

connected

For families with disabled children and all those who work with them



A problem shared

THE IMPORTANCE OF MEETING UP WITH OTHER PARENTS

OUR CAMPAIGNS
How you can help us campaign for better services for families

NEWS FROM THE NATIONS
Our photo exhibition in Scotland and new social care law for Wales

CONFUSED ABOUT YOUR CHILD'S EDUCATION?
Our education advisers help you make sense of it

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connected magazine

Edited by Karin Beeler, Tom Bobbin, Michele Cefai & John Clarkson

✉ library.team@cafamily.org.uk Design johnclarksondesign.co.uk Print RAP Spiderweb Ltd

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contact a family
for families with disabled children

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

Contact a Family
209–211 City Road, London EC1V 1JN
020 7608 8700
info@cafamily.org.uk

Contact a Family Northern Ireland
63-75 Duncairn Gardens, Belfast BT15 2GB
028 9262 7552
nireland.office@cafamily.org.uk

Contact a Family Scotland
Craigmillar Social Enterprise & Arts Centre
11/9 Harewood Road, Edinburgh EH16 4NT
0131 659 2930
scotland.office@cafamily.org.uk

Contact a Family Cymru
33–35 Cathedral Road, Cardiff CF11 9HB
029 2039 6624
cymru@cafamily.org.uk

Contact a Family North East England
The Dene Centre, Castle Farm Road
Newcastle upon Tyne NE3 1PH
0191 213 6300
northeast.office@cafamily.org.uk

Contact a Family Midlands
Prospect Hall, 12 College Walk
Selly Oak, Birmingham B29 6LE
0121 415 4624
westmids.office@cafamily.org.uk

Contact a Family Ealing and Southall
Lido Centre, 63 Mattock Lane,
London W13 9LA
020 8280 2267
ealingandsouthall@cafamily.org.uk

Contact a Family Ealing and Southall
St. Georges Community Centre
8–12 Lancaster Road, Southall UB1 1NW
020 8571 6381
ealingandsouthall@cafamily.org.uk

Contact a Family Lambeth
Weare336 Brixton Road, London SW9 7AA
020 7326 5270
lambeth.office@cafamily.org.uk

Contact a Family Lewisham
Leemore Central Community Hub
Bonfield Road London SE13 5EU
020 8297 8056
lewisham.office@cafamily.org.uk

Contact a Family Southwark
Cambridge House, 1 Addington Square
London SE5 0HF
020 7358 7799
southwark.office@cafamily.org.uk

Contact a Family Wandsworth
1 Siward Road, London SW17 0LA
020 8947 5260, Fax: 020 8947 9506
wandsworth.office@cafamily.org.uk

All in it together

Update from our Chief Executive Officer
Amanda Batten



Someone said to me recently that when you are a parent of a disabled child, you come across all these other families, and it is like finding out there is this club you didn't know about, but once you find it, you realise that all the best people are in it.

At Contact a Family we are in on the secret, which is why a lot of what we do is about supporting families to get together. There are lots of stories in this edition about this, from forums and support groups, to families who know how important peer support is for all of us. And when it comes to being all in it together, we can all support other families in loads of different ways – from sharing knowledge or information, to providing a listening ear, or by just being there. There are other ways to show support too, including fundraising, so that support is available for those who need it.

Unfortunately, Contact a Family doesn't run on fresh air. We are a charity and we need support if we are to continue to be able to do the work we do. That's why this September I'll be doing the Thames Path Challenge, to do my bit on a personal level for our fundraising efforts. Our chairman Paul Streets and members of our senior management team are doing it with me. So I wondered if you might like to join us? You can walk 25km (16 miles) or the whole 100km (60 miles!) along the river path, raise a bit of money for our family support work, and have a chat along the way. If you are interested, email me at amanda.batten@cafamily.org.uk or fundraising@cafamily.org.uk or call 020 7608 8786. If this isn't for you then keep an eye out for more fundraising ideas in the near future.

