



Understanding your child's behaviour

Information for families

UK

Incorporating **The Lady Hoare Trust**

Introduction

This guide is for parents who are worried about their child's behaviour. Your child may be beginning to develop some difficult behaviour or may have already established some challenging behaviour. They may have a recognised disability, be in the process of getting a diagnosis or you may not be sure if they have an additional need.

Whatever the case, parents can feel under a lot of pressure to 'solve' behaviour problems and are naturally very worried about the best approach to take. Parents can feel very alone and it can be a relief to discover that other parents feel the same.

All children are different and there is no single answer to any of the difficulties or problems you may face. There are often complex reasons behind a child's behaviour and it is rarely anyone's 'fault'.

Fortunately, there are some ways you can help your child and a number of people and organisations who can help too. In this guide we explain who can help and how, and where to get support.

Note: the guide covers the whole of the UK with any differences in the nations highlighted. National contacts are listed at the end of the guide for more detailed advice.

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When is behaviour a problem?

It is not always easy to spot a behaviour problem in its early stages. Many young children naturally have tantrums and some teenagers seem to enjoy ignoring their parents. But behaviour becomes a problem when it is harmful to the child or other people and when it persists and is severe. If it is very difficult, it may be called 'challenging behaviour' (see 'When is behaviour 'challenging'?' on page 11).

It is important to tackle problems with your child's behaviour early. If you notice certain behaviours getting more frequent, occurring over longer periods of time and becoming unmanageable, do not let them continue.

Getting help

If your child has a specific diagnosis, the support group for their condition can usually offer tips and strategies to prevent or manage problem behaviours. Many parents say their best tips come from the other parents they meet at groups. Our freephone helpline can put you in touch with a support group for your child's condition. Call 0808 808 3555.

You may also need to seek help from professionals involved with your child, (see 'Sources of outside help' on page 23). You can speak to any professional involved in their care, like your GP, health visitor or staff at their school, and explain their difficulties. They should be able to refer your child for more help if necessary.

Help at school or nursery

If you're concerned about your child's behaviour, it's helpful to know that schools and early years' settings have legal obligations to support children who have difficulty learning, and to treat disabled children fairly. This extends to the way they enforce behaviour and discipline policies, which should take account of a child's disability.

Laws are in place to help protect disabled children from being seen as simply naughty or deliberately disruptive, because their behaviour difficulties may arise because of their disability, or because of a lack of reasonable

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Ireland, and *Additional Support for Learning* (Scotland) available free from our helpline.

Understanding behaviour

It is helpful to remember that it's likely that all behaviours are a way of your child trying to tell you something.

The challenge for parents is to work out what your child is trying to tell you through their actions, and to help them find other, more acceptable, ways to communicate.

For example, your child may be trying to express one or more of the following:

- frustration: they can't do something or can't tell you what they want
- fear: they are frightened of something
- strong feelings: they are unhappy or angry about something
- hyperactivity: they have excess energy and cannot seem to burn it off
- discomfort: they are in pain and can't tell you
- attention: they have learnt they get your attention by behaving in a certain way, and carry on using that behaviour to get your attention
- lack of understanding: if your child has limited understanding, they may not know what is expected. They may need time to work out what you mean and so don't respond to an instruction when you expect them to
- difficulty processing or making sense of sensory experiences in the environment: for example if they have hearing or sight problems.

adjustments made to accommodate their disability. School staff should receive adequate disability training so they can recognise disabled children and respond to their needs.

Depending on the age of your child, you should talk to your health visitor, someone in their early years education setting, their teacher or the special educational needs coordinator (SENCO) or other member of staff in an early years setting or a mainstream school who is responsible for coordinating help for children with special educational needs. Tell them what your concerns are, giving examples to illustrate your concerns, and ask what support can be put in place. The school should work with you to ensure your child's needs in early years education and school are met (see 'Help at school' on page 21). For more information on your rights and how to get help at school, please see our guides *Special Educational Needs* for England, Wales, and Northern

Some behaviour difficulties are more likely in children with particular medical conditions or disabilities. For example:

- children with attention deficit hyperactivity disorder (ADHD) may find it very hard to stay still or concentrate for long periods of time. They are often impulsive, reacting before thinking through the consequences
- children with an autism spectrum disorder (ASD) can be very upset by changes in their routine. They can also react strongly to their environment, for example they may not like being in crowds
- children with learning, sensory or physical disabilities may have delayed or no speech and need alternative ways to communicate. If they are helped to express choices, they will have more control over their behaviour. There are a variety of communication strategies you can both learn to help them express themselves, (see the following section 'Setting the scene for good behaviour')
- some behaviours are a result of a genetic condition that may lead to a child having an increased tendency to be obsessive, anxious, over eat, sleep badly or self-harm. If your child has a diagnosis of a genetic condition, it is worth finding out more about the condition to see if they are at risk of developing particular behaviour patterns, and whether there are strategies to help
- some problem behaviour is classified by professionals as an 'emotional and behavioural' difficulty. This can be indicated by low self-esteem, difficulty making friends, being tearful,

or not wanting to go to school. Some children who feel like this can be disruptive and become aggressive

- children with specific learning difficulties or speech and language difficulties may be disruptive at school if they find it hard to complete a task or have not understood the instructions.

Details of where to get more information and help for your child's specific condition, including condition-specific support groups, can be found in 'Useful organisations' on page 25.

Setting the scene for good behaviour

All children will communicate their needs and respond to situations differently. But there some general rules that will help you manage your child's behaviour day-to-day. These rules are particularly important for children with disabilities, who may be struggling to make sense of a very confusing world.

Establishing daily routines

Most children cope more easily if they know in advance what is going to happen. Carrying out tasks in the same way or at the same time every day helps children become familiar with what is expected of them. Children with severe

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learning and communication difficulties can start to respond more positively and appropriately as they develop this understanding.

Routines can also be used to set up clear boundaries and acceptable behaviour, which can be reinforced with rewards (see 'Rewards' on page 7). For example, if your child won't sit at the table and eat a meal, you can try to establish firm meal-time routines and reward them for cooperating.

For routines to work, it's important that everyone involved with your child follows the same routines, so let them know what you are doing and why.

Building communication

Children who wish to communicate their needs and wishes but can't, can be deeply frustrated. This may mean their frustration is acted out as difficult behaviour.

It is vital to have two-way communication with your child. It's important to find a way communicate with them about your daily routines and, as part of that, help them to understand what you would like them to do.

If your child has limited understanding or speech, there are ways of communicating you can try. This may be by using simple language, for example one-step instructions, or key words.

You can also learn to communicate by using picture exchange communication systems (PECS) symbols, by signing,

learning Makaton (a mixture of signing and symbols), or by showing photographs or other familiar pictures or objects. For example, show your child their coat to let them know it's time to go out.

Giving children time to understand what you've said or signed and repeating key instructions is important.

Don't forget the power of your own non-verbal language/behaviour. Your tone of voice, warmth, posture, eye contact and facial expression all speak volumes about your own feelings and will affect how your child responds to you.

You can get help to find the best communication system for your child by speaking to professionals. Portage workers (for pre-school children), speech and language therapists, psychologists or the support group for your child's condition should be able to help. See 'People who can help you' on page 23.

Minimising risks

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

You may be entitled to certain equipment from your local authority through the occupational therapy service. Call our freephone helpline on 0808 808 3555 for information about this or for our free guide to *Aids, equipment and adaptations*.

Play and exercise

Research has shown exercise is very effective in relieving stress and getting rid of frustrations. It can also have a positive effect on behaviour generally.

Trampolining in a safe garden or swimming can work wonders in using up a child's excess energy. Exercise can also be very helpful for children with sensory processing difficulties. Most local authorities have a range of exercise, sport or play classes for disabled children at community facilities.

Living Made Easy for Children is a website and helpline run by the Disabled Living Foundation who can help you find play equipment (see 'Useful organisations' on page 25).

However, if your child has very limited mobility/understanding or is very unwell you may need advice about specific exercises, therapies and treatments that may be helpful. Call our helpline for more information.

There are a range of organisations across the UK who organise activities for disabled children, from days out to summer programmes of activities and adventure holidays. For more information on organisations in your area and to

order a free copy of our *Holidays, Play and Leisure* guide, call our freephone helpline on 0808 808 3555.

Rewards

If you make a point of highlighting or praising appropriate behaviours throughout the day, you will reinforce and increase good behaviour. You may already know what works for your child, but if you are thinking of using a reward system, it's a good idea to get professional advice.

This is because it's important that the reward system you choose to use is appropriate for your child and takes into account any medical or other condition that may be causing the behavioural problems. For example, if your child has Prader-Willi syndrome, this can cause them to over-eat. If you were to offer food rewards, this could make over-eating worse.

Examples of rewards may be verbal praise and attention, favourite activities, toys and tokens. Make it clear which good behaviour you are rewarding and what the reward is. For this to work, you have to be sure your child really wants and values that particular reward and that they can't have it at other times. Remember to seek advice before setting up a reward system.

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Recognising triggers of difficult behaviour

Sometimes children find themselves in situations that make them anxious or distressed, which can trigger difficult behaviour. You may know these triggers, or at times you may be baffled and caught off guard. It can take time and practice to work out the triggers but it's important you do, so you can find ways to deal with the behaviour.

If your child does start to display behaviour that indicates they are anxious or distressed, try to work out the cause and address it.

Children who can speak can still find it very difficult to say what is upsetting them, so those with limited communication are likely to find it even harder to both understand and communicate these feelings. Does your child have particular likes or dislikes or feel overwhelmed? For example:

- do they understand what they are being asked to do?
- is the task you want them to do too difficult?
- are they familiar with the person working with them?
- are they hungry?
- are they thirsty?
- are they in pain?
- are they tired?
- is the situation too noisy for them?
- are they too hot or too cold?
- are they finding change too difficult to cope with?

Devising strategies that remove or reduce the effect of triggers

If a behaviour keeps happening and you are unsure about the actual triggers, it can be helpful to keep a diary or a behaviour chart to try to learn more about it. A good example is an ABC chart:

- 'A' stands for antecedents – the things that lead up to difficult behaviour. For example, where people are, what is happening, who is there, what the time is.
- 'B' stands for behaviour – what the child is actually doing.
- 'C' stands for consequences – what happens in response to the child's behaviour. It's these consequences that can encourage or discourage (whether you mean to or not) the behaviour from recurring.

Remember

Your child may be trying to tell you something with their behaviour. For example, they may be screaming because they cannot bear the door being shut and they have no words to say this. Your child's behaviour may be serving a purpose, for example, they are screaming because it gets your attention. If their difficult behaviour gets your attention, they will do it again.

Using an ABC chart or a diary may help you identify and remove triggers (see figure 1 and 2 on next page).

What if you can't remove a trigger?

It won't always be possible to avoid certain triggers. For example, your child loves going out for walks in the park but is really frightened of dogs and runs out

Figure 1 – ABC Chart

Once you have filled in the ABC chart, you then may be able to devise a strategy to remove the trigger, for example:

Date and time	Antecedents	Behaviour	Consequences	Other comments
04/12/11 5.30pm Child is four years of age and displays difficult behaviour.	I ask my child to stop playing, come to the table and eat his dinner. I explain that it is his favourite meal. He ignores me. I pick him up and bring him to the table.	He hits and kicks me and screams. He moves from the chair to the floor under the table.	I tell him off and try to get him to sit up, but he won't move from the floor.	I feel exasperated. I have gone to all the trouble of cooking beef as it is his favourite to encourage him to cooperate. I realise that he may not understand complex instructions.

Strategy

You may find strategies such as stressing key words, using fewer words and more visual cues, pictures or signs can also help.

Behaviour	Strategy
My child won't come to the table to eat and tantrums when I pick him up. He does not understand complicated verbal requests and I get cross when he does not respond. When he senses I am cross, he lashes out and cries.	Speak in simple and brief sentences, using key words: 'Dinner is on the table', not, 'Come along and get your dinner – it's your favourite, roast beef, come and sit down on your chair at the table and enjoy it!' Give your child time to process the request, repeating the command calmly if they do not respond the first time.

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Figure 2 – ABC Chart				
Date and time	Antecedents	Behaviour	Consequences	Other comments
03/10/11 3pm Child is seven years old and has learning difficulties.	My seven year old was watching Teletubbies, which is her favourite TV programme. Her brother came in from school and changed the TV channel.	She screamed and hit and kicked me. Continued to scream.	Brother told off by me. She got her programme back. She stopped screaming but still lashed out at brother if he came near her.	It did not feel fair or right on either child. Her brother is only five years old.

Strategy	
Behaviour	Strategy
My child loves Teletubbies and screams and tantrums if she cannot watch the entire episode.	Set up a daily routine for when she can watch Teletubbies without interruption and an equal daily routine for her brother's favourite programme.

of the park into the road, or screams or attacks you if a dog approaches.

You will need strategies to reassure your child and gain their confidence in these situations. It is likely that you will learn what works best. For example, you may learn that telling a particular story or using a favourite toy or singing a favourite song will help to calm your child.

Professionals and other parents may be able to offer suggestions of ways to remove triggers from your routine.

Learning from other parents through local support groups or linking services can also be useful.

Contact a Family has a linking service you can access by calling our helpline or visiting our website at www.makingcontact.org. We also have a lively Facebook page www.facebook.com/contactafamily

Other help

You may find it useful to attend a parenting course on managing difficult behaviour in children with additional



needs. These courses can give you lots of practical hints and tips, increase your confidence and allow you to meet other parents facing similar challenges.

Call our helpline for information on local courses.

When is behaviour 'challenging'?

In some cases, children develop behaviour that is persistent and severe. The behaviour may be a risk to the child or people around them and prevent them using ordinary community facilities, like a leisure centre or day centre. This kind of behaviour can also have a severe impact on family life.

When a difficult behaviour reaches this level of severity, it could be defined as 'challenging behaviour'. Often, challenging behaviour may be associated with severe learning difficulty and can lead to aggression, self-injury or disruptive and destructive behaviours.

It is important to seek outside help if your child's behaviour has become challenging. A list of people and organisations that can help you can be found in 'Sources of outside help' on page 23.

If you have been experiencing problems with your child's behaviour, you may already have been in touch with professionals or teams that can help you to manage the situation, such as your GP, school nurse, health visitor or a child development team.

If your child's behaviour becomes very challenging, approaching a professional who is familiar with your child's needs is a good place to raise your concerns about their behaviour.

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First, it's important to rule out any underlying health problems like toothache or earache, which may be causing pain. A visit to your GP or dentist should rule these out.

Medical professionals should consider your child's initial medical diagnosis, as some behaviours are associated with particular medical conditions (for example, hand biting is common in children with Fragile X syndrome).

In some children, sleep problems, incontinence, problems with feeding and eating, self-harming, emotional and behaviour problems may suggest a mental health or other issue that exists in addition to your child's diagnosis or diagnoses.

A specialist assessment of your child's challenging behaviour may need to be carried out. Depending on the area where you live, a multi-disciplinary team may conduct this assessment. Once under the care of a multi-disciplinary team, your child might be referred onto other appropriate specialists.

Examples of challenging behaviour include:

Inappropriate social behaviour

This is a problem if a child is persistently rude, disruptive, doesn't cooperate at school and is aggressive towards staff and other pupils. They may also get into fights and it can eventually result in children being excluded from school. Some children may also have other

inappropriate reactions to situations. For example, they may laugh when someone is hurt, swear at strangers in public or cry a lot for unexplained reasons.

Who can help: school counsellor (although not every school has one), Child and Adolescent Mental Health Teams, CAMHS or any of the professionals your child is in contact with.

Kicking, spitting, hair pulling, and other physical outbursts

Some children with learning difficulties may display extreme behaviour like regular or lengthy tantrums. They may kick, pull hair, self-harm or damage clothes or property. This type of behaviour can cause harm to your child or those around them.

It's important to discuss these behaviours with your child's clinical coordinator and/or the professional that knows your child well to seek further help. As children get older and stronger, unless they're helped to bring their behaviour under control, it will become more of a problem and may mean they are denied access to community facilities like youth clubs and leisure centres.

Who can help: in addition to your local professionals, some specialist services such as the Challenging Behaviour Foundation, CAMHS or condition-specific support groups may also be of help.

Sleep problems

Many children have problems around sleep and bedtime. These are very common in regularly developing

children, and especially children with learning difficulties, with autistic spectrum disorders or with sight problems. For example, they may not settle in bed until late or get up in the night, refuse to sleep in their own

bed, make noise which wakes up the household, as well as waking up very early.

These issues may not seem urgent at first, but long periods of poor sleep

What are multi-disciplinary treatment teams?

These are teams that your child may be referred to for assessment if they are showing challenging behaviour. The idea is that a range of professionals might contribute to the assessment of your child's difficulties. Examples of multi-disciplinary/multi-agency teams include Child Development Centres (CDC), Child and Adolescent Mental Health Services (CAMHS) and Community Learning Disabilities Team (CLDT).

Child Development Team/Centre (CDC)

This is a healthcare team specialising in working with children when there are concerns about their development. Many different professionals can work in this type of team including paediatricians, physiotherapists, occupational therapists, psychologists, speech and language therapists and child and adolescent psychiatrists.

Child and Adolescent Mental Health Services (CAMHS)

CAMHS teams promote the mental health and psychological wellbeing of children and young people. They include professionals that work in a number of different organisations such as health, education and social services. The professionals can include occupational therapists, clinical psychologists, psychiatrists, and social workers (amongst others). You may have a CAMHS Learning Disability team in your area. These teams specialise in meeting the psychological and emotional needs of children and young people with a learning disability.

Community Learning Disabilities Team (CLDT)

Some CLDTs promote a lifespan service. It can help plan and arrange care and support for people (across the age ranges) with learning disabilities and their carers. The team is made up of staff from health and social care and can include social workers, community nurses, psychiatrists, psychologists and a range of therapists.

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can mean you and your child are very tired. Lack of sleep can cause feelings of depression and make you feel less able to cope. Contact a Family produces a free guide *Helping your child sleep*, available from our freephone helpline on 0808 808 3555.

Who can help: Cerebra, Sleep Scotland, Scope, Contact a Family Helpline.

Smearing faeces and urinating

Some children and young people may smear faeces or urinate in inappropriate places. There can be various reasons for this. It could be they simply enjoy the feel of the faeces and need more sensory stimulation. You can use other ways to achieve this like giving them play dough, which has a similar feel.

They may be extremely upset and agitated, or have a medical problem. Try and rule out any medical or behaviour issues by getting help from professionals.

Other parents will have experienced this behaviour and may have worked out strategies that work, so get in touch with your child's condition support group, or call our helpline for contact details.

This behaviour can be very hard to deal with because of the extra washing and disinfecting, and the expense of replacing ruined carpets, wallpaper and bedding. You may become exhausted

and anxious about the behaviour and the endless explanations you may feel you have to make to other people.

Who can help: ERIC (a continence support organisation), occupational therapist, school nurse, the Disabled Living Foundation and Fledglings provide clothing solutions/equipment that may be useful.

Self-harming

Watching a child with behaviour that includes self-harm is one of the most difficult and distressing issues parents may have to face. For severe self-harm, (for example, if your child has a fracture, injury to their eye or swallows a potentially dangerous substance), you will need to take them to casualty for emergency care. If the risk of self-harm is very great, children may need short, medium and longer-term plans.

For children with significant learning disabilities and/or complex needs, there is usually a need for careful, systematic, multi-disciplinary team assessments. These might include CAMHS/CLDT and other child health professionals, together with education and the local authority to develop an individualised package of care and support.

Behaviours can vary and, may include the child:

- biting the back of their hand
- picking at areas of their skin
- scratching one particular area on their body a lot
- head banging

Remember, getting advice from support organisations and other parents can be invaluable during this time.

- pulling hair out
- eye poking
- sticking objects into ears or nostrils
- eating inappropriate things.

You can try to stop the behaviour by working out what is causing the episodes, but you will almost certainly need to seek help from an expert if your child is showing these types of behaviour frequently, intensively or dangerously.

Who can help: CAMHS or CLDT should have specialists who can help with these issues. Psychiatrists and psychologists may help and other parents may also be able to offer support from having had similar experiences.

Dealing with challenging behaviour

You may have to wait to get outside help to deal with your child's challenging behaviour. The first step would be to talk to your general practitioner (GP) or another professional involved in your child's care, who can make the appropriate referrals to other specialists.

Remember, getting advice from support organisations and other parents can be invaluable during this time. Assessments by professionals and referrals to services can take some time so try to access all the support you can while you are waiting. In the meantime, there are useful techniques you can try yourself.

First of all, decide which behaviour you want to focus on if your child has several worrying ones. This will avoid confusing them (and you). For some parents, this means deciding which behaviours you can live with and which ones you must tackle because they are dangerous for your child and others.

There is no single solution for dealing with challenging behaviour and not everything can be solved at once. There are some common approaches you can try, which may have some effect:

Rule out any medical or dental problems: in case your child is in pain and cannot tell you. If they are constipated, tell the doctor as this can also be a cause of discomfort. Work out the triggers for the behaviour (as described previously).

Stay neutral: keep your responses to a minimum by limiting verbal comments, facial expressions and other displays

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of emotion, as these may encourage the child to behave in this way. Try to speak calmly and clearly (using just key words and phrases) and keep your facial expression neutral.

Focus on changing the behaviour: it's important for your child's self-esteem that they know you want to change their behaviour, not them and who they are. Otherwise they will be unhappy, which is likely to affect their behaviour and may make things worse.

Be positive: state or show how or what you would like your child to do in a positive way, for example, 'please do ...' rather than 'do not do...'. Children can find it very hard to interpret 'no' messages. The word 'stop' can be more effective. If you can re-direct them into good behaviour, reward them at once, for example with a hug or praise.

Be consistent: tell everyone involved about your strategy for this behaviour problem so that everyone is working on it in the same way. Children get very confused if handled differently. It can sometimes be helpful to agree a written behaviour plan, with strategies that work, for all involved with your child, particularly if they go to day centres, have a support worker or short break support. Give this plan to everyone who looks after your child in your absence, such as friends, family or other carers while you are having a short break.

Time out: this involves moving 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 length of the time out should correspond with age, for example a five-year old should spend five minutes in the place you put them in.

The use of 'time out' is only appropriate and effective if your child truly understands the meaning of staying in the time out place. **This means it is not suitable for every child, and unsuitable for a child with severe learning disabilities.**

Removing your child from the situation, allowing them time to calm, with limited interaction, then distracting them onto a positive activity would be more productive for a child with severe learning disabilities.

Build in positive experiences for your child: if you make a point of praising and rewarding appropriate behaviours whenever possible, you will reinforce and increase good behaviour. Remember to get advice from a health professional before using a reward system. (see 'Setting the scene for good behaviour' and 'Rewards' on page 5 and 7).

Remember
Punishment rarely works (for example using 'time out' for a child who can't understand its meaning) because many children do not see the connection between what they did and the punishment that follows it. There are rarely overnight miracles so remind yourself to be patient. Don't worry if things get worse before they get better – your child will take time to adjust to your strategies.

Top tips for managing challenging behaviour

When difficult behaviours occur, it is generally helpful to:

- take time, stay calm and neutral
- give reassurance in a way your child is able to understand
- make yourself appear less threatening, for example by sitting down
- keep language simple, give clear messages or demonstrate or show a visual cue card to show the behaviour that you want
- remove other adults and children from the situation
- look and sound confident – even if you're not feeling it
- intervene quickly, try diverting or distracting your child.

It is less helpful to:

- look angry or upset
- lose your temper
- intimidate
- talk a lot
- confuse your child
- have other people chip in
- look nervous
- do nothing
- re-ignite the situation
- be negative, saying 'naughty', 'bad', 'no' or 'don't'
- threaten punishments, particularly ones you are unlikely to be able to see through.

Look after yourself

None of this is easy especially when you are tired. You will need time to relax and take care of yourself. Parents are often so busy thinking about everyone else that they can find it very hard to set aside time to do something they really enjoy. This might be as simple as having a bath in peace, reading a book or seeing a friend. Without taking a break from caring, your health can suffer. If you are a single parent or you do not feel that you can ask family or friends to help out, you can contact our helpline who can advise you on how to get help or a short break on 0808 808 3555.

Parents of disabled children have the right to ask for an assessment of need by social services, (see 'Sources of outside help' on page 23). They may provide you with some options for taking a break from caring for your child. If you are assessed as needing a short break from caring, then this must be supplied by the local authority.

The break could happen in a number of ways, for example, providing a carer to support your child in a social or sporting activity. Other types of short breaks include

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short breaks for the whole family, where your child stays with another family or goes to a residential centre for a short while. It may be that a sitter could come into your home to look after your child while the rest of the family has a break.

Parents of disabled children assessed as needing services can opt to receive direct payments. Direct payments allow you to receive cash instead of services so you can arrange your own help.

This means you might be able to employ a care worker who can then be trained to meet your child's needs. To find out if direct payments would be suitable for you and your family, see our free guide *Getting direct payments for your disabled child*, available from our freephone helpline on 0808 808 3555.

Support for siblings of a disabled child is provided by the Princess Royal Trust for Carers, who have a website Youngcarers.net. They also offer social opportunities for young carers who may need a break from helping to care for their disabled sibling. Sibs can help siblings of disabled children with ideas for coping with difficult situations and help them learn about the experiences of other siblings. Contact a Family produces a free guide *Siblings*, with hints and tips, available from our freephone helpline on 0808 808 3555.

The teenage years

Puberty and teenage years are times of change and adjustment for all children

and young people. Parents of disabled children can find it difficult to know what allowances to make for their child's puberty and hormonal changes. But even allowing for hormones, there are some real concerns for many parents during the teen years.

School transition

Many children with additional needs will have transferred from primary to secondary education with a statement of special educational needs and have appropriate, on-going support. But 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 numbers of pupils, different teachers and unfamiliar routines.

Children become more conscious of their peers' independence and the fact that they cannot keep up or are not allowed similar freedoms. They may feel they are 'different' and lose confidence in themselves.

Parents sometimes comment that their children's behaviour and their mental health gets worse when moving from primary to secondary school. You may find yourself despairing of teachers who fail to see your child's difficulties and feel they blame them unfairly for 'day dreaming' or for being aggressive and getting into fights.

The worsening behaviour may also coincide with your child being bigger and stronger and harder to control as they get older.

Despite this, children and young people can be well supported in secondary school (whether mainstream or more specialist provision) and settle happily. It's important that you prepare the way as much as possible.

Remember there are laws in place to help protect disabled children from being seen as simply naughty or deliberately disruptive, when their behaviour difficulties may arise because of their disability. If your child doesn't have 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) (see 'Help at school' page 21). Your child has the right to have their needs for support properly met.

The school should work with you to ensure your child's needs in education and further education are met. This process should start in school Year 9 (when your child is 14). Call our freephone helpline for a copy of our free guides to *Preparing for adult life and transition* in the area you live, which takes you through the process.

Sexuality and inappropriate sexual behaviour

This can be a major worry for parents. Parents of disabled young people generally accept that their children will naturally develop sexual awareness and feelings but they also worry about their extra vulnerability. Some disabled young people find it hard to know where they can express their sexuality and where it is inappropriate.

Parents, young people and their advocates need access to good information and support. It is important to remember that professionals are often familiar with the sorts of behaviours that can occur, so it should be possible to have honest and open discussions without being embarrassed by the nature of the problem. You may find it helpful to discuss this with your child's school as well.

Contact a Family has produced three separate guides on young disabled people *Growing up, sex and relationships* – one is aimed at young people, another for parents (available on the web only) and a third for teachers working with young disabled people. You can get a free copy of these guides from our helpline or download them from our website.

Other organisations also produce excellent materials for young people with specific conditions, for example Brook has a web page dedicated to sex and disability and also produces an information booklet on this topic. Talking to other parents can also be helpful and reassuring.

Emotions and mental health

Sometimes you, or the professionals working with your child, may notice other emotional and behavioural

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

changes. You may be concerned about your child's mental health. If you are worried about this, contact your GP, consultant paediatrician or child health professional to talk about it. They may suggest a referral to the local CAMHS or a CAMHS learning disability service for an assessment to understand your child's behaviour, moods and feelings.

The assessment may involve one or more members of the CAMHS team and will usually involve seeing you as parents, 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 professionals 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 behaviour needs.

Some mainstream secondary schools are able to provide a school counsellor to support emotionally troubled teenagers and some schools (including special schools for children with significant learning disabilities) have regular outreach clinics and links with community specialist services.

Further information about mental health issues is available from YoungMinds 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.

If your son or daughter is in trouble with the police

Sometimes a young person with behaviour difficulties may come into contact with the police. If your child has a particular learning disability or disorder, sharing information with the police about their particular difficulties and needs (communication especially) can be helpful.

The National Autistic Society produces information cards, which can be carried by a young person with communication problems who may not be able to explain their situation.

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 parents 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 who work to prevent crime in young people. They are generally well aware that young people with special

Help at school

SENCO

A special educational needs coordinator (SENCO) is 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.

Statement of special educational needs or coordinated support plan in Scotland

These are legal documents produced in agreement with the local authority, or education authority, following an assessment of your child's needs. The assessment sets out the additional support your child needs in school and, if agreed, your child's assessed needs must be met. The framework for supporting children with special educational needs is intended to address the needs of children with behaviour problems that can't be solved through the school's standard behaviour and discipline policies.

In England and Wales, **Parent Partnership Services** provide advice, information and support to

parents and carers whose children have special educational needs. To find your local service, contact the National Parent Partnership Network Tel: 0207 843 6058 www.parentpartnership.org.uk

In Northern Ireland, the Special Educational Needs Advice Centre (SENAC)

provides an independent advice, information and advocacy service for parents of children and young people with special educational needs. Advice Line: (028) 9079 5779 www.senac.co.uk

In Scotland, Enquire offers independent and impartial advice and information to parents, carers, practitioners, children and young people. Helpline: 0845 123 2303 <http://enquire.org.uk>

For more information on your rights and how to get help at school in the teenage years, please see our guides *Preparing for adult life and transition for England and Wales, Scotland and Northern Ireland*, available free from our helpline.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

educational needs can get into trouble and they seek ways to prevent this and to help them.

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

Children under ten: 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 ten 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. Call our freephone helpline on 0808 808 3555 to find your nearest one.

Children aged over ten: can be held responsible for a crime if it can be proved they were aware that their actions were wrong. Parents must be informed if a child has been arrested and the parent or another 'appropriate adult' (for example, a social worker) must be present if they are questioned.

Children have the same right to a solicitor as adults. If this happens to your child, it is important that you make the solicitor aware of any disability or illness and what this means for the child, for

example, any link with challenging behaviour, and the degree to which they can understand what is being communicated to them.

Sources of outside help

In this section is a list of the people, organisations and resources that exist to help parents cope with difficult or challenging behaviour.

There are a large number of professionals and other sources of support who can be involved in helping you and your child. These organisations include statutory services such as local health, education and social services.

Local and national support voluntary organisations and independent providers can also help, as well as specific condition support groups and different parent-led and other types of support groups.

People who can help you

Support groups: there are several different types of support group. They may be local (covering a certain area or region), national or even international. They may be a generic (for all parents of a child with an additional need) or condition-specific group (for example, for parents of a child with ADHD or fragile X syndrome).

Even if you do not meet a parent of a child with the same needs as your child, you may find it helpful to share experiences with other parents anyway. Condition-specific support groups will be able to give you information on the condition and how it might affect

your child. They may also be able to link you with other parents of children with the same condition as your child. Support groups offer a wealth of other services according to their size.

Please call our helpline on 0808 808 3555 to find out about groups in your local area.

Parents: often parents find the best advice that they get is from other parents who may have gone through, or are currently going through, similar experiences to their own. You can link with other parents through parent support groups run by voluntary organisations, carers' centres, or support groups for your child's specific condition. Our freephone helpline has details of these. You can also contact other parents through our web-based linking service at: www.makingcontact.org or find us on our lively Facebook page.

Professionals: the assessment and advice about the successful management of challenging behaviours often needs a multi-disciplinary approach from one or more professionals as part of the assessment and intervention team. In this document we have made reference to several different professionals and services including:

Clinical psychologist: children with behaviour that is very challenging for

Setting up a circle of friends to support your child

If your child is experiencing difficulties because of their disability or their challenging behaviour towards others, it could be helpful for them to have a 'circle of friends'. The circle should help to improve the inclusion of your child in their mainstream school.

The circle of friends idea works by getting other children in the school to provide support and help the child in difficulty to solve problems.

In the early stages, an adult teacher/facilitator will probably need to meet with the circle and the 'focus child' to

help them with choosing their circle of friends and problem solving.

After the early stages, you and your child and/or their teacher will probably be able to review the amount of help the circle needs on a regular basis.

If your child is in mainstream school, talk to a professional involved in their care, like the SENCO or their form teacher. For more information visit: www.inclusive-solutions.com/circlesoffriends.asp

parents to manage may need to see a clinical psychologist. They will look at the child and their behaviour, assess whether the types of behaviour they are showing are associated with a specific condition and discuss practical strategies you can use to manage them.

Community psychiatric nurse: a children's nurse from either CAMHS or Community Learning Disability Teams, who provides support and interventions. They may have a wide range of knowledge and suggestions to help with specific behaviours.

Educational psychologist: challenging behaviour may occur in different settings, including schools. Children may be referred by the school to an educational psychologist to look at setting up strategies to help your child in the school setting. These strategies always need to be shared between school and home to ensure consistency.

GP: your child's General Practitioner or family doctor may be able to give some useful advice, but may also want to refer you on to a professional or community team with more specialist knowledge.

Health visitor: your health visitor is likely to have had face-to-face contact with you and your child in your home over a period of time and will have experience and expertise in the assessment and management of common problems in childhood. In addition, the health visitor can work with colleagues from other agencies (such as portage and early

years service) to contribute to a multi-agency assessment and care plan for your child.

Occupational therapists: an occupational therapist will assess and treat physical and psychiatric conditions using specific, purposeful activity to prevent disability and promote independent function in all aspects of daily life. They can either be hospital-based or based in the community.

Paediatrician: a child's paediatrician may have seen them over a period of time, so will often be consulted about a change in the clinical presentation and/or the development of a difficult or challenging behaviour. The paediatrician and other members of the child health or child development team may contribute to the assessment of the problem behaviour and may offer advice on how to deal with it. However, they may also refer your child on to any of the other professionals on this list.

Paediatric nurse: these are children's nurses (who may be hospital or community based) who often come across different behaviours and have experience of working with children who are ill or disabled. They may have a wide range of knowledge and suggestions to help.

Physiotherapist: these 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 worker: as part of a team that visits a pre-school child at home, the portage worker may well have seen the behaviours that are causing concern at home and may be able to give some suggestions on how to manage these.

Psychiatrist: child and adolescent psychiatrists assess and contribute to the treatment of children who attend mainstream schools. Psychiatrists who are experts in learning disability will contribute to services for children with more severe special needs, who may attend a special school.

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

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

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 may help to improve your child's interpretation of some situations.

Social workers: they are based in your local children with disabilities team. You have the right to ask for an 'assessment



of need' to see if your child's difficulties make you eligible for a regular short break from care. 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 buy in some help in caring for your child.

Useful organisations

General

British Psychological Society (BPS)

Tel: 0116 254 9568

www.bps.org.uk

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

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

Challenging Behaviour Foundation – Family Support Network

Tel: 0845 602 7885

www.thecbf.org.uk

This network is for families caring for, or individuals with, severe learning disabilities (both children and adults) who typically display challenging behaviour.

Family Lives

Helpline: 0808 800 2222

<http://familylives.org.uk>

24-hour helpline for all general aspects of parenting.

Call Contact a Family's helpline for specific information about caring for a disabled child.

Royal College of Psychiatrists

Tel: 020 7235 2351

www.rcpsych.ac.uk

The professional body for psychiatrists in the UK. Its website has information leaflets covering many different mental health conditions affecting children, young people, their parents, carers and professionals supporting them.

YoungMinds

Tel: 020 7336 8445

Helpline for parents: 0808 802 5544

www.youngminds.org.uk

YoungMinds is a UK charity that is committed to improving the emotional wellbeing and mental health of children and young people by empowering their parents and carers.

Carers' organisations

The Princess Royal Trust for Carers

Tel: 0844 800 4361 (England)

Tel: (0141) 221 5066 (Scotland)

Tel: (029) 2022 1788 (Wales)

www.carers.org

The Princess Royal Trust for Carers has branches of carers centres throughout the UK, providing quality information, advice and support services, including short break provision.

Carers' UK

Tel: 020 7378 4999

Helpline: 0808 808 7777

www.carersuk.org

Provides advice support and information for carers, including short break provision.

Crossroads Care Association

Tel: 0845 450 0350

www.crossroads.org.uk

Crossroads Care provides services to carers through a network of local providers across England and Wales. Crossroads care can offer care workers and advice on getting a short break.

Continence

ERIC (Education and Resources for Improving Childhood Continence)

Tel: 0117 960 3060

Helpline: 0845 370 8008

www.eric.org.uk

ERIC is a national children's health charity dealing with bedwetting, daytime wetting, constipation and soiling in children and young people.

Equipment

Disabled Living Foundation (DLF)

Tel: 020 7289 6111

Helpline: 0845 130 9177

www.livingmadeeasy.org.uk/children

DLF is a national charity that provides impartial advice and information on daily living aids. Its website has a section about equipment for children, some of which has been mentioned in this guide.

Fledglings

Tel: 0845 458 1124

www.fledglings.org.uk

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

Picture Exchange Communication System (PECS)

Tel: 01273 609 555

www.pecs.org.uk

PECS is 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 Ltd. They run the PECS courses, and their website has a wealth of information on PECS. You can buy many resources from their website. Other PECS and symbol websites that are free of charge: www.do2learn.com www.symbolworld.org www.enchantedlearning.com/Dictionary.html <http://pdictionary.com> <http://trainland.tripod.com/pecs.htm>

The Makaton Charity

Tel: 01276 606 760

www.makaton.org

Uses signs and symbols to promote understanding and language for children with communication and

learning difficulties. The charity runs Makaton courses for parents.

The National Autistic Society

Helpline: 0845 070 4004

www.autism.org.uk

Produces information cards which can be carried by a young person with communication problems who may not be able to explain their situation.

Growing up and sexual health

Brook

Tel: 020 7284 6040

Helpline: 0808 802 1234

www.brook.org.uk

Brook provides free and confidential sexual health advice and services specifically for young people under 25.

Siblings

Sibs

Tel: 01535 645 453

www.sibs.org.uk

Sibs is a charity that supports siblings of disabled children, they can help them with ideas for coping with difficult situations and help them learn about the experiences of other siblings.

Youngcarers.net

www.youngcarers.net

A website for young carers and siblings with moderated chat room, resources for siblings and a place to share experiences.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk



Getting help from professionals

You, or any professional involved with your child, can ask for a multi-disciplinary meeting between you and all the professionals involved with the care of your child. This allows communication between social care, healthcare and educational professionals and ensures everyone can contribute to your child's care plan.

Here are a few tips to help you get the most out of meetings with professionals helping your child:

- take a partner or friend with you if you can – it makes it easier when there are two people listening to the advice
- it's helpful if the professional you are meeting has met your child before. If this has not been possible and you have to take your child with you, then it might be helpful for an extra person to be on hand to take them into a separate room while you discuss any behaviour that's causing concern
- write down all your questions in advance of the meeting – it is very easy to forget some of the things you are concerned about when face-to-face with the professional
- don't be afraid to ask questions, especially if you are nervous about some of the advice given, or if you don't understand anything. The professional will want to be sure they have made everything very clear for you
- make your own notes if you would like to, and ask for a summary of the advice you receive to be written and sent to you by email or post – whatever suits you best
- keep everyone informed – ask for copies of minutes or notes to be circulated to all present and any other relevant professionals or parties not able to attend the meeting.

Sleeping

Cerebra

Tel: 01267 244 200
Helpline: 0800 328 1159
www.cerebra.org.uk

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

Sleep Scotland

Tel: 0131 651 1392
www.sleepscotland.org

A charity providing support to families of children and young people with additional support needs and severe sleep problems in Scotland.

Scope – Face 2 Face Sleep Solutions

Tel: 0844 800 9189
www.face2facenetwork.org.uk/SleepSolutions.htm

As well as providing information on sleep, Sleep Solutions have several trained sleep counsellors in England. They have produced a sleep workshop package, in consultation with parents, where basic information can be given to parents by a trained sleep counsellor.

Organisations with support groups for specific conditions that can help

There are more than 430 medical conditions and disabilities in the *Contact a Family Directory*, with details of support groups where there is one. If your child has a diagnosis of a

specific condition, the support group for that condition will almost certainly have information about coping with challenging behaviour common in that condition. This information will have been developed by parents with experience of bringing up a child with the condition in question. You can access the Directory on our website at www.cafamily.org.uk or by calling our freephone helpline on 0808 808 3555. They will be happy to send you any information. If a condition isn't listed in the Directory we may still be able to find you information about it on our database, so please do call.

Benefits and financial help

Extra financial help available to parents of children with behaviour problems includes Disability Living Allowance (DLA), which is payable if your child needs significantly more care or supervision than other children of the same age because of a disability, and if your child has mobility issues.

Other financial help may be needed to pay for new furniture, bedding or clothing if, for example, your child tears fabric or damages furniture. Help may be provided from the Social Fund if you are on Income Support, income-based Jobseeker's Allowance or Pension Credit. Children with challenging behaviour should be given additional priority for grants.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

Contact a Family publishes a number of guides on money issues, available free from our helpline. You can also ask our helpline to check that you are getting all the financial assistance you are entitled to.

The Family Fund

Tel: 0845 130 4542

www.familyfund.org.uk

The Family Fund gives grants to families who have severely disabled children up to 17 years of age. See their website for more details on their criteria.

About Contact a Family

Contact a Family

Freephone helpline: 0808 808 3555

Textphone: 0808 808 3556

Email: helpline@cafamily.org.uk

www.cafamily.org.uk

We provide advice, support and information for the families of disabled children no matter what the child's disability or additional need. We also campaign to increase investment in services for families with disabled children.

We have a team of parent advisers who can put parents in touch with support groups for the disorder affecting the child, offer a listening ear, offer advice on rights and entitlements, give approved medical information and give details on our linking services.

Linking

We run a web-based linking service, which is available at www.makingcontact.org.uk. If there is no support group offering linking for a certain condition, then we can try to arrange one-to-one family linking.

Free guides

We produce a range of free guides for families which can be accessed at www.cafamily.org.uk/publications.html or by calling our helpline.

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Social networking

Contact a Family is on Facebook and Twitter. Join us at:

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www.facebook.com/contactafamily

Twitter

www.twitter.com/contactafamily

Podcasts

You can download podcasts from our website at: www.cafamily.org.uk/news/podcasts.html

iTunes users can listen to our podcasts at: www.cafamily.org.uk/itunes

Videos

You can watch videos on our YouTube channel at: www.youtube.com/cafamily

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Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Monday–Friday

Access to over 170 languages

www.cafamily.org.uk

www.makingcontact.org

Contact a Family Head Office:

209–211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **info@cafamily.org.uk**

www.cafamily.org.uk



Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

- Concerned about your child? (UK)
- Relationships (UK)
- Special educational needs (England)
- The tax credits guide (UK)
- Working (UK)
- Disabled children's services in England and Wales, Scotland

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