

Website: <https://pavingtheway.works/resources/>

Resources for family carers, available free online. The Paving the Way website, includes a free set of Positive Behavioural Support resources for family carers.

■ Royal college of psychiatrists

Website: <https://tinyurl.com/mv9e5xps>

Telephone: 020 7235 2351

General enquiries email: reception@rcpsych.ac.uk

Has a large variety of useful leaflets and information for families on all aspects of mental health.



■ Triple P – Positive Parenting Programme

Website: <https://www.triplep-parenting.uk.net/uk/triple-p/>

Triple P is a parenting programme, but it doesn't tell you how to be a parent. It's more like a toolbox of ideas. You choose the strategies you need. You choose the way you want to use them.

■ Young minds

Website: <https://youngminds.org.uk/>

Telephone: 0808 802 5544

Email: parents@youngminds.org.uk

YoungMinds provides information to parents and professionals. It produces leaflets on various topics, a directory of child guidance, psychiatric and psychological services and a newsletter.

Guide to CAMHS weblink: <https://www.youngminds.org.uk/young-person/your-guide-to-support/guide-to-camhs/>

“ One successful idea I had when dealing with M. aged 32 years... He hates being told to clean his room or put things away, e.g. clothes or towels on the floor of his room. I tried explaining that it was dangerous and he might fall, this annoyed him, his response was to scream at me and say "I hate you telling me what to do". So, I sat with him and we devised a special secret action, the action means.....I'm not going to tell you what to do, you already know, this is just a reminder. Ours was quite comical, I'd say "Jellyfish" then wave my arms around and say "bloop, bloop" noises, this always ended with both of us giggling and M. trying to wink at me, give me a thumbs up, and as soon as I left the room (so it didn't look like I was checking up on him) he'd pick up the things on his floor, he'd then, very proudly call me in to show me...and we celebrated with our secret handshake and hug. ”

Books

■ Books beyond words

Website: <https://booksbeyondwords.co.uk/bookshop>

Email: admin@booksbeyondwords.co.uk

Books on a variety of topics, no words, just pictures.



■ Functional Behavior Assessment for People with Autism

by Beth Glasberg. Parents and professionals caring for people with autism sometimes encounter baffling, challenging behaviour noncompliance, aggression, or repetitive actions which they don't know how to stop. The key to resolving problem behaviour is to first determine its purpose by conducting a functional behaviour assessment (FBA). Available from Amazon Website: <http://amzn.to/2tHCTkQ>

■ Helping children who are anxious or obsessional

A guidebook by Margot Sunderland & Nicky Armstrong to help children who:

- Are insecure or worry too much
- Suffer from phobias or nightmares
- Find it difficult to concentrate to let go and have fun
- Have suffered a trauma
- Are worryingly good or seem like little adults
- Use order and routine as a way of coping with 'messy' feelings
- Retreat into dullness as a way of managing their being in the world
- Develop obsessive-compulsive behaviour in order to ward off their too-powerful feelings

It is available to buy from Website: <https://www.amazon.co.uk/Helping-Children-Who-Anxious-Obsessional/dp/0863884547> and other booksellers.

■ How to manage children's challenging behaviour

by Bill Rogers. Dr. Bill Rogers taught for many years before becoming an education consultant and author; he lectures widely on behaviour management, discipline, effective teaching, stress management and teacher welfare across the UK and Europe, Australia and New Zealand. Chapters look at: finding a way back from inappropriate behaviour; dealing with very challenging behaviour on a daily basis; creating a peaceful school and developing positive practice. Available to purchase through Amazon and other online retailers.

■ Jessica Kingsley publishers

Website: <https://uk.jkp.com/>

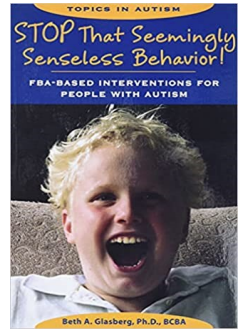
Telephone: 020 7833 2307

Email: post@jkp.com

Jessica Kingsley have a huge variety of books on behavioural problems, disability, practical, legal, social issues, therapies etc. If you aren't online, you can contact them by phone for a brochure.

■ **Stop That (Seemingly) Senseless Behavior!**

Fba-Based Interventions for People with Autism (Topics in Autism) by Beth A. Glasberg (Author). A guide to developing an effective behaviour intervention plan to stop undesirable behaviours such as hitting, screaming or repetitive questioning. It outlines an educational approach for parents, teachers and service providers that not only reduces the problem behaviour but also teaches the individual with autism new skills to get his needs met. Available from Amazon and other booksellers.



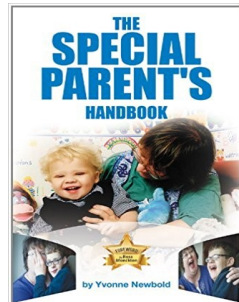
■ **The Special parent's handbook**

by Yvonne Newbold

Website : <https://yvonnenebold.com/>

Email : yvonne@yvonnenebold.com

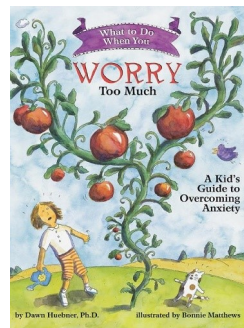
Yvonne Newbold is a writer, speaker, workshop facilitator and consultant in issues relating to disability who has written a book named 'The Special Parent's Handbook' based on her experiences of bringing up her own disabled children.



■ **What to do when you worry too much: A Kid's Guide to Overcoming Anxiety**

by Dawn Huebner, PhD.

An interactive self-help book designed to guide 6 -12 year olds and their parents through the cognitive-behavioural techniques most often used in the treatment of generalized anxiety. Engaging, encouraging, and easy to follow, this book educates, motivates, and empowers children to work towards change. It is available to buy from Amazon and other booksellers.



Never underestimate a child's ability to get bored or their need for attention. It is impossible for parents to be on constant entertainment duty, so it is useful to prepare something that will keep a child amused for short periods of time. Musical mobiles, interactive toys or DVD's can help.

Coping mechanisms as a parent carer

If your child displays behaviour that challenges and you are finding it difficult to cope, support is available. It is particularly important that you seek support if you are experiencing harm from the person you care for (whether intentional or unintentional). Many organisations have strategies for coping with challenging behaviour. Some of these organisations also provide opportunities for carers to connect with other people in a similar situation, for example, through family linking schemes or parent carer groups. Sharing your experiences, for example, with a local carers' group – can be a good way of getting support. Contact your local **Carers support organisation** (you should be able to find them on your county council website) or via:

■ Carers UK

Website: <https://www.carersuk.org/>

Helpline: 0808 808 7777

Email: advice@carersuk.org



Talk to other Unique parent members to ask how they cope. Sometimes other parents are the best source of information and they may suggest something you haven't already tried. Talk to your GP or paediatrician or social worker to see if they can offer additional support. Often parents just need a break, so don't be afraid to ask for a referral to social care services for more support. As a parent you can also request a **carer's assessment** for yourself.

Unique has a guide on **Carers wellbeing**, which is available to read or download from our website, in the family practical information guides section:

<https://rarechromo.org/practical-guides-for-families/>

“ My daughter loves to pick up books and fan the pages. She has always and still does love to spit water like a fountain and has a fascination with sticks, sand and stones, she will pick up stones between her forefinger and middle finger (like scissors), and she is able to imitate a dog's bark, her and the neighbour's dog regularly bark at each other, almost as if in conversation. ”

Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE,
United Kingdom
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at www.rarechromo.org/donate Please help us to help you!

Unique lists external websites in order to be helpful to families looking for information and support. This does not imply that we endorse their content or have any responsibility for it. This information guide is not a substitute for personal medical advice. Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health. Information on genetic changes is a very fast-moving field and while the information in this guide is believed to be the best available at the time.

Our thanks to all of the parents that contributed towards this guide.

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Version 2 (MM)

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