“ Sharing knowledge or information, providing a listening ear and just being there. ”

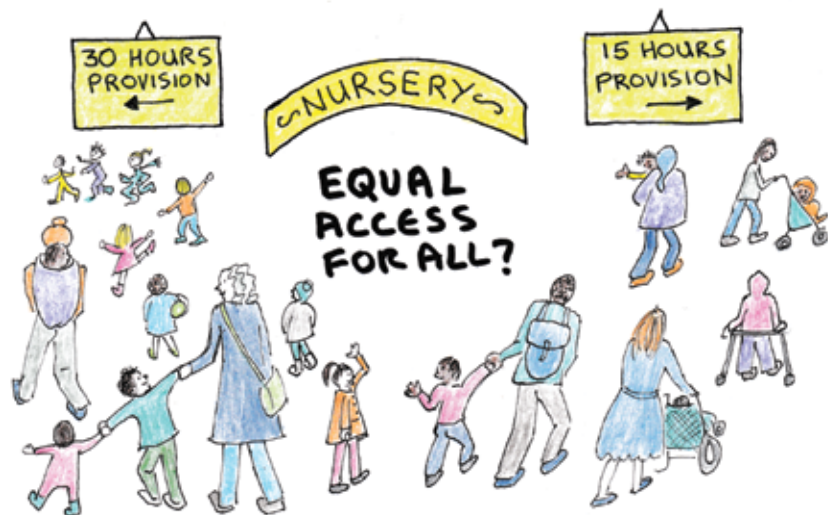
Amanda

Childcare providers turning away disabled children

The Childcare Act 2016 (England) means from September 2017, working parents of three- and four-year-olds will get 30 hours of free childcare a week (for 38 weeks of the year). This sounds like good news for many families, however our survey of parents who care for young disabled children shows that 40 per cent of families with disabled children are not accessing the current free entitlement of 15 hours a week. That's ten times more than families with non-disabled children.

Parents told us they are often asked to pay excessively high fees and the choice of suitable settings is limited at best. At the same time there is a significant shortfall of the knowledge and skills needed to provide quality care and education to disabled children in the childcare and early years' workforce.

Siobhan Bain from Southwark is mum to three-year-old Fintan, who has a variety of undiagnosed disorders and global development delay. She sums up the problems: "I have been discouraged by many of the attitudes that I have encountered while trying to find suitable childcare for Fintan. He has been rejected outright by certain childcare providers as soon as his additional needs were mentioned. Others have been unable to seek funding for the 1:1 care Fintan requires.



"I currently pay for a full time nanny for my children rather than take up the government's offer of 15 hours free childcare per week due to a lack of suitable facilities in my local area. No attempt has been made to address the glaring gap in provision of wrap-around care and pre-school care

for disabled children such as Fintan."

Thanks to your help supporting our childcare campaign *Levelling the playing field*, the government has said it will be looking at the issues that make it difficult for parents with disabled children to access the new 30 hours of free childcare.

Have you been refused childcare?

There are laws around childcare that local authorities and childcare providers must follow. If you are refused childcare you can use the law to help you change the decision. We have put together three template letters for you to use, based on the most common barriers to accessing childcare for disabled children, and what can or can't be done to overcome them.

Download the template letter at www.cafamily.org.uk/refused-childcare or call our helpline on 0808 808 3555, who can send you a free copy

Help us campaign to save short breaks services

Short breaks are a life line for families with disabled children, and our latest campaign is aimed at stopping the cuts to these vital services. Can you write to the person in charge of funding decisions at your council to tell them why short breaks matter, and why they shouldn't be cut? Visit www.cafamily.org.uk/campaigning If short breaks are being cut in your area, we have template letters that you, or a local group you're involved in, can use to write to your local authority to challenge this. See page 13 of our guide, **Challenging cuts to short breaks services**. Our free factsheet **Short breaks – how you and your family can benefit** also explains your rights to short breaks services. They are available free from our helpline on 0808 808 3555, email helpline@cafamily.org.uk or download them free from www.cafamily.org.uk.

Explaining disability to children

The *Tale of Me* website has been developed by Professor Alastair Sutcliffe, and aims to provide family-friendly stories which young children aged 6+ can understand. It has examples of conditions which affect children, creates characters out of the conditions and then makes the characters real. The character is then involved in a story that is suitable for a young child to read, to help them understand their illness.

The stories are created by volunteer medical students, and they were given some initial artist support from an illustration company. Professor Sutcliffe says, "One thing we have in mind is not only for children to write their own stories about their own illnesses, and their parents, but also siblings giving their views too. It is important such a resource is accurate and so we would still expect the initial characters to be created by our volunteer undergraduates.

"Each child with a different illness will, in time, have chance to have story about their illness."

Professor Sutcliffe is a paediatrician and young people's doctor at University College London with 25 years' experience. He started the project with Dr Anna Waldie, driven by the needs of families and their children.

www.thetaleofme.com



Professor Sutcliffe and patient



Love, Life and Laughter – My Family exhibition

Contact a Family Scotland is hosting a photographic exhibition in Edinburgh for families and donors, showcasing the diversity and strengths of families with a disabled child in Scotland.

We will be showing images from families across Scotland who have shared their family photos and stories for the exhibition, alongside the work of award-winning photographer Rebecca Lee. Rebecca spent a day with two families, capturing the special and everyday moments in their lives. We will share more of these wonderful images with you in the next edition of *Connected*.

New law to improve social care for children in Wales

On 6 April 2016, the Social Services and Well-being (Wales) Act came into force. It means that for the first time, there is separate social care legislation for Wales. The new law aims to improve the wellbeing of people (children, adults and older people) who need personal care and support, and for carers who need support.

This new law will directly affect families with disabled children in Wales. The Act imposes a duty on councils in Wales to assess the needs of carers who are providing, or intending to provide, care for a disabled child. The Act removes the requirement in the previous legislation that carers should be providing a 'substantial amount of care on a regular basis' to have an assessment. This means families will be entitled to an assessment of needs as a carer regardless of level of need, the amount of care provided, whether or not the child cared for has had an assessment, and even if the child has been considered ineligible for support. The Act also confirms there will be no upper or lower age limit to being recognised as a carer.

The Act will also affect the assessment and care process for children with disabilities and additional needs. Under the Act, all children in need are eligible for a social care assessment, and importantly the Act states that there is a presumption that disabled children have needs for such care and support. The needs assessment takes into account the outcomes the child would like to achieve and the outcomes their parents would like them to achieve, and determines whether care and support services can contribute to meeting these outcomes. The assessment will consider the child's circumstances, capabilities, any barriers to meeting their outcomes and any risks if they are not met. Councils can combine a children's assessment and a carer's assessment if it is beneficial to do so.

For more about the Act visit www.ccwales.org.uk/the-act

If you have questions on how the Act could affect your family, call our freephone helpline on 0808 808 3555.

Help at hand in hospital

Through Contact a Family's new Hospitals and Hospices Project in England, we can now give advice, information and emotional support to families in hospitals and hospices. Our parent advisers are there to help families navigate their way through the maze of different organisations and difficult terminology, and offer advice and information in certain areas such as welfare, benefits and education.



Midlands

Meet our parent adviser Emma at our drop-in session each month at the Patient Experience Hub at Birmingham Children's Hospital. Helen (left), our volunteer, also helps out on our information stands in the main outpatients area of the hospital every Tuesday morning. Contact Emma Taylor on 0121 415 4624 / 07920 655003 or email emma.taylor@cafamily.org.uk




North East

We hold a monthly information stand outside children's outpatients/child development at the Great North Children's Hospital. Families can drop in or contact Kathleen on 0191 213 6300 / 0773 8896474, or email kathleen.ingleby@cafamily.org.uk



London

Ruth is at Great Ormond Street Hospital for Sick Children (GOSH) on Thursdays every week in the social work department. We also have an information stand. Please drop by and say hello! We are also at the Evelina London Children's Hospital on Mondays in the outpatients clinic. Drop by, or contact Ruth Stone on 020 7608 8729 / 07920 654 863 or email ruth.stone@cafamily.org.uk

 To find out what's happening in your local area, please call our free helpline 0808 808 3555 or visit the 'in your area' pages of our website at www.cafamily.org.uk/inyourarea


Confused about the changes to education in England? We can help!


We have a dedicated team of Contact a Family parent advisers working in every region in England, delivering special educational needs and disability (SEND) information sessions, workshops and events for parents.


We can help make sure parents of children with SEND understand the changes so they feel less confused and more able to make informed choices with, and on behalf of, their child. At the same time we aim to help disabled children and young people get the best education and achieve their goals.

The project will work alongside what we currently offer families through our education helpline and online services, enhancing what we offer families over the phone and online, with our team of parent advisors working face-to-face with families.

We've also produced free factsheets for parents about the extra help children may be entitled to in education, and how to access it. They are available on our website, or by calling our helpline on 0808 808 3555 or emailing helpline@cafamily.org.uk

 To find out about our information workshops and events in your area please visit the 'in your area' pages of our website www.cafamily.org.uk/inyourarea

 Questions about your child's education? Call our free helpline on 0808 808 3555.

 Download our education factsheets free at www.cafamily.org.uk/the-sen-process or you can ask the parent advisers on our helpline to send you a copy.

Benefit changes from April 2016

A number of changes came into force in April affecting the benefits system. Most apply across the whole of the UK but some may be delayed in Northern Ireland. Our benefits expert **Derek Sinclair** explains some of the changes.

National living wage and Carer's Allowance

A new national living wage of £7.20 per hour was introduced in April for adults aged 25 and over. This means a parent working 16 hours should now have minimum earnings of £115.20 per week. Unfortunately, this will mean some parents no longer qualify for Carer's Allowance – as it has an earnings limit of £110 per week. Some parents will be tempted to drop their hours so that their earnings are below the limit, but cutting your hours to below 16 hours may mean you no longer qualify for Working Tax Credit.

When calculating earnings for Carer's Allowance, certain expenses can be deducted, including half of anything paid to a pension scheme, and certain care costs, for example, paying someone to care for children while you are working. Starting to have such costs may help you to keep your Carer's Allowance, without needing to cut your hours. Contact our helpline for further advice on 0808 808 3555.

Cut in 'income rise disregard' for tax credits

Before April, if your annual income increased, the Tax Credit Office ignored the first £5,000 of that increase until the following tax year. Now only the first £2,500 of an increase in your income is ignored. As a result, more families are likely to have tax credit overpayments.

The amount that can be deducted from your tax credit award if you have been overpaid in a previous year, has also increased from 25 per cent to 50 per cent of your award. This increase only applies if your income is over £20,000.

Cuts to Housing Benefit

The family premium is an amount included in Housing Benefit calculations for private or social housing tenants with dependent children. This is no longer being included in new claims made on or after 1 May, or for existing Housing Benefit claimants who have their first child after that date. This means many families making new claims will get less Housing Benefit. Backdating of Housing Benefit is also to be restricted to four weeks.

Longer wait for help with mortgage interest

Home owners claiming certain means-tested benefits can get help with paying their mortgage interest. In April the waiting time before these payments start to be included was increased from 13 to 39 weeks.

Roll-out of Universal Credit

Universal Credit will replace all means-tested benefits and tax credits for people of working age. Up until now families with disabled children have been exempt from Universal Credit in most parts of the country. However, during the rest of 2016 the government will roll out the full Universal Credit digital service to an increasing number of areas.

You will be asked to claim Universal Credit if:

- you are in one of the areas where the 'digital service' applies

AND

- you make a new claim for one of the means-tested benefits or tax credits that Universal Credit is replacing.

This applies to everyone making a new claim in one of these 'digital service' areas – including families with disabled children. See our website for details of the areas where this will apply.



For advice about these changes or any other benefits issue call our free helpline
0808 808 3555



contact a family
for families with disabled children

JOIN US ON THE Thames Path Challenge!

10-11 September

Join our CEO Amanda,
Chairman Paul and others
in the Contact a Family
team and help raise
funds for our vital life-
changing services.

The Thames Path Challenge offers something for all abilities. Choose the distance that suits you best – 100km, 72km, 50km or 25km – and do it at your own pace, walking, running or a bit of both.

To find out more and sign up contact our fundraising team today:

☎ **020 7608 8786**

✉ **fundraising@cafamily.org.uk**

🌐 **www.cafamily.org.uk/thamespath**



Parents from our Lewisham office held a fundraising cake sale to help us raise funds in Lewisham Shopping Centre. Our London projects provide vital advice and information and also family fun days and trips throughout the year.



If you have a fundraising idea or would like to take part in one of our challenges, please get in touch today.

020 7608 8786

fundraising@cafamily.org.uk



Tina Emery from Somerset Parent Carer forum presented a workshop with Sarah Hayes from the LA and Shane Dangar, who explained how disabled young people are involved in decision making in Somerset

Workshops guide local authorities through education reforms

Parent carers from forums across England teamed up with the Department for Education's national partner, Mott McDonald, to present a series of workshops on producing quality Education, Health and Care (EHC) plans.

Parent carers gave presentations about how they worked with local authorities to make sure EHC assessments and plans meet the needs of disabled children and young people. They explained how local authorities, parent carers and young people can work together to agree aspirational outcomes for children and young people.

Download training materials from the workshops from www.sendpathfinder.co.uk/education-health-and-care-plan-workshops.

You can also watch a presentation explaining what good 'outcomes' are for disabled children, made by one of the parents involved: <https://youtu.be/K6rBkVpCnqc>



Edward Timpson meets members of the NNPCF

National Network takes parent carers' views to government

In December, local forums and parent representatives from the National Network of Parent Carer Forums (NNPCF) met with the government to talk about the progress of the special educational needs (SEN) reforms.

Parent carers met with the Minister of state for children and families, Edward Timpson, and director for children, families and communities at the Department of Health, Flora Goldhill. The meeting gave parents the chance to share their experiences directly, and it allowed the Minister to hear about the progress of the recent changes.

The group discussed accountability, Education, Health and Care plans, moving into adulthood, SEN support, health and social care and the local offer. Parents shared what is working in their area, raised concerns and put forward suggestions for building upon things that had worked well.

To find out more about the NNPCF and its work, visit www.nnpcf.org.uk

Awards for forum members

Gail Hall has been awarded a British Empire Medal in the Queen's New Year's Honours list in recognition of over seven years of outstanding dedicated work with parent carer forum Warrington Parents and Carers.

Gail (right, centre) acknowledged that she could not have achieved it without the support of her fellow



forum colleagues who share her passion for making a difference to the lives of disabled children and young people.

Well done also Rachel Trueman (left), the CEO of South Glos Parents and Carers, who received the Prime Minister's Point of Light award. The daily award recognises outstanding individuals who are making a change in their community.



“ I would have benefited from parents’ support because when my son was diagnosed in 2012, I felt lost. I did not know what to do and I could not come to terms with the fact that my little baby had a disability. ”

“ I know from personal experience that other parents tend to trust and listen to someone who has experienced what they are experiencing. ”

“ Parents want to talk to someone who knows, sees, feels, talks and lives with special needs or physical disabilities, because for us it is a way of life. ”

A problem shared is a problem halved

Our theme this edition of *Connected* is ‘family linking’. *Contact a Family* was born from the need of families with disabled children to ease the problems of isolation they experienced. Linking families together is the cornerstone of all we do. **Noreen Siba (Miller)**, our founder and first director from 1979–1988, recalls how it all started

It may be hard to believe that the *Contact a Family* you know now started with two small self-help groups for families with disabled children in Wandsworth and Ealing in 1974, run by the charity *Make Children Happy*. Three or four families first met in the Balham/Tooting area and gradually the group grew to thirty families meeting at weekends and holiday time. Parents usually met every week in each other’s home to support one another and plan the group’s events. These expanded to include swimming lessons, a sibling group and holidays away in an adventure centre in Burwash, East Sussex. So much fun was had by all ages, lots of escapades and happy times, especially in the long six week summer holiday when we met nearly every day, come rain or shine! A while later a group started in Battersea and then in Putney and Southfields, helping over 100 families in total.

However, the whole project nearly collapsed in 1979 when *Make Children Happy* closed down.

Luckily a film had been made of our success in Wandsworth and parents rallied together to hold a public meeting. There was a lot of local and national publicity and Wandsworth council came through with a large grant to save the project. Just in time to achieve the same in Ealing, and respond to enquiries to set up similar groups nationwide. I managed to form a separate charity *Contact a Family*. It was an amazing experience to save the original groups and go on to set up as a national charity. National interest led to more projects being set up and soon there were demands from all over the country, especially from parents whose children had rare syndromes.

It was such an exciting time and hugely satisfying to know how many families were getting support. So many had such a great sense of humour and optimism despite their hardships. Our motto ‘A problem shared is a problem halved’ certainly kept us all going through those early years.



Marie (second right) and families meet their local MP

“ If I could help just one family to get the support they needed then it would be worth doing. ”

Supporting the family, in as many ways as we can

Marie tells how her search to find families in the same situation led to her becoming chair of her local support group

My husband Richard and I live in Seaton in Cumbria and have two boys, aged 6 and 13. I work part time as a senior teaching assistant in a local junior school.

My eldest son has ADHD. We were having a particularly difficult time with him and I asked the CAMHS nurse if there were any one-to-one sessions or counselling services that we could access. I distinctly remember her reply.

“No. There is me, the doctor and a caseload of 500. I would love to run a support session, but there is just no time. You can register with your local children’s centre.”

I took her advice. Then I started scouring newspapers and online resources for any events where I might be likely to run into parents with similar experiences. I was certain that it couldn’t just be our family banging our heads against a brick wall. And that’s how I bumped into Rachael, the outgoing chair of ADHD West Cumbria. We got chatting and it was then and there that my journey as chair began!

I know how difficult it can be to navigate complex systems and procedures, the endless paperwork and the confusing terminology that goes along with it all. My aim was that if I could help just one family to get the support they needed then it would be worth doing. I started to publicise the group as much as I could. A colleague built the website and I made a list of local schools and visited each one in turn with our leaflets and my card. I contacted the local press just before our first meeting. Slowly, the group started to grow.

We hold monthly drop-ins for parents to come along and have a chat, a cuppa, get some advice, or just sit and listen to

the experiences of others. It’s so good to see the relief in parents’ faces when they realise that they are not alone, and that many of the things they are worried about, we have also experienced.

I wanted to do something for the children too so I decided to have a kids’ session. Before our first activity I remember thinking to myself, “...a room full of kids with ADHD, am I crazy?” but it was great and they all got on well. We always invite siblings as it is important that they too have access to any additional support or guidance that they might need. It’s about supporting the whole family, in as many ways as we can.

I am no stranger to the demands of raising a child with ADHD or additional needs. I know first-hