



# 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 behaviour that challenges you, or may already have behaviour that challenges. They may have a recognised disability, be in the process of getting a diagnosis, or you may be wondering if they have additional needs.

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 ways you can help your child and a number of people and organisations who can help. In this guide, we offer suggestions that may help, explain who else can help and how, and where you and your child can get support.

**Note:** this 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.

## Contents

Introduction.....	2
Understanding behaviour .....	3
Getting support .....	4
Setting the scene for good behaviour.....	5
Recognising behaviour triggers.....	7
Dealing with behaviour issues .....	11
When is behaviour 'challenging'? .....	14
The teenage years .....	18
If your son or daughter is in trouble with the police.....	20
Sources of outside help.....	23
Useful organisations .....	25
About Contact a Family.....	30

## Understanding behaviour

It is not always easy to spot a behaviour that will challenge us during its early stages. Many young children naturally have tantrums and some teenagers seem to enjoy ignoring their parents. But behaviour becomes challenging 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 'behaviour that challenges', or 'challenging behaviour' (see 'When is behaviour challenging?' on page 14).

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.

Some behaviour that challenges is 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
- children with an autism spectrum disorder (ASD) may become unsettled by changes in their routine, causing

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**



them to become upset or anxious. They can also react strongly to their environment, for example they may not like being in crowds

- some children who have sensory impairments may be over- or under-stimulated by sounds, sights smells and noise. This can affect the way they behave
- some children have physical disabilities that mean they have no speech. These children need alternative ways to communicate their needs. See 'Setting the scene for good behaviour' on page 5)
- some behaviours happen because of a genetic condition. For example, a child may have a tendency to be obsessive, anxious, over eat, sleep badly or self harm. If your child has a genetic condition, you may want to find out more about the condition and whether there are strategies to help with behaviours
- some behaviour is classified by professionals as an 'emotional and behavioural' difficulty. Signs of this include low self-esteem, difficulty

making friends, being tearful, or not wanting to go to school

- children with specific learning difficulties or speech and language difficulties may find learning at school difficult without good support. If support is lacking a child's behaviour may change or become challenging.

## Getting support

It is important to tackle issues with your child's behaviour early. If you notice certain behaviours getting more frequent, occurring over longer periods of time and becoming unmanageable, look at strategies to manage them (see page 7).

If your child has a specific diagnosis, the support group for their condition can usually offer tips and strategies to prevent or manage behaviours that challenge. Many parents say the best advice comes from 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 your child's care – like your GP, health visitor or children's centre or school staff. 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. Behaviour and discipline policies should take into account a child's disability or special educational needs.

Laws are in place to help protect disabled children from being seen as simply naughty or deliberately disruptive, because behaviour that challenges may arise because of their disability, or because of a lack of reasonable adjustments 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 page 21 for where to get help with school.

More information about where to get help, including condition 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 are some general rules that will help you manage your child's day-to-day behaviour. 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 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.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

## **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 behaviour that challenges.

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

If your child has limited understanding, or little or no speech, there are ways of communicating you can try. This may be by using simple language; for example one-step instructions, or key words. 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 also learn to communicate by using picture exchange communication systems (PECS) symbols, by signing, learning Makaton (a mixture of signing and symbols), 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.

You can get help to find the best communication system for your child by speaking to professionals such as portage

workers (for pre-school children), speech and language therapists, psychologists (see 'Sources of outside help' on page 23 for more information).

## **Minimising risks**

It is important to find ways to reduce the risk of children hurting themselves and to make them as comfortable as possible. Simple ideas include using locks on 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. See page 26.

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 sports, play classes and clubs for disabled children.

Living Made Easy for Children is a website and helpline run by the Disabled Living Foundation who can help you find play equipment (see page 26).

If your child has very limited mobility/ understanding or is very unwell you may need advice about exercises, therapies and treatments that may be helpful. Call our freephone 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. If you are thinking of using a reward system, it might be helpful to discuss it with the professionals involved with your child.

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 behaviour that challenges. For example, Prader-Willi syndrome can cause children to over-eat. So offering food as a reward would 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.

## Recognising behaviour triggers

In some situations, children become anxious or distressed, which can trigger behaviour that challenges. 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.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

Children who can speak can find it very difficult to say what is upsetting them. Children with limited communication are likely to find it even harder to both understand and communicate their feelings. Your child may have particular likes or dislikes, or may feel overwhelmed. Questions you might consider include:

- 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 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 the 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 challenging 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 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 trust in these  
(continues on page 10)

### 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
10/6/14 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.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

**Figure 2 – ABC Chart**

Date and time	Antecedents	Behaviour	Consequences	Other comments
10/6/14 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.

situations. It is likely that you will learn what works best. For example, you may learn that telling a particular story, 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 freephone

helpline on 0808 808 3555 or visiting our website at [www.makingcontact.org](http://www.makingcontact.org)  
We also have a lively Facebook page [www.facebook/contactafamily](http://www.facebook/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 freephone helpline for information on local courses.



## Dealing with behaviour issues

You may have to wait to get outside help to deal with your child's 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 behaviour that challenges 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 (see page 7).

**Stay neutral:** keep your responses to a minimum by limiting verbal comments, facial expressions and other displays of emotion, as these may encourage the child to behave in this way. Try to speak calmly and clearly (using just key

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

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. Just saying "Stop," can be more effective. If you can re-direct your child 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 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.

**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

## Top tips for managing 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.

before using a reward system. (see 'Setting the scene for good behaviour' on page 5 and 'Rewards' on page 7).

### **Punishment rarely works**

Punishment – for example using 'time out' for a child who can't understand its meaning – rarely works 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.

### **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, call our

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

freephone helpline and ask for advice 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 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 Carers Trust, who

have a website [Youngcarers.net](http://Youngcarers.net) They also offer social opportunities for young carers who may need a break from helping to care for their disabled sibling. Sibs is an organisation that can help siblings of disabled children with ideas for coping with difficult situations and learn about the experiences of other siblings. Contact a Family has a free guide *Siblings*, with hints and tips, available from our freephone helpline on 0808 808 3555

## 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 'behaviour that challenges' or 'challenging behaviour'. Often, behaviour that challenges may be associated with a 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 find it helpful to discuss this with people such as your GP, paediatrician, learning disability nurse or child development

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

team to get help in managing the situation.

If your child's behaviour becomes very challenging, they might refer you to a specialist such as a psychiatrist or clinical psychologist.

It is important to rule out any underlying health problems like toothache or earache, which may be causing pain. If you find it difficult to take you child to the dentist, the community dental services can help.

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).

Sleep problems, incontinence, problems with feeding and eating, self-harming, emotional and behaviour problems may be associated with your child's diagnosed condition, but could be due to another underlying medical or mental health issue.

This is why different health professionals might need to be involved in carrying out an assessment of your child and their

behaviour, to decide what help is most appropriate.

Examples of behaviour that challenges 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

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

## What are multi-disciplinary teams?

These are teams which include health professionals with specialist knowledge and expertise. Different specialists might be needed for an initial assessment to understand what is causing the child's behaviour and agree the best way to help them. Examples of multi-disciplinary/multi-agency teams include child development teams/centres (CDCs), Child and adolescent mental health services (CAMHS) and community learning disabilities teams (CLDTs).

### Child Development Team/Centre (CDC)

This is a healthcare team specialising in working with children with disabilities or where there are concerns about a child's development. A child development team usually includes paediatricians, physiotherapists, occupational therapists and speech and language therapists. They also work with child and adolescent psychiatrists and psychologists.

### 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. 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 what is called a 'lifespan service'. This means they can help plan and arrange care and support for people of any age with learning disabilities and their carers. CLDTs are made up of staff from health and social care. They might include social workers, learning disability nurses, psychiatrists, psychologists and a range of other therapists.

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:** as well as local professionals and CAMHS, some groups have specialist knowledge, like the National Autistic Society (see page 27). For children and young people with severe learning difficulties, the Challenging Behaviour Foundation can help (see page 25).

## Sleep problems

Many children have problems around sleep and bedtime. These are common in all 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 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 has a free guide for parents *Helping your child sleep*, (also translated into six community languages) available from our freephone helpline on 0808 808 3555.

### Who can help:

Cerebra, Sleep Scotland, The Children's Sleep Charity.

## 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:** Contact a Family, occupational therapist. The Disabled Living Foundation and Fledglings have clothing solutions/equipment that may be useful (see page 26).

## Self-harming

Having 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 to help them manage this.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

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
- 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.



## 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 who have transferred from primary to secondary education will have appropriate, on-going support in place. But children who have had good support in primary school may 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.

Behaviour becoming more challenging 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 you feel your child is not receiving appropriate support at school, ask to speak to the person responsible for supporting children with additional needs in your child's school. Or call our Education Advice Service on 0808 808 3555. Our parent advisers can tell you about support your child may be able to get in school.

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.

### **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.

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.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

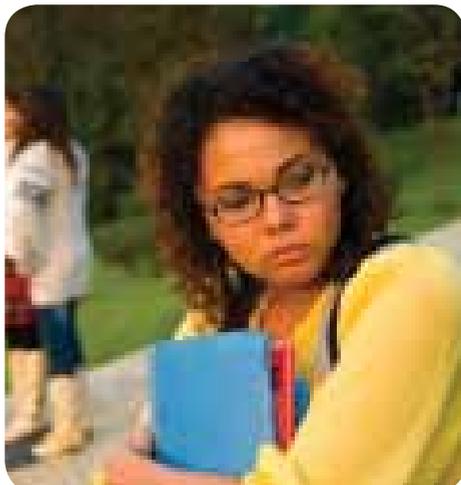
## Emotions and mental health

Sometimes you, or the professionals working with your child, may notice other emotional and behavioural 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 your local Child and Adolescent Mental Health Services (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 (see the 'Useful Organisations' section from page 25). 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 that challenges 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) is important. The National Autistic Society produces information cards which can be carried by a young person with communication difficulties 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

## Help with school

### England and Wales

#### Parent Partnership Services

Give 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](http://www.parentpartnership.org.uk)

#### SNAP Cymru

Charity working throughout Wales giving advice, information and support to families, young people and professionals around additional learning needs and disabilities. They can help with choosing a school, getting support for your child in school and help resolve disputes. They also have an advocacy service for children and young people. Helpline: 0845 1203730  
<http://www.snapcymru.org>

### Northern Ireland

#### The Special Educational Needs Advice Centre (SENAC)

in Northern Ireland, 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](http://www.senac.co.uk)

### 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 call our Education Advice Service on 0808 808 3555. Our parent advisers can tell you about the help school should be providing at any age.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

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 young people getting involved in crime or re-offending. They are generally well aware that young people with special 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. Social services are responsible for dealing 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 offer advocacy services and advice about legal rights. Call our freephone helpline on 0808 808 3555 and we can tell you where your nearest advice service is.

## Setting up a circle of friends to support your child

If your child is experiencing difficulties because of their disability or their 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/circle-of-friends](http://www.inclusive-solutions.com/circle-of-friends).

**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 your child is arrested, it is important that you make their solicitor aware of any disability or illness and what this means for the child, for example, any link with behaviour that challenges, 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 behaviour that challenges.

There are a large number of professionals and other sources of support that 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 may also help, as well as condition support groups, parent-led and other types of support groups.



## People who can help you

**Support groups:** They may be local (covering a certain area or region), national or even international. They may be a generic (for all parents of children with any additional need), or condition groups (for example, for parents of a child with ADHD or Fragile X syndrome). Support groups offer a different services according to their size.

Even if you do not meet a parent of a child with the same needs as your child, you may still find it helpful to share experiences with other parents. Condition 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

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

offer a wealth of other services according to their size.

Please call our freephone 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](http://www.makingcontact.org) or our lively Facebook page.

**Professionals:** the assessment of and advice about the successful management of behaviour that challenges often needs a multi-disciplinary approach. In this guide, we have made reference to several different professionals and services including:

**Clinical psychologist:** will look at the child's behaviour, assess its causes and discuss practical strategies you can use.

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

**Educational psychologist:** behaviour that challenges may occur in different settings, including nurseries or school. Children can be referred by the parents, health professional, nursery or school to an educational psychologist to look at setting up strategies to help with behaviour.

**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:** health visitors are likely to have had face-to-face contact with you and your child and will have experience and expertise in the management of common problems in childhood. Health visitors can also work with colleagues from other agencies (such as portage and early years service) to contribute to support for your child.

**Occupational therapists:** can provide advice on practical issues for children whose behaviour that challenges may be linked to a need for support in developing physical coordination and mobility.

**Paediatrician:** a child's paediatrician may offer advice on how to deal with behaviour that challenges or refer your child to any of the other professionals in this guide.

**Paediatric nurse:** often come across different behaviours in their working with children who are ill or disabled. They can have a wide range of knowledge and suggestions to help.

**Physiotherapist:** 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:** may be able to help children whose behaviour is linked with mental health issues.

**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:** can offer strategies around communication that may help to improve a child's interpretation of some situations.

**Social workers:** 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](http://www.bps.org.uk)

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

#### Challenging Behaviour Foundation

Family Support Network:

0845 602 7885

[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

Information and advice for families caring for, or individuals with, severe learning disabilities (both children and adults) who display behaviour that challenges.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://www.cafamily.org.uk)**

## 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](http://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 7089 5050

Helpline for parents: 0808 802 5544

[www.youngminds.org.uk](http://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

### Carers Trust

Tel: 0844 800 4361 (England)

Tel: 0300 123 2008 (Scotland)

Tel: 029 2009 0087 (Wales)

[www.carers.org](http://www.carers.org)

The Carers Trust has branches 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](http://www.carersuk.org)

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

## Continence

### ERIC (Education and Resources for Improving Childhood Continence)

Tel: 0117 960 3060

Helpline: 0845 370 8008

[www.eric.org.uk](http://www.eric.org.uk)

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

## Equipment

### Disabled Living Foundation (DLF)

Tel: 020 7289 6111

Helpline: 0300 999 0004

[www.livingmadeeasy.org.uk/children](http://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

Helpline: 0845 458 1124

[www.fledglings.org.uk](http://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.

## Communication

### Picture Exchange Communication System (PECS)

Tel: 01273 609 555

[www.pecs-uk.com](http://www.pecs-uk.com)

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 PECS courses, and their website has a wealth of information on PECS. You can buy many resources from their website.

Other picture and symbol websites that are free of charge include:

[www.do2learn.com](http://www.do2learn.com)

[www.symbolworld.org](http://www.symbolworld.org)

<http://pdictionary.com>

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

### The Makaton Charity

Tel: 01276 606 760

[www.makaton.org](http://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: 0808 800 4104  
(freephone)

[www.autism.org.uk](http://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

Helpline: 0808 802 1234

[www.brook.org.uk](http://www.brook.org.uk)

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

### Siblings

#### Sibs

Tel: 01535 645 453

[www.sibs.org.uk](http://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.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://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 ask a friend or family member to come along and take your child 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
- 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 people.

## **Youngcarers.net**

[www.youngcarers.net](http://www.youngcarers.net)

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

## **Sleeping**

### **Cerebra**

Tel: 01267 244 200

General Helpline: 0808 328 1159

Sleep Assistant: 01267 244 210

[www.cerebra.org.uk](http://www.cerebra.org.uk)

Cerebra have resources for help with managing sleep issues for children with brain related conditions. Trained phone counsellors can give advice, and sleep practitioners may be able to visit your home, or you may be able to go to a sleep clinic near you.

### **The Children's Sleep Charity**

[www.thechildrenssleepcharity.org.uk/](http://www.thechildrenssleepcharity.org.uk/)

Offers training around sleep for parents and professionals.

### **Sleep Scotland**

Tel: 0131 651 1392

[www.sleepscotland.org](http://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.scope.org.uk/face2face](http://www.scope.org.uk/face2face)

As well as providing information and workshops on sleep, Scope have trained sleep counsellors in England.

## **Organisations with support groups for specific conditions that can help**

There are more than 400 medical conditions and disabilities listed on the Contact a Family website, 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 medical information on our website at [www.cafamily.org.uk](http://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 on our website, 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.

Freephone helpline: **0808 808 3555**  
**[www.cafamily.org.uk](http://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: 08449 744 099

[www.familyfund.org.uk](http://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

Email: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

[www.cafamily.org.uk](http://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 condition 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](http://www.makingcontact.org). 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/resourcelibrary](http://www.cafamily.org.uk/resourcelibrary) or by calling our helpline.

## **Acknowledgements**

Contact a Family would like to thank the Challenging Behaviour Foundation for their comments on this guide.

This guide was contributed to and agreed by the Royal College of Psychiatrists' Child and Family Public Education Editorial Board.

Written by Pauline Shelley  
with contributions from Sheila  
Davies, Carmel McDermott and  
Karin Beeler.

### **Social networking**

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

#### **Facebook**

[www.facebook.com/contactafamily](http://www.facebook.com/contactafamily)

#### **Twitter**

[www.twitter.com/contactafamily](http://www.twitter.com/contactafamily)

#### **Videos**

You can watch videos on our  
YouTube channel at:

[www.youtube.com/cafamily](http://www.youtube.com/cafamily)

## Getting in contact with us

Free helpline for parents and families

**0808 808 3555**

Open Monday to Friday,  
9.30am–5pm

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 for parents and professionals. Guides include:

- Concerned about your child? (UK)
- Relationships (UK)
- Siblings (UK)
- Fathers (UK)
- Special educational needs (England)
- Benefits, tax credits and other financial help (UK)
- Holidays, play and leisure (UK)

All Contact a Family publications can be downloaded from our website [www.cafamily.org.uk](http://www.cafamily.org.uk)

Registered Office: 209–211 City Road,  
London EC1V 1JN  
Registered Charity Number: 284912  
Charity registered in Scotland No. SC039169  
Company limited by guarantee  
Registered in England and Wales No. 1633333  
VAT Registration No. GB 749 3846 82

© Contact a Family is a registered trade mark  
Although great care has been taken in the  
compilation and preparation of this guide to  
ensure accuracy, Contact a Family cannot take any  
responsibility for any errors or omissions.  
The photographs in this booklet do not relate to any  
personal accounts.