



**Rare Chromosome Disorder
Support Group,
PO Box 2189,
Caterham,
Surrey CR3 5GN,
UK**
Tel/Fax: **+44(0)1883 330766**
info@rarechromo.org
www.rarechromo.org

Support Groups

YoungMinds - www.youngminds.org.uk provides information and advice for anyone with concerns about the behaviour or mental health of a child or young person. It has newsletters, leaflets, an information centre and a confidential Parents' Information Helpline 0800 018 2138. Monday and Friday 10am – 1pm; Tuesday, Wednesday, Thursday 1pm – 4pm

Challenging Behaviour Foundation - www.thecbf.org.uk provides information and support to parents caring for individuals with severe learning difficulties and challenging behaviour. They have a number of fact sheets that, for example, look at communication, physical intervention, and the use of medication. They are also setting up a support network to put parents in contact with other families. Telephone : 01634 838739

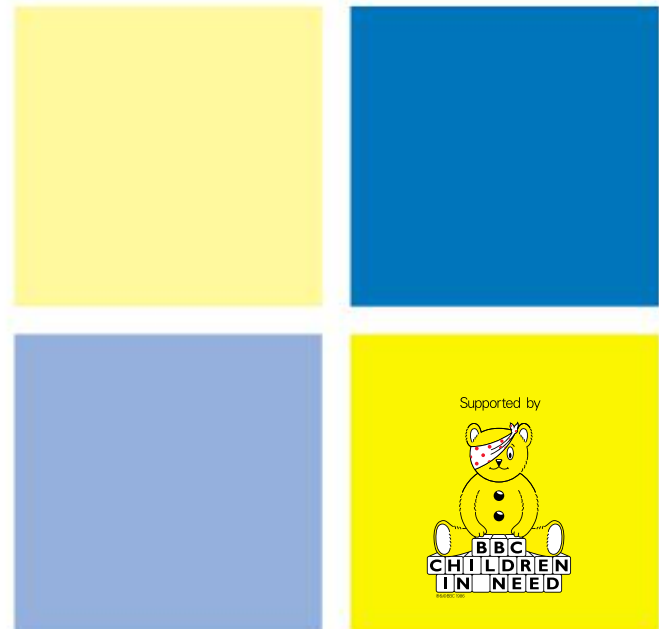
Contact a Family - www.cafamily.org.uk Free helpline for parents & families 10am - 4pm, Monday – Friday. Telephone : 0808 808 3555

Unique mentions other organisations' message boards and websites to help families looking for information. This does not imply that we endorse their content or have any responsibility for it. This leaflet 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. The information is believed to be the best available at the time of publication and has been verified by Dr Sarah Bernard, Consultant Psychiatrist for children with learning disabilities and Natasa Momcilovic, Behavioural Therapist. (The Michael Rutter Centre, London)

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Behaviour Difficulties



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

- They expect their actions will give them a response or a reward.
- They have a message they need to give out.
- They have a medical or physical need that creates the behaviour.

Sudden changes in behaviour may indicate that there is an undiagnosed medical, physical or emotional problem. This can happen in a young child and when a child has communication difficulties. For example, a child might start to head bang or cry all the time if they are in pain. It is important to check that your child does not have any physical or medical problems.

Behaviour Difficulties: What do we mean?

All parents at one time or another have problems with their children regardless of whether they are disabled or not. There may be difficulties at play, meal, bed and bath time; with going out, toileting; or their children may hit out, bite or push. Behaviour is sometimes described as 'challenging'. What does this mean? Generally it is a description of actions that could be seriously damaging to the person themselves or others, or to their environment: kicking, biting, throwing objects, smearing contents of a nappy, throwing food or drink about, running off, destroying furniture or property. It might also mean endless crying, screaming, chewing on objects, wandering about, 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 for parents to manage.



Behaviour becomes a problem 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.

**No parent is perfect and no child is perfect.
Everyone has good and bad days**

Parents of a child with a disability face many hurdles: to find and get the right treatment, support and education for their child. This is in addition to coming to terms with their child's disability 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. If the behaviour problems are severe it is very difficult to see the child in a positive light. Sometimes that can affect the relationship to such an extent that it becomes impossible to separate the 'good' behaviour from the 'bad'. It is important to think about what your child does well - perhaps smiles at people, sits still while watching TV or holds a spoon. It could be any number of small achievements. Then look at what you have done. You have given your child a loving home where they are cared for, 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. A famous Chinese proverb says: "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.

Contact Details

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 your local Child Development Centre.
- If your child is in school then many Local Education Authorities (LEAs) will have specialist teams that advise on behaviour management. Your school will have contact information.
- The National Health Service has set up a Child and Adolescent Mental Health Service (CAMHS). It 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. Some of these services are based in National Health Service (NHS) settings such as Child and Family Consultation Services, in-patient and outpatient departments of hospitals, in GP surgeries and health centres. Others are based in educational settings such as schools, colleges and 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.
- Support groups often have useful leaflets and information.

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' that your child is sending to you.
- ◆ Ignore bad behaviour. Behaviour can become worse before it improves because a child will try to gain attention. Behaviour that is ignored will eventually lessen or disappear unless there is an underlying medical, physical or emotional problem that will require expert assessments.
- ◆ Reward good behaviour. Behaviour that is rewarded tends to be repeated. It may not be obvious that you are giving a reward. Any reaction to undesirable behaviour will offer a 'reward' to a child even if it is yelling and shouting. Equally if you smile, clap hands, say encouraging words and give hugs, they can be just as rewarding as a bag of sweets.
- ◆ Don't forget to reward or praise a child when they are not behaving badly, perhaps just sitting quietly or watching the TV.
- ◆ 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 use 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, will 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 minutes, five minutes, 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 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!

Why does it 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 because they learn that their behaviour gives them what they need and what they want. If a child has difficulty with speech or cannot sign or has very little understanding, then behaviour becomes the only way a child can show a parent what is needed. For example:-



Biting – Think about what happens after a child has just bitten someone. There are often screams, loud noise, lots of jumping up and down, people rushing about to see what has happened. The biter might even be picked up and talked to for a few minutes. This can be quite a rewarding experience for the biter. So much activity and noise. A child will quickly learn that if they are bored, biting someone close by 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 gets the reward, more attention.

Don't forget to ask yourself if the child could be teething, or have toothache? It might even be part of their development. 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 extreme 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.

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 videos can help.

Is it part of the chromosome disorder?

Some types of behaviour are known to be associated with a child's particular chromosome disorder. For example:

- children with idic 15 tend to show many features of autistic spectrum disorders but are more sociable than is common in autism. Mood swings are common, with bouts of angry behaviour.
- many children with 8p23.1 deletions have outbursts of aggression and destructiveness. Their frustration tolerance is low and they are sensitive to stress.

An early diagnosis, from the geneticist or paediatrician, should include a description of behaviours that might be associated with the disorder and help to identify the best approach to managing them. This would require a multi-disciplinary team approach involving one or more professional such as: behaviour, educational or clinical psychologists; social workers; psychiatrist; GP; physiotherapist; speech and language therapist; occupational therapist. If your child is in school then the SENCO or teacher could also be involved. Parents can seek advice and help from their local Child Development Centre, Portage Group, Health Visitor or school.

If a child is also autistic then that can add to the behaviour problems. *If you suspect that your child might have an autistic spectrum disorder then it is important to have an assessment done because there are specific ways to help a child with autism manage their behaviour.*

What to do?

A child may have a number of behavioural problems or just one. You have to decide which one of these problems 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 find out why a child behaves in a certain way. Usually parents see a Behavioural or Clinical Psychologist to discuss any problems but there are often long waiting lists. 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 problem behaviours that most concern you so that they can assess the meaning of the behaviours. If there is no obvious reason why it 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.

ABC Chart

- A**ntecedents - what happens directly before the behaviour happens
- B**ehaviour - what the behaviour was
- C**onsequence - what happened afterwards

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?
17/01/05 Monday 10.00 am	Jane is watching a video	When Jane is asked to get ready to go out, she screams and has a tantrum	Mum switched off TV and yelled at Jane. Jane carried on screaming and kicking. Mum gets angry and holds Jane until she stops.

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

Medication, when used properly, can make some behaviour occur less often or make it less severe. There can be many possible reasons for the behaviour and medication should only be offered after a proper assessment. There must be clear reasons for the medication and parents need to be aware of the benefits and disadvantages.