

Early Support

for children, young people and families

Information about behaviour



About this resource

This information resource is for parent carers who are concerned about their child's behaviour. Sometimes parent carers are unsure if their child's behaviour is a sign that they have some kind of impairment or other additional need. In this resource you will find information to help you:

- understand why children might exhibit behaviour that is challenging
- provide strategies to prevent or minimise behaviour that is challenging
- identify where to go for further support and information

The guide has been written with the help of families. It was developed by [Contact a Family](#) for [Early Support](#) in partnership with in response to requests from families, professional agencies and voluntary organisations for better standard information.

The [Royal College of Psychiatrists](#) and [The National Autistic Society](#) were involved in the original version of this resource.

Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

Early Support is a core partner supporting the implementation of the strategy detailed in [Support and aspiration: A new approach to special educational needs and disability](#), the Government's 2011 Green Paper. This identified Early Support as a key approach to meeting the needs of disabled children, young people and their families.

Early Support helps local areas implement the Government's strategy to bring together the services families need into a single assessment and planning process covering education, health and care. Early Support provides a wide range of resources and training to support children, young people, families and service deliverers.

To find out more about [Early Support](#), please visit www.ncb.org.uk/earllysupport.

Where a word or phrase appears in colour, [like this](#), it means you can: look them up in the [Glossary](#) at the back of the resource; find contact details for the organisation or agency highlighted in the [Further information and useful links](#) section; and/or find out more in the [Who can help](#) section.

Explanation of the term parent carer

Throughout this resource the term 'parent carer' is used. It means any person with parental responsibility for a child or young person with special educational needs or disability. It is intended as an inclusive term that can cover foster carers, adoptive parents and other family members.

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Part 1

Introduction

It is natural to worry if your child displays unusual behaviour, or behaviour you find difficult (often known as 'challenging behaviour'). Parent carers can feel under a lot of pressure, especially in public, when their child behaves in a way that is considered inappropriate. Many of you will be familiar with the 'supermarket tantrum' when it can feel like everyone is staring and making judgments. This might make you dread going out with your child, which can impact on the freedom of the whole family.

If your child has additional needs, you may find that you need different rules and techniques to help your child.

Parent carers sometimes feel that they are to blame for their child's behaviour. It can be hard to know what to do about behaviour that is difficult to deal with. Parenting is never simple and can be even more complicated if you have child with additional needs. It is essential to identify the causes of behaviour and to learn how to help your child resolve these issues.

Why do children behave in different ways?

Small children find ways to express their wishes and test the boundaries of their parent carers' authority. Less verbal children are more likely to have tantrums if frustrated – most people are familiar with the 'terrible twos' where the child's feelings of frustration can lead to very angry behaviour.

Tantrums are physical – screaming, drumming feet, throwing things around. Children who are able to speak or communicate may whine and fuss, and refuse to cooperate. Children with additional needs may get more frustrated. If they have learning difficulties they can find it harder to concentrate and understand what is expected of them, and find it more difficult to deal with their emotions.

Children with visual impairment, hearing impairment or physical impairment will need different systems to communicate their needs in order to avoid feelings of anxiety, frustration and rage, which could trigger undesirable behaviour.

When is behaviour an issue?

Behaviour becomes an issue when it starts to affect the parent carer and the child's family. All children can become cross and behave in ways not considered appropriate, but many will respond to strategies put in place by parent carers. Children with additional needs may not be able to respond in the same way and behaviour that causes problems may escalate and become persistent.

Examples of persistent behaviour in young children that families might find problematic are:

- frequent screaming and tantrums
- kicking and hitting parent carers and siblings
- breaking things
- biting people and objects
- not sleeping
- feeding problems
- smearing faeces, urinating in odd places

What are the causes of problematic behaviour?

Children with additional needs can be affected by any of the following:

- **Frustration** – This is particularly true if your child requires support physically to do something and/or communicate their needs.
- **Anxieties, fears and phobias** – These can be an issue if your child has difficulty in accepting any change in routine or appears to be frightened of something. Being bullied or discriminated against can also result in children with additional needs presenting reactive behaviour that others might find challenging.
- **Lack of understanding** – Some children have limited understanding of what is happening and do not know what is expected of them or how to respond.
- **Emotions** – Your child could be unhappy or angry and, if they cannot communicate their feelings, they may show this in their behaviour.
- **Hyperactivity** – Some children have excess energy and need to be constantly on the move in the daytime and sleep little during the night.
- **Discomfort or illness** – Your child might be hungry, thirsty, in pain or unwell, which could show itself in their behaviour, particularly if they can't communicate to you what is making them uncomfortable.
- **Sensory issues** – Your child may be sensitive to certain noises or textures, which could show itself in their behaviour, particularly if they have difficulty in communicating this to you.
- **Misplaced attention** – If your child has learnt that a certain behaviour gets your attention, they may continue to behave in that way, even if the attention they receive is negative and meant to stop them doing something.

Is behaviour linked to certain medical conditions?

Some behaviour is more likely to be displayed by children with particular conditions or impairments. For example, children with **attention deficit hyperactivity disorder (ADHD)** find it very hard to stay still or concentrate for very long. They are often impulsive, reacting without thinking through the consequences.

Some behaviour has its roots in genetic conditions, which may make a child more likely to be obsessive or anxious, to overeat, sleep badly or self-harm. If your child has a diagnosis of a genetic syndrome it is worth finding out more about the condition to see if they are at extra risk of developing particular behavioural patterns. The charity **Contact a Family** can help you find out more about specific conditions.

Although children with some conditions and disabilities are at increased risk of developing behaviours that are considered problematic, it is important to recognise that it is not a foregone conclusion - it is just an increased risk. They will not necessarily develop that behaviour and even if they do, they can be helped to reduce its frequency and minimise its effects.

How to help your child

Step 1: Establishing your basic approaches to behaviour

The following points can help you to help your child avoid or minimise behaviour that others find challenging. It works best if **everyone** caring for your child follows the same rules so that your child receives consistent messages from all their carers.

Set routines

Children need clear, daily routines. Routines help them to understand and make sense of a confusing world. Some children and young people with developmental impairments may have a need for routines for much longer.

Build communication

It is important to communicate with children and some young people, as their needs require, about routines throughout the day:

- You can use pictures and photos to explain what is going to happen if they have limited understanding or are non-verbal.
- You can show your child objects (for example, a nappy if you are going to change them) before commencing the next step of your routine.
- You can demonstrate the routines visually (for example, if you are going out show your child your coat and point to the door).
- Try to break down your sentences into single words and keep them simple.
- Many parent carers find they can help their child to understand and communicate using signs for basic needs, such as sleep, hunger and thirst.

Picture Exchange Communication System (PECS) is a way of using pictures to help children request what they want. You can find out how to get more information about this and signing using **Makaton** in the [Resources](#) section.

Make sure that any communication system you use with your child is culturally appropriate and sensitive to your child and family.

Give choices

Giving certain choices to children and young people helps them feel more in control. It helps them to feel that their views are being taken into account. This leads to less frustration and can improve their behaviour. For example, you could show two items or pictures to children who are non-verbal and teach them to point to or indicate their preferred choice, or you can ask a child or young person for their opinion on the choices available.

Give enough time

It is important that children and young people have time to respond to choices or requests; give them plenty of time to think about what's being asked before expecting a response. Some children and young people with additional needs take more time to process information and respond. This means that they may need things repeated slowly several times to help them understand what you want them to do.

Provide opportunities to exercise

Exercise is very effective in relieving stress and getting rid of frustrations and excess energy. Studies have shown that it has a positive effect on behaviour generally. If you have a safe garden, trampolines can work wonders in using up a child's or young person's excess energy levels, or you could play some energetic games with them. If not, find the nearest park or playground and try to take them there as often as possible.

Many attractions have schemes enabling someone with additional needs to bring a carer or assistant free of charge. You can also find particular events in cinemas, museums and theatres adapted for children and young people who have autism, and for children and young people with a visual or hearing impairment.

Calm and relaxation for your child

It is very important to know what calms your child when they are stressed or overexcited. Calming techniques may include music, lights (for example, bubble lights), television, water play, massage and time outside of their flat or house. Your **health visitor** might be able to teach you how to massage your child. You can buy sensory toys quite cheaply, or improvise some of your own. Ask your children's centre about sensory rooms your child can access.

Strategies for changing behaviour you and others find difficult

Here are some key ways you can work on changing behaviour that concerns you:

- **Rule out any medical or dental problems** – Your child might be in pain and cannot tell you. For example, if you think your child is constipated, tell the doctor because this can cause a great deal of discomfort.
- **Rule out the possibility of bullying or discrimination** – They might be displaying reactive behaviour that challenges as a result of this.
- **Focus on changing the behaviour** – It is important for your child's self-esteem that they know it is their behaviour you don't like, not them. If they feel it's them you want to change they could become unhappy and their behaviour might get worse.
- **Try to stay neutral** – Keep your responses to a minimum by limiting verbal comments, facial expressions and other displays of emotion, as your reaction may reinforce their behaviour. Any attention can be rewarding, even if it's negative. Try to speak calmly and clearly, and keep your facial expression neutral.

- **Remain positive** – Say things in a positive way, for example, “Please do…” rather than “Do not do…”. Some children find it very hard to interpret “no” messages; the word “stop” can be more effective. If you can redirect your child into positive behaviour, reward them at once with a form of praise that they will appreciate – this is very important because it makes it more likely that the desired behaviour will occur again.
- **Be consistent** – Involve all those working with your child in your strategy to change the behaviour so that everyone is using the same approach. Make sure that you remain consistent and be persistent and eventually things will start to change. It might take a long time, remain patient and be prepared to use a lot of repetition.
- **Give appropriate rewards** – Throughout the day, make a point of rewarding behaviour you consider appropriate to reinforce and increase positive behaviour. Rewards can be anything that your child would value, such as verbal praise and attention, favourite activities, or toys and tokens. You should make it clear which behaviour you are rewarding and what the reward is. For this to work, rewards must follow good behaviour as soon as possible, otherwise the child might not recognise that the good behaviour and the reward are related. In addition, the rewards should be things they do not get at other times.
- **Give your child time out** – This should only be used as a last resort, after other strategies to prevent misbehaviour have failed. It involves removing your child from whatever they are doing and insisting they stay in a safe place for a period of time, during which you ignore them and make no eye contact. The time should be about one minute for children with learning difficulties. You could use an egg timer to demonstrate the time visually. ‘Time out’ should only be used if your child has sufficient understanding to know why you are doing this, otherwise it may cause confusion and distress. There are two advantages to ‘time out’: to allow the child time to reflect, which may be a positive break if the child has become overwhelmed and anxious; and to give the parent carer time to recharge ready to engage positively with the child.
- **Ignore attention-seeking behaviour.**

Remember, punishment does not work because many children do not see the connection between what they have done and the punishment that follows it. There are rarely overnight miracles, so be patient. Do not worry if things get worse before they get better – your child will take time to adjust to your strategies and it may take time for you to get it right.

Step 2: Recognising triggers

There may be different factors that cause your child to react in a way you find challenging, some may be obvious to you, others not. It is very important to work out the triggers so that you can then work out strategies to deal with the behaviour.

If your child has several behaviours that are worrying you then you need to decide which one/s you want to focus on. This will avoid confusing your child (and you). For some parents, this means deciding which ones you can live with and which ones you are finding most challenging. Ask yourself if they are:

- a danger to your child and others
- creating challenges and problems that you and your family are finding very hard to cope with

Behaviour charts

If you are unsure about what triggers different behaviours it can be helpful to keep a behaviour chart to learn more about them. A good example is an **ABC chart**: the A is for antecedent (something that happened before the event); B for behaviour; and C is for consequence. To complete an ABC chart you will need to ask yourself the following questions:

- **Antecedent** – What was happening in the environment before the behaviour occurred? Who was there? Where did it happen?
- **Behaviour** – What did your child do?
- **Consequence** – How did the behaviour finish? Any changes in the environment? What did you or your child's carer do? How did your child feel at the end?

There are two key things to think about when using an ABC chart. The first is **what is your child trying to tell you through their behaviour?** For example, James is screaming because he cannot bear the door being shut BUT has no words to say this. Secondly, **why is your child behaving the way they are?** For example, Fran is screaming because it gets your attention AND if her behaviour gets your attention she will do it again.

If you keep asking yourself these two questions when a behaviour occurs it can help you to work out what the ABC chart is telling you about your child's behaviour.

Below is an extract from an ABC chart for a four-year-old girl with learning difficulties:

Date and time	A – antecedent What happened before?	B – behaviour How did your child behave?	C – consequences What happened as a result of your child's behaviour	Other comments
3rd March 2010 4pm	My four-year-old was watching her favourite TV programme in lounge, her brother came in from school and changed channel	She screamed, hit and kicked me She continued to scream	Brother was told off by me; she got her programme back; she stopped screaming but still lashed out at her brother if he came near her	It did not feel fair or right on either child. Also it didn't seem to work because she was still lashing out and didn't seem to understand what was wrong with her behaviour

If you keep an ABC chart over a period of time, recording events, you may find that you can clearly identify the source of distress and finds ways to avoid them happening.

It helps to consider the type of behaviour your child displays. Some children might react aggressively when they are frustrated and can't express their wishes clearly. Sometimes children become aggressive because they are frightened. They may calm down when they know that you understand their fear and will help to keep them safe.

If you don't want to keep an ABC chart like the one above you could simply keep a record of your child's behaviour over a period of time in a **behaviour diary**. You could use an everyday diary or just a notebook and note down the kinds of behaviour that are cause for concern. This 'behaviour diary' could help you work out why your child does things and in what circumstances – and how frequently the behaviour occurs.

It could also be useful to show your ABC chart or diary to a professional if you decide that you need additional support. A record of your child's behaviour will help the professional to understand the challenges you are facing. The Early Support [Our family](#) resource is a good place to keep your notes/behaviour diary/ABC chart, and to put them in the context of the rest of your child's and family's life.

Helping your child with specific issues

This section looks at particular examples of behaviour and offers ideas on how you can work out the cause and find solutions. It is a good idea to involve any practitioners working with your child.

Tantrums

Many children have tantrums between the ages of one and four years. This is often because they want to do things for themselves and get very angry and upset if they cannot do what they want, or are stopped by their parent carer.

Sometimes, tantrums happen in public because the child wants something they cannot have, or they are very tired or hungry. Tantrums usually stop by the time the child starts school because by then they have more language and social skills.

Children with additional needs can have tantrums for the same reasons as other children. However, some with specific impairments or difficulties can become overwhelmed more easily and have fewer coping skills, less language and not as much patience. This can make temper tantrums more likely. Parent carers might find this embarrassing, especially when the child has tantrums in public places, such as in the supermarket or on the bus.

You may know what triggers your child and generally avoid them. However, you might get caught out by an unexpected trigger. If you are not sure about your child's tantrum triggers, keep an **ABC chart** to help you identify them.

What you can do

Here are some strategies to help bring tantrums to an end and stop them from reoccurring:

- **Distract your child** – This works especially well with toddlers or children who tend to focus on one item or activity at a time and can easily be led on to something else.
- **Remove your child** – Some children become so overwhelmed they need to be taken to a new setting before they will calm down. If this is the case, even taking them to a different room in the house or stepping outside the supermarket can help. If necessary abandon your shopping!
- **Ignore your child** – Some behaviour is a way for the child to gain your attention. Simply ignoring this type of behaviour may help to defuse it. Once your child is calmer, it may be helpful to redirect them to a positive activity.
- **Praise your child when they stop** – Once your child has calmed down and is behaving appropriately, pay attention to them again and praise them for stopping. If you reward the new behaviour like this, your child is more likely to stay calm and learn that positive behaviour gets positive attention.
- **Ask for advice and support** – If the tantrums are getting worse, ask your health visitor for advice and local help.

Hitting, kicking and pinching

All small children can feel very frustrated at not being able to communicate their needs and wishes. They may occasionally hit other children because they are jealous, or because they don't want to share their toys. With help from parents, they learn to deal with their anger and frustration in more acceptable ways. Children with additional needs can sometimes become more easily frustrated or angry with other children. They may not be as quick as their peers in developing social skills. Typical frustrations are:

- difficulty waiting for something because they do not understand time concepts
- disliking a change in routine
- being upset if familiar staff or care workers leave
- being hypersensitive or having sensory overload. Some children with additional needs can be very sensitive to one or more of the following: loud noises, colours and patterns; particular smells; the feel of certain materials; being hot or cold; visiting a strange place; being among lots of people.
- wanting more sensory stimulation
- not wanting to do something

They may express these frustrations through hitting, pinching or kicking other children and adults. If you are not clear what the cause is, try keeping an **ABC chart** or a **behaviour diary**.

What you can do

Here are some strategies to help your child avoid resorting to hitting, kicking and pinching:

- **Provide sensory stimulation** – If your child is looking for sensory stimulation provide it in other ways by, for example, pinching play-dough, clapping hands, singing a clapping song/rhyme, kicking a football, using a punch bag, going on a swing, etc.
- **Use rewards** – Reward your child for doing something you want them to do. Tell them why you are rewarding them. Make sure the reward is something that they like and give the reward straight away where possible.
- **Be calm and redirect** – Straight after the undesirable behaviour, using a calm voice without showing emotion, direct them to another activity telling them what to do rather than what not to do.

If your child is upset by changes of routine or unfamiliar people, you may wish to use visual aids to support their understanding. You should try to use these visual clues daily and refer to them regularly throughout the day.

The **Picture Exchange Communication System (PECS)** and/or other visual supports can be helpful in showing your child a sequence of events or routine for the day. For example,

if your child finds meeting new people difficult you could show them a photo of the person before they meet, or keep the initial meeting brief, gradually increasing the time they spend together.

Usborne publishes a range of picture books for children to help prepare them for new experiences, such as going to school, travelling on a plane, moving house, visiting the dentist or hospital, etc.

A **social story** describes a situation and possible sequence of events to a child to prepare them for what is likely to happen. **The Gray Centre** provides more information on social stories and how to write them at www.thegraycenter.org/social-stories.

Biting

Biting is a common behaviour in children between the ages of 14 months and two-and-a-half years. It mostly occurs in very young children who have little language and it tends to stop as language develops. Small children may also bite because of hunger, teething, anger or boredom. They may not have enough access to favourite toys or may be reacting to a transition, such as giving up a dummy or having a new sister or brother. Biting may persist in children who have additional needs for various reasons:

- It is a powerful way of telling people something is not right if the child lacks communication skills. Children in this situation can feel overwhelming frustration or distress and biting is a way of expressing this.
- Some children, such as those on the autistic spectrum, experience sensory processing difficulties. Biting stimulates the part of their nervous system that helps them know what their body is doing.
- Putting objects in their mouths to explore their size, shape and texture is a normal part of child development. Some children with additional needs may go through this phase later or longer – for example, you might find this if your child has a **visual impairment** or takes longer with their development.

What you can do

First you should rule out any medical or dental reasons, such as toothache. If there is no medical reason, you need to work out the cause of the biting. The **ABC chart** or **behaviour diary** is a good way to identify causes. Possible solutions could include:

- **helping your child to express their feelings** – If your child is biting because of frustration your strategy could be to find different ways to help them express their feelings. For example, if the problem is lack of ability to communicate, provide pictures and symbols that they can use to convey their feelings.
- **offering more sensory input** – If your child needs more sensory input, consider offering more crunchy snacks, such as apples, carrots, crackers and dried fruit. You could keep a bag of chewy things ready as needed. You could offer teething rings to chew on or '**chewy tubes**', which are cylindrical pieces of safe, non-toxic, rubber

tubing. Studies have shown that chewy tubes provide a focusing and calming function and release stress.

- **calming and distracting** – Straight after the undesirable behaviour, say in a calm voice without showing emotion, “Stop pinching/slapping/kicking” and then direct them to another activity

Sleeping

Small children can usually sleep through the night by the age of one unless they are disturbed by teething or illness. Children with additional needs may have persistent difficulties with sleeping. They may be overactive, anxious, physically uncomfortable, or have a neurological condition, such as cerebral palsy or epilepsy, which makes it more difficult to relax. Young people who have additional needs can also experience sleep difficulties.

What you can do

Regular and calming bedtime routines are essential. You may find it useful to keep a **sleep diary**. This might contain:

- the time your child went to sleep, the number of times they woke and for how long they stayed awake each time during the night
- the number and length of naps during the day to see if these should be cut down
- the way you prepare your child for bed to see if changes made to their sleep routine would help
- the medication your child is on and the times at which they take it, as medication can affect your child’s sleep patterns

For more on sleep problems read the Early Support information resource on [Sleep](#). This resource has detailed information about keeping a sleep diary and many other ideas to aid sleep. It is available from www.ncb.org.uk/early-support/resources.

Eating

Mealtimes can be a challenging time for all parent carers with young children. Many young children ‘play up’ at mealtimes as they become more independent. Babies who are good eaters may become picky toddlers. Their appetite can vary and they can seemingly eat little for days on end; they may have food fads; be too full for dinner but have room for crisps; or be too busy playing to want to sit at a table. Some children regress and want to be spoon-fed like their baby brother or sister.

Mealtimes can be more challenging for parents of children with additional needs, and problems can continue into adulthood. They may display other types of behaviour. For example, some children and young people with additional needs:

- are hyperactive and find it impossible to sit still for a few moments at a time

- are obsessed by a particular activity and have a tantrum if stopped in order to have a meal
- cannot bear particular food textures or the feel of cutlery
- would like their food presented in very particular ways
- may be obsessive about food and overeat, leading to weight problems
- grab food off other people's plates

What you can do

Small changes can make a big difference at mealtimes. Try the following tips:

- **Establish regular routines for meal times** – Sit down as a family at a table for meals so your child gets into a routine. If this is not possible, ensure that your child is sitting with at least one other person rather than on their own. Let your child know when the meal will soon be ready by talking to them and giving them signs, such as showing pictures of food and laying the table. Try encouraging your child to sit still for longer periods by using a large egg timer and allowing them to move when the time is up. This will give them a visual link for 'sitting down time', which you can gradually build up.
- **Look for patterns** – This is particularly useful if your child is obsessive about food. You might want to keep a note of what they accept and reject, and see if you can find a pattern to it. You may find that there are certain textures, tastes and smells that they dislike and which you could avoid; or they may dislike food being on a plate together or mashed up. If you use cutlery, they may dislike the sensation of the cutlery in their mouth. Try to find out what it is and make adjustments. If your child will only eat one or two kinds of foods, seek advice from an eating specialist.
- **Don't force your child to eat** – If your child won't eat, it is possible that they are overwhelmed by the amounts you are giving them. Try offering a little bit of food on the plate at a time. If your child spits food on the floor, try not to react as this will reinforce the behaviour.
- **Provide regular meals and healthy snacks** – Some medical conditions or medications might make your child overeat and this can be very difficult to manage. Try regular meal times and healthy snacks such as fruit between meals. Distract your child at other times with fun activities. Keep food out of sight and out of reach outside mealtimes and snack times.

Smearing

Some children and young people handle and smear their poo. There can be various reasons for this. It could be that the child has learning difficulties and has simply not understood the process of wiping with paper properly. Others enjoy the feel of the texture of the faeces. Some will use smearing as a way of getting attention or because they have learnt they are rewarded for such behaviour by being given a nice warm bath. Some

children and young people can also behave in this way because they are extremely upset and agitated.

What you can do

- **Look for behaviour patterns** – If your child smears, try to see if there is a pattern to their behaviour as it might help you understand why they are doing it. If it started suddenly the smearing might be in response to something upsetting that's happening to your child. Try using a [behaviour diary](#) or [ABC chart](#).
- **Stay neutral** – Try to react to the behaviour as neutrally as possible, with no eye contact and very little conversation.
- **Provide alternative activities** – If your child enjoys the sensation of smearing, provide an alternative, such as playdough or cornflour and water.
- **Use specialist clothing** – Dress your child in clothes, such as dungarees or large-size baby grows, that restrict access to faeces. Information about where you can buy these can be found by contacting the [Disabled Living Foundation](#).

Toilet-training

This can be more difficult for parent carers if your child has additional needs. [Contact a Family, Scope](#) and [The National Autistic Society](#) all provide information and practical tips on toilet-training for disabled children. [ERIC \(Education and resources for improving childhood continence\)](#) can give advice about toilet-training children with additional needs. You can also ask your health visitor or specialist nurse if they can give advice to help you with this.

Looking after yourself

All these strategies require a huge commitment from parent carers. You need time out to care for yourself and see to your own needs.

Parent carers are often so busy thinking about everyone else that they can find it very hard to set aside time to do something they enjoy, or that helps them relax. This might be as simple as having a bath in peace, reading, or talking to a friend. The important thing is that you take your own needs for relaxation seriously. You need time out to care for yourself and see to your own needs. To help your child as best you can, you need to be as fit and healthy, and relaxed and calm as possible. **Early Support** has a resource called **Looking after yourself as a parent** to help you with this – see www.ncb.org.uk/early-support/resources

Support from other parent carers

Many families find talking to other parent carers very useful and a great emotional comfort. Being involved with a support group means you'll be able to talk to other parent carers in similar situations who can share valuable information, experience and support. **Contact a Family** and your local **Family Information Service** can tell you about groups in your area. Some organisations, like the **Challenging Behaviour Foundation** and **Contact a Family**, also run family-linking schemes.

Getting a break

It is a good idea for children and young people to have a break away for their own development and as part of their ordinary life. It is also a good idea for the parent carer to have some time away from caring responsibilities, especially if they are a single parent carer. Many people take breaks from caring by asking other members of the family, friends or neighbours to take charge from time to time. You may prefer a more formal arrangement that means you and your child don't have to depend on other people being available and willing to help you when you need it.

If your child has severe challenging behaviour, the carer may be eligible for a regular short break from care. In England all local authorities are required to provide a range of short breaks, including:

- overnight care in the family home or elsewhere
- daytime care in the family home or elsewhere
- educational or leisure activities for disabled children and young people outside their homes
- services available to assist carers in the evenings, at weekends and during the school holidays

You would need to ask for an assessment from social services to find out if you are eligible for any of these. There is no fixed entitlement to carer breaks and arranging one can take some time.

If you are not able to access short breaks or direct payments, you can ask your local **Family Information Service** about local organisations offering relaxation sessions for carers, as well as activities in the holidays and at weekends for you, your disabled child and any siblings.

Minimising risks in the home

It is important to find ways to reduce the risk of children hurting themselves and also to make them comfortable. Simple ideas include using cooker guards, wall-mounted televisions, locks on the fridge and cupboard doors, and electric plug socket covers.

The charities **Fledglings** and the **Disabled Living Foundation** can give advice and information on what is available and where to find aids, equipment and clothing to keep your child safe and comfortable.

The **Challenging Behaviour Foundation** provides an information sheet on specialist equipment, including supplier contact details, for children, young people and young adults with severe learning difficulties who are described as having 'challenging behaviour'.

You may be entitled to certain equipment from your local authority. You can get more information on this from **Contact a Family**.

When should I seek outside help?

If you can see behaviour developing that concerns you it is always helpful to get professional advice before it becomes a habit. Speak to your health visitor or your local children's centre about what kind of help is available in your local area.

All local areas have NHS child development teams where community paediatricians work in collaboration with speech therapists, occupational therapists and other helpful practitioners. If you are worried and the problems you are experiencing are persistent then you can ask your GP to refer your child for assessment by this team.

If your child's behaviour suddenly changes always check that there are no medical or dental reasons for this – speak to your GP and your dentist. If your child finds going to the dentist difficult ask to be referred to the **community dentist**.

Some frequently asked questions

Q: My two-and-a-half-year-old daughter has a diagnosis of global development delay. She is not speaking and has screaming fits. I cannot seem to communicate with her. She is a danger to herself and me – turning on taps, climbing and jumping, and grabbing. What can I do?

A: Seek advice from the specialist in charge of your child's care. Your child might be referred to the **Portage Service**, which works with early years children with very complex needs. The service provides a worker to assess your child's learning needs and help you and your child to gradually develop their skills. Parent carers usually find that portage is very helpful in improving the behaviour of children with learning difficulties.

Q: My four-year-old finds it very difficult to sit still and concentrate at nursery and, according to the staff, her behaviour is often very disruptive. Could she have **ADHD**?

A: Many four year olds find it a challenge to sit still and concentrate for a length of time. This is why ADHD is very difficult to diagnose in early years children. If their behaviour is very extreme or is leading to problems with other children, ask your **GP** for a referral. In some areas you will be seen by a community paediatrician and in other areas by the **child and adolescent mental health services**.

Q: I think my 8 year old son may have **autism**. How can I find out?

A: Speak to your **health visitor** or **GP**.

Q: I am concerned about my three-year-old son. I think he has **speech difficulties**. He has tantrums every day and bites and kicks his sister. He refuses to go to nursery. My **GP** keeps telling me he will grow out of it. What can I do?

A: Keep a record of your concerns over a typical week and then share this with your **health visitor**. This will help them see if they should refer your child to the **paediatrician** or to an **educational psychologist** for an assessment. Alternatively, if his **nursery staff** are also concerned they can refer him for an assessment.

Q: My 11 year-old's behaviour has completely changed since I split up with his dad. How can I help him?

A: Children are likely to feel angry, anxious, shocked and sad, and may not have appropriate ways of understanding or expressing these feelings. It may take several months to work through them. You can help him express his fears and feelings through talking to him, using play and stories, which are a chance to find out what he feels and to reassure him (for example, that it is not his fault). If there is no change or his behaviour gets worse over the next few months, consider asking your **GP** or **health visitor** for a referral to your local **child and adolescent mental health service (CAMHS)**. CAMHS has a team of practitioners who help children cope with emotional and behavioural difficulties.

Part 2

Working with others

Communicating about your child's needs with others

It is very important to tell everyone involved with your child what might trigger your child to behave in a challenging way and what strategies work in preventing and minimising this. You might need to share this with relatives, childminders, nursery/school staff and health practitioners.

You can use the Early Support [Our Family](#) resource to record this information. You can use this to make a **communication passport** to give to anyone working with your child for the first time. You will find it useful to share this when meeting people who are going to become responsible for looking after your child.

Helping your child's self-esteem

It is very important that you, and everyone working with your child, support their mental health and well-being. Do all you can to build a positive outlook and to focus on your child's abilities. The following suggestions on how to promote self-esteem are from young people with additional needs and parent carers:

- Reinforce the fact that everyone is different.
- Encourage your child to take interest in their appearance and give them age-appropriate clothes.
- Encourage your child to keep clean, wash their hair regularly and so on.
- Be generous with compliments.
- Remind them of the things they are good at.
- Encourage them to be assertive.
- Encourage them to be involved in decisions about their life as far as possible.
- Try not to be over protective.

These suggestions will help children and young people to become confident, independent and assertive, and to feel that they have some control over their own lives. If you think they need more support, ask for an assessment. #Assessments by practitioners and referrals to services can take some time so try to access all the support you can while you are waiting. #

Early years settings and schooling

Early years settings and primary school

Attending nursery, or other early years settings, provides opportunities for children to play with other children and learn what is acceptable and unacceptable behaviour outside of their own home. As well as helping children to learn and develop, these settings help prepare children for school. They can be especially helpful for children with additional needs.

Early years staff in nurseries, children's centres and other early years settings can support young children to develop social skills. Extra support can be put in place for a child to attend nursery, early years settings/school if they need it. This may involve your child going through a statutory assessment process to see what is needed. The system at present could lead to a statement of special educational need that sets out your child's entitlements. This process is currently undergoing changes – for updated information see www.gov.uk/children-with-special-educational-needs/overview

If you think your child needs additional support, it is best to speak to the special educational needs coordinator (SENCO) who will work with the settings equality named coordinator (ENCO) at the early years setting/school well before your child is due to start.

You can also ask for help from your local [Parent Partnership Service](http://www.parentpartnership.org.uk), www.parentpartnership.org.uk. It provides advice, information and support to parent carers whose children have special educational needs.

Support for schools is also available from various organisations, for example Achievement for All is a national charity which supports schools to improve the aspirations, access and achievement of learners and young people. The Achievement for All framework improves pupils' progress, parental engagement, pupil attendance and behaviour, peer relationships, participation in extra-curricular activities and access to future opportunities for pupils. More information can be found here: www.afa3as.org.uk

[Contact a Family](http://www.contactafamily.org.uk) has a [special educational needs \(SEN\)](http://www.contactafamily.org.uk) helpline offering specialist advice on getting support in place for your child at school.

Preparing for secondary school

Moving to secondary school is a big change for any child, but if your child has additional needs it can be even more daunting.

Ask well in advance to meet with the **special education needs coordinator (SENCO)** at the secondary school. Discuss how your child will be supported and how information about them will be shared with other staff in the school. Take information with you about what might trigger behaviour that could be challenging and strategies that minimise this. It might also be helpful to take any letters from health practitioners about your child's condition and support needs, as well as your Early Support **Our Family** resource.

Discuss with the school what might be difficult for your child and how they will be supported – for example, reading the timetable, finding their way to the next class, or break time.

Children who have had good support in primary school can struggle in a large secondary school. They can feel overwhelmed by the size of the school, the number of pupils and teachers, and unfamiliar routines.

Allow time to prepare your child for the move. It might help to arrange extra visits to the new school to allow your child to become familiar with it. You might want to write a **social story** to help prepare your child for the change.

The National Autistic Society provides more ideas on preparing your child for secondary school on its website.

If your child doesn't have a current statement of special educational needs and you think they may benefit from one, speak to the special educational needs coordinator (SENCO) or talk to your local advice service or your local **Parent Partnership Service**, www.parentpartnership.org.uk.

You can read more about this at www.gov.uk/children-with-special-educational-needs.

Contact a Family has a special **SEN** helpline offering specialist advice on getting support in place for your child at school.

At secondary school

Children and young people can be well supported in secondary school (whether mainstream or more specialist provision) and settle happily, particularly if the school has a good relationship with the parent carers and work in partnership with them to support the child.

Children with additional needs can become more conscious of their peers' independence, particularly if they cannot keep up, or if they are not allowed similar freedoms. They may feel they are 'different' in a negative way and lose confidence.

Some parent carers comment that their child's behaviour and their mental health gets worse when moving from primary to secondary school. You may find yourself frustrated with teachers who fail to see the difficulties and challenges your child is facing, and feel they blame them unfairly for 'daydreaming' or being aggressive and getting into fights.

This worsening behaviour may also coincide with your child growing bigger and stronger, and may mean they are harder to control as they get older.

It's important that you prepare the way. There are laws in place to help protect children and young people with additional needs from being seen as simply 'naughty' or deliberately disruptive, when their behaviour becomes challenging to others. This behaviour may arise because of their impairments or additional needs.

If your child doesn't have a statutory assessment (which currently might lead to a statement of special educational needs) and you think they may benefit from one, speak to your local advice service or the **special educational needs coordinator (SENCO)**.

You can also ask for help from your local **Parent Partnership Service**, www.parentpartnership.org.uk. It provides advice, information and support to parent carers whose children have special educational needs.

Contact a Family has a special **SEN** helpline offering specialist advice on getting support in place for your child at school.

Leaving school

This can be an exciting and challenging time for every young person, and it is important that you have an opportunity to plan together as a family. If your child has a statement of special educational needs in year 9 (the year young people turn 14 years of age), the head teacher will write to invite you to an annual review. This review must include drawing up a transition plan for when your child leaves school.

This process should help you and your child find out what opportunities exist for your child after leaving school and give you and your child an opportunity to talk about your plans and ideas for the future. This might include school sixth form, further education colleges, specialist colleges, higher education institutions and work-based learning.

It might be appropriate for your child to live away from home once they have left school and it is important this is included in the transition plan. There are several options that can be considered, including a residential home, supported living, college, university or employment opportunities.

It is vital that the transition plan takes into account what your child wants for the future. Some young people find it helpful to work with a local **advocacy** or support scheme to help them identify what they would like to do.

When your child turns 18, if they need ongoing support they will come under Local Authority adult services. This might affect support you are receiving, such as direct payments or short breaks.

Contact a Family has a parent guide, *Preparing for adult life and transition: England and Wales*, which takes you through the process. You can call its freephone helpline for a free printed copy.

Preparing for Adulthood has a range of resources to support families and young people with the transition into adulthood on their website.

Similar strategies used for changing school also apply to leaving school:

- Plan early to make sure you are aware of all the options available and to allow your child time to decide what they want to do.
- Tell the people who will be involved in supporting your child what triggers their challenging behaviour and strategies to minimise this.
- If possible, arrange visits so your child can gradually become familiar with the new place. Use pictures/photos/**social stories** to help prepare them for the change.

Health information

Health appointments

If your child finds waiting difficult and is anxious about going to new places and/or meeting new people, taking them to the doctor or hospital can be extremely stressful – for yourself and them. Here are some tips that other parent carers have found useful in this situation:

- Try to get appointment times at the start of clinics when there is likely to be less of a wait.
- If your child does not like to be in crowds of people, explain the problem to the receptionist and ask if there is a quieter room you can wait in.
- Write on a postcard what might be difficult for your child and give it to the receptionist, so you do not have to say it out loud for others to hear.
- Ask the receptionist to let you know if there is going to be a long wait, so you can take your child for a walk and come back later.
- Ask if you can wait in the car outside and be called on your mobile when the doctor is nearly ready to see you.
- If possible, try to get appointments with the same doctor/health professional on subsequent visits, so they get to know your child's additional needs and you do not have to keep repeating your story.
- Before the doctor examines your child explain what might upset your child and trigger challenging behaviour, and suggest strategies that might help.

“The doctor asked me if my son would object to him looking in his ear. I said he probably would. He then asked me what my son liked doing. I told him he liked banging doors. The doctor said if I let him bang my door do you think he would let me look in his ears? This worked!” Parent

Hospital admission

If your child is to be admitted to hospital, call in advance to let them know your child has additional needs. Ask for a **pre-admission meeting** with a senior nurse who will be on your child's ward to discuss their stay. Make sure the hospital is aware of anything that might be particularly stressful for your child, and which might trigger their challenging behaviour – for example, noise, people, bright colours, or medical procedures.

It might be helpful to visit the ward with your child prior to their stay, so they start to familiarise themselves with the place and with the people who will be caring for them. If the hospital has a **learning disability nurse** try to speak to them. They can be very helpful in liaising with hospital staff to make sure the stay is less stressful for your child.

Information to take with you

Write down all the things that your child might find particularly stressful and how they are likely to respond and take this with you. You might already have this information written down in your Early Support [Our family](#) resources.

As your child grows older they might have a [health action plan](#), which will include information about their health needs and how they communicate, as well as information to help them stay healthy. This would also be helpful to take when visiting or going into hospital.

Some hospitals have their own [hospital passports](#), which can be used to communicate your child's needs and culture to hospital staff. The staff at the hospital should be familiar with using these.

Getting help for emotional and behavioural issues

Sometimes you, or the practitioners working with your child, may notice new emotional and behavioural changes. If you are concerned about your child's mental health, contact your [GP](#), [consultant paediatrician](#) or child health professional to talk about it.

They may suggest a referral to your local [child and adolescent mental health service \(CAMHS\)](#) or a [learning disability service](#) for an assessment to understand your child's behaviour, moods and feelings. The assessment may involve one or more of the CAMHS team and will usually involve seeing you, as parent carers, your child and probably other members of the family. The CAMHS team will usually ask for permission to request reports from your child's school and any other practitioners and services already involved in supporting you and your child. The assessment is likely to lead to an intervention plan to help you and your child manage their mental health and behavioural needs.

Some mainstream secondary schools are able to provide [a school counsellor](#) to support young people with mental health difficulties, and some schools (including specialist schools for children with significant learning difficulties/impairments) have regular outreach clinics and links with community specialist services.

Further information about mental health issues is available from [Young Minds](#) and the [Royal College of Psychiatrists](#). For information about where to get help locally, speak to your [GP](#), [health visitor](#), or your child's [consultant](#).

Relationships, sexuality and sexual behaviour

Learning about relationships, sex and sexuality can be difficult for anybody. However, for young people with disabilities negotiating the 'minefield' of more intimate relationships can be much harder. Not knowing how to behave or the consequences of sexual activity can also leave young people with disabilities more vulnerable to getting into trouble, abuse or exploitation. It is important that as parents we can help our children develop the knowledge and skills they need to keep them safe. For young people with disabilities, a lack of privacy in daily life, cultural prejudice, professional and parental attitudes and lack of opportunity

can often make accessing sexual health services and having sexual relationships more difficult. Young people today are bombarded by sexual images in every area of their lives, as parents seeking information to help your child understand this complex area is essential. There are a number of places where you can access this information:

The [Royal College of Psychiatrists](#) has a picture booklet called *Hug me touch me*, which is helpful when explaining inappropriate behaviour to non-verbal children.

[Contact a Family](#) has a series of three guides entitled *Growing up, sex and relationships* – one is aimed at young people, another is for parents and the third is for teachers working with young people with additional needs (available on the web only).

The [Challenging Behaviour Foundation](#) and [The National Autistic Society](#) also have information on this topic.

The [Early Support](#) website has a developing specialist area with resources and information for young people on this issue.

Practitioners are often familiar with the sorts of behaviour that can occur, so it should be possible to have honest and open discussions without being embarrassed by the nature of the changes. You may find it helpful to discuss this with your child's school as well.

Talking to other parent carers can also be helpful and reassuring.

If your child is in trouble

Some young disabled people don't realise it's inappropriate to touch a stranger or may take something from a shop, not realising it must be paid for. Perhaps your child's behaviour and intentions have been misunderstood by others.

Some parent carers worry that their child is falling in with the 'wrong crowd' outside of school and does not grasp the seriousness of the group's anti-social behaviour.

If you are worried about this, it may be worth contacting your local **youth offending team (YOT)**. Every local council has one of these teams, which work to prevent crime perpetrated by young people. They are generally well aware that those with special educational needs can get into trouble and they seek ways to prevent this and to help them. If your child has a particular learning impairment or disorder/condition, sharing information with the police about their particular difficulties and needs (communication especially) can be helpful.

The National Autistic Society produces information cards that can be carried by a young person with communication impairments to help explain their situation if they come in contact with the police.

Know their rights

If your child does get into trouble with the police, it is useful for them and you to know their rights.

Children under 10 can't usually be held legally responsible for a crime. It would be up to social services to deal with a young child who has committed an offence. Social services may already be aware of your child's needs and behaviour and should assess whether the behaviour is a risk and work closely with you.

If your child is under the age of 10 and has committed an offence, it is important to seek outside help. There are local family rights groups that can offer **advocacy** services and advise you of your rights in this situation. The **Contact a Family** freephone helpline can help you find your nearest one.

Children over 10 can be held responsible for a crime if it can be proved they were aware that their actions were wrong. Parent carers must be informed if a child has been arrested and the parent carer or another **appropriate adult** must be present if they are questioned.

Children and young people have the same right to a **solicitor** as adults. If they consult a solicitor, it is important that you make the **solicitor** and **appropriate adult** aware of any impairments, additional needs or illness and what this means for the child. For example, if they have any history of challenging behaviour, and the degree to which they can understand what is being communicated to them.

Who can help

Clinical psychologists – Children with behaviour that is more challenging for parent carers may need to see a clinical psychologist. They will assess whether the types of behaviour your child is showing are associated with a specific condition or to do with their environment in some way, and discuss practical strategies parents can use to manage them.

Community dentist – The community dental service provides treatment for people who may not otherwise receive dental care, such as disabled children, individuals with learning difficulties/impairments, mental health needs or other conditions that may prevent them from visiting a local dental practice.

Community paediatrician – Community paediatricians often take the lead in coordinating care for disabled children, working closely with physiotherapists, speech and language therapists, and occupational therapists. They often see patients in community settings rather than hospitals.

Consultant – A medical professional with many years experience who is in charge of a medical team/service. A named consultant normally has overall responsibility for your child's care, although you might be seen by more junior members of the team when you visit.

Educational psychologists – Any behaviour that is challenging may occur in different settings, including nurseries and other early years settings. Children may be referred by the early years setting to an educational psychologist to look at setting up strategies to help the child. These strategies need to be shared between the early years setting and home to ensure consistency.

Family Information Service (FIS) – Provides a range of local information on all services available to parents, to help them support children up to their 20th birthday, or 25th if their child is disabled. FIS also holds up-to-date details of local childcare and early years provision in the local area.

GP – Your child's doctor may have some useful advice to offer but they may want to refer you on to a professional with more specialist knowledge.

Health visitor – Your health visitor may have had face-to-face contact with you and your child in your home for a period of time and may well have some experience of certain behavioural issues.

Learning disability services – They help plan and arrange care and support for people (across the age ranges) with learning difficulties/impairments and their carers. The team may be made up of staff from health and social care, and can include social workers, community nurses, psychiatrists, psychologists and a range of therapists.

Learning disability nurses – Work with children and adults with a learning difficulties/impairments and their families.

Music therapists – Music therapy is available in some areas. It can provide a way of communicating with a child and allowing them to express feelings and emotions through music. It can be valuable for children unable to express themselves in any other way.

Occupational therapist – Can be a good source of advice on practical issues for children whose challenging behaviour may be linked to a physical cause in either coordination or mobility.

Paediatrician – A child's paediatrician may have seen them over a period of time so should be able to offer advice on how to deal with behaviour. However, they may also refer them on to any of the other practitioners on this list.

Paediatric nurses – These are children's nurses who have often come across different challenging behaviour and have experience of working with children who are ill or who have impairments or additional needs. They may have a wide range of knowledge and suggestions to help.

Physiotherapists – Can help children who require support in the physical aspects of their life, and who experience limitations in their mobility which may be at the centre of their frustration and behaviour problems.

Portage workers – Visit very young children with complex needs at home. The portage workers may have seen the behaviour that is causing concern and may be able to give some suggestions on how to manage situations that arise at home.

Psychiatrists – Some children may show behaviour that is linked with mental health issues. It may be necessary for them to see a psychiatrist who can decide what type of mental health issues they have and suggest what treatments may be needed.

Settings equality named coordinator (ENCO) – A member of staff in an early years setting, playcare service or school, who is responsible for supporting the setting to plan for and support each child's equalities needs.

School counsellors – A qualified counsellor employed by a school so that children experiencing difficulties can be referred to them to discuss their concerns.

Social workers – Are based in your local children with disabilities team. You have the right to ask for an 'assessment of need' for your child, to see if you are eligible to have a regular short break. If you are, they can arrange for a carer to help, put you in touch with local play schemes or arrange for you to have Direct Payments, which you can use to pay for some help in caring for your child.

Solicitor – Provides advice about legal issues, including your child's rights if they are arrested on suspicion of a criminal offence. Your child is entitled to consult with a solicitor while in police custody before answering questions.

Special educational needs coordinator (SENCO) – A member of staff in an early years setting or a mainstream school, who is responsible for coordinating provision for children with special educational needs.

Speech and language therapist – If your child has been referred for speech and language therapy, the therapist working with them will have some direct knowledge of how they behave. They may also offer some strategies around communication that can help to improve your child's interpretation of some situations.

Youth offending team – Offers support and help to prevent or stop young people from offending. It also works with victims of youth crime offering them support and giving them a voice in youth justice processes. You can find its contact details from your local authority.

Top tips

- Be patient.
- Try to understand what is causing your child's behaviour.
- Try to get to your child's level, speak calmly and use clear, concise and simple instructions.
- Model good behaviour and reward behaviour that is considered appropriate.
- Communicate with other parent carers – by phone, social media (eg. Facebook, Twitter) or through local groups.
- Help your child learn ways to communicate their needs (for example, hunger, pain, thirst).
- Divert your child from behaviour considered inappropriate.
- Be consistent and ensure other people supporting your child are aware of the strategies you use.
- Seek help from practitioners – for example, the GP, health visitor, SENCO or other people involved with the child.
- Take time to look after yourself.

Further information and useful links

Achievement for all 3AS

A national charity supporting schools to improve the aspirations, access and achievement of all learners.

www.afa3as.org.uk

British Psychological Society (BPS)

This is the regulatory body for psychologists in the UK. You can search for details of psychologists on its website.

www.bps.org.uk

enquiry@bps.org.uk

0116 2549568

Cerebra

Cerebra provides resources for help with management issues for children with ADHD and with sleep issues. It has trained phone counsellors who are available to give advice and good sleep management fact sheets.

www.cerebra.org.uk

Helpline: 0800 328 1159

Tel: 01267 244200

Challenging Behaviour Foundation

Offers a support service to families and practitioners caring for children, young people and adults with severe learning disabilities and challenging behaviour. It has a range of information sheets on its website.

support@theCBF

www.challengingbehaviour.org.uk

0845 6027885

Chance UK

Offers one-to-one mentoring in areas of England and Wales to improve the lives of primary school children with behavioural difficulties who are at risk of developing anti-social or criminal behaviour in the future.

www.chanceuk.com

Contact a Family

This national charity provides information for parents on any aspect of caring for a disabled child. Contact a Family can help you find out more about your child's condition as well as put you in touch with national and local support groups. You can download free parent guides from the website or call the freephone helpline and ask to be sent free copies.

helpline@cafamily.org.uk

www.cafamily.org.uk

0808 8083555 (freephone 9.30am to 5.30pm, weekdays)

Disabled Living Foundation (DLF)

A national charity that provides impartial advice and information on daily living aids. Its website has a section on equipment for children, some of which has been mentioned in this guide (for example, large-size baby grows).

www.dlf.org.uk

0845 1309177

ERIC (Education and resources for improving childhood continence)

Offers information and support on childhood bed-wetting, daytime wetting, constipation and soiling, to children, young people, parents and practitioners. ERIC is the UK's only childhood continence charity. It works to improve the quality of life of children, young people and their families in the UK who suffer from the consequences of childhood continence and to assist them to manage or overcome these problems.

www.eric.org.uk

0845 3708008

Family Fund

The Family Fund gives grants to families who have children whose additional needs have a severe impact on the family and whose family earnings are less than £23,000 per year (excluding tax credits, DLA and benefits). It helps many young children with behaviour difficulties. If you are eligible for a grant, the Family Fund will pay for items that can ease the strain caused by your child. Examples include grants for outings, holidays, replacement items (for example, a bed which has been broken by the child jumping on it), trampolines, bikes, computers, toys, music, televisions and other sensory and relaxation equipment.

www.familyfund.org.uk

0845 1304542 or 01904 621115

Fledglings

A national charity assisting parents and carers of disabled children, or those with additional needs, by identifying, sourcing and supplying practical, affordable products to address everyday issues.

www.fledglings.org.uk

0845 458 1124

The Gray Centre

Provides information and support to help individuals with autism and those who interact with them to maintain effective social connections. Its website includes a useful section on social stories and how to write them.

www.thegraycenter.org/social-stories

IPSEA

IPSEA is a national charity providing free legally-based advice to families who have children with special educational needs. All the advice is given by trained volunteers.

www.ipsea.org.uk

0800 0184016

The Makaton Charity

Makaton users are first encouraged to communicate using signs, then gradually, as a link is made between the word and the sign, the signs are dropped and speech takes over. Signing seems to positively encourage speech development. The charity runs Makaton courses for parents.

info@makaton.org

www.makaton.org

01276 606760

Mencap

Mencap offers a wide range of support and activities for children and young people with learning difficulties. One of its projects, Inspire Me, works with young people with learning disabilities, aged 14 to 25, all across the UK in a variety of different ways.

inspireme.mencap.org.uk

The National Autistic Society (NAS)

Its helpline provides impartial and confidential information, advice and support for people with autistic spectrum disorders and their families on a range of issues, including behaviour. Many information sheets on behaviour can be found on its website.

www.nas.org.uk

0808 8004104

EarlyBird and EarlyBird Plus programme

NAS provides EarlyBird and EarlyBird Plus programmes in some local areas. These three-month programmes for families of young children with an ASD diagnosis, consist of eight two-and-a-half-hour weekly sessions and two home visits. They give details on autism, communication and behaviour, and involve sharing information and problem solving.

www.nas.org.uk/earlybird

01226 779218

Preparing for Adulthood

Preparing for Adulthood is a 2 year programme funded by the Department for Education as part of the delivery support for 'Support and aspiration: A new approach to special educational needs and disability' green paper.

www.preparingforadulthood.org.uk

Royal College of Psychiatrists

This is the professional body for psychiatrists in the UK. It has lots of information leaflets freely available to download on its website about many different mental health conditions affecting children.

www.rcpsych.ac.uk

Scope

Scope is a charity for people with cerebral palsy and their carers. It provides a range of information on its website and offers confidential advice from 9am to 5pm, weekdays.

response@scope.org.uk

www.scope.org.uk

0808 800 3333

Young Minds

Offers information, support and advice for young people with mental health and behaviour concerns, as well as parents and practitioners

www.youngminds.org.uk

0808 802 5544 (for parents)

Resources

Autism Alert Cards – Can be carried by a person with autism and used in difficult situations, where they may find communication difficult. Visit:

www.autism.org.uk/our-services/services-for-people-with-autism/the-autism-alert-card.aspx

Behavioural charts – Includes the ABC chart and can be used to help identify what triggers challenging behaviour. Visit:

www.challengingbehaviour.org.uk/learning-disability-files/functional-assessment-charts.pdf
www.ukparentcoaching.co.uk/behaviour_diary.asp

Chewy Tubes – Cylindrical pieces of rubber tubing (which are safe, non-toxic, washable and latex-free) that can be sucked or chewed on and provide good resistance for people who need the sensory input provided by biting. Studies have shown that they appear to provide a calming and focusing function, and act as a release for stress. They can be bought from **Fledglings**, which also has other useful safety products, such as harnesses and toys for soothing or stimulating children's senses.

Communication passport – Widely used in home, care, social work, health and education settings. You can read more about them and download templates at:

www.communicationpassports.org.uk

Health action plan – These are for young people and adults with learning disabilities and contain useful information such as the medicine they take, the health practitioners they meet and what they need to do to stay healthy, for example, when they should have health checks. Visit: www.pmlidnetwork.org/resources/mencap_hap.pdf

Hospital passports – Some hospitals use passports that you can use to communicate information about behaviour triggers to hospital staff. Bristol Children's hospital has an online version at: www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/information-and-support/hospital-passport/

PECS (Picture Exchange Communication System) – A way of using pictures to help children request what they want. The central resource for PECS in the UK is Pyramid Educational Consultants UK. It runs courses, and its website has a wealth of information on PECS. Visit www.pecs.org.uk or call 01273 609555. Other PECS and symbol websites which are free of charge:

www.do2learn.com

www.symbolworld.org/

www.enchantedlearning.com/Dictionary.html

www.pdictionary.com/

<http://trainland.tripod.com/pecs.htm>

Preparing for secondary school – The National Autistic Society has information on preparing for school at: www.autism.org.uk/living-with-autism/understanding-

behaviour/behaviour-common-questions-answered/my-son-is-anxious-about-moving-to-secondary-school.aspx

Sand timer/egg timer – These can be bought from the education shop online. Visit: www.the-education-shop.co.uk

Social stories – Describes a situation and possible sequence of events to a child to prepare the child for what is likely to happen. **The Gray Centre** can provide more information on social stories and how to write them. Visit: www.thegraycenter.org/social-stories

Specialist equipment – The Challenging Behaviour Foundation offers information on specialist equipment useful for people with challenging behaviour. Visit: www.challengingbehaviour.org.uk/cbf-resources/information-sheets/specialist-equipment.html. Contact a Family offers a parent guide on specialist equipment: *Aids, Equipment and adaptations*: www.cafamily.org.uk/parent-guide-aids-equipment-adaptations

Sexuality – The following organisations offer helpful information about issues surrounding sexuality:

- The Royal College of Psychiatrists offers a picture book, *Hug me touch me*, to help explain inappropriate behaviour www.rcpsych.ac.uk/publications/booksbeyondwords/bbwonlineversions.aspx.
- Contact a Family has a series of three guides entitled *Growing up, sex and relationships* – one is aimed at young people, another is for parents and the third is for teachers working with young disabled people
www.cafamily.org.uk/media/379598/growingupsexrelparents.pdf
www.cafamily.org.uk/media/379646/growingupsexrelyoungpeople.pdf
www.cafamily.org.uk/media/379567/growingupsexrelteachers.pdf
- The National Autistic Society's website provides information on sex education and children and young people with an ASD www.autism.org.uk/living-with-autism/communicating-and-interacting/sex-education-and-children-and-young-people-with-an-asd.aspx
- Me-and-Us produces educational resources on sex and relationships education (SRE) and personal, social and health education (PSHE) www.me-and-us.co.uk
- The Challenging Behaviour Foundation offers an information sheet entitled *Difficult sexual behaviour amongst men and boys with learning disabilities* www.challengingbehaviour.org.uk/learning-disability-files/17_Difficult-Sexual-Behaviour--2012.pdf

Toilet-training – Contact a Family offers a parent guide, *Toilet Training*, at www.cafamily.org.uk/parent-guide-toilet-training; The National Autistic Society have information on toilet training at www.autism.org.uk/living-with-autism/understanding-behaviour/toilet-training.aspx; Scope also offers information at www.scope.org.uk/help-and-information/cerebral-palsy/developing-independent-toileting-skills

Glossary

Additional needs – A term used in this and other Early Support resources to refer to any child or young person who has a condition, difficulty, challenge or special educational need, whether diagnosed or not, who is likely to need additional support beyond universal services.

Advocacy – Supports the young person in communicating what they want, independently of their family. You will be able to get details of local advocacy services from social services and local disability organisations.

Appropriate adult – A defined term in the United Kingdom legal system for a parent, guardian, or social worker who must be present if a young person or vulnerable adult is to be searched or questioned in police custody. If these are unavailable, a volunteer from the local community may fill the role instead.

Attention deficit hyperactivity disorder (ADHD) – A common condition affecting approximately 4 per cent of school-age children. Children with ADHD tend to be always on the go, do not settle to anything for long, have poor concentration, and poor ability to organise activities or engage in tedious activities or tasks.

Autistic spectrum disorders (ASD) – A developmental disorder characterised by difficulties with social interaction, social communication and rigidity of thinking. It is an umbrella term and covers autism and Asperger's syndrome. The term 'spectrum' is used because the symptoms can vary from person to person and range from mild to severe. The wide range of symptoms are grouped into three categories:

- **Problems and difficulties with social interaction**, including lack of understanding and awareness of other people's emotions and feelings
- **Impaired language and communication skills**, including delayed language development and an inability to start conversations or take part in them properly
- **Unusual patterns of thought and physical behaviour**, including making repetitive physical movements, such as hand tapping or twisting (the child develops set routines of behaviour and can get upset if the routines are broken)

Developmental delay – The term is used when a child is markedly slower than normal in achieving various milestones, for example, sitting, crawling or talking. If a child is slower in most areas of their development they are said to have 'global developmental delay'.

Health action plan – These are for young people and adults with learning disabilities and contain useful information such as the medicine they take, the health practitioners they meet and what they need to do to stay healthy, for example, when they should have health checks.

Pre-admission hospital meeting – In a pre-admission hospital meeting the parent visits the ward to discuss their child's additional support needs with the ward staff before the child is

admitted. This can also provide an opportunity for the child to become familiarised with the environment.

Sleep diary – A sleep diary can be used to record the time your child goes to bed, the time they take to settle, the number of times they wake during the night and the time they wake up. A sleep diary can be useful aid when seeking help for a child's sleep problems and to measure whether strategies to help them sleep are working.

Special educational needs (SEN) – A child has special educational needs if they have a disability or learning difficulty which makes it harder for them to learn than other children of their age.

Speech difficulties – A child can find it difficult to develop and acquire speech. This might be because of a physical disability (for example profound hearing loss) or because of a learning disability.

Visual impairment – Is when a person experiences some degree of sight loss that cannot be corrected using glasses or contact lenses. There are two main categories of visual impairment: being partially sighted; and blindness or severe sight impairment.

Early Support

for children, young people and families

www.ncb.org.uk/earllysupport

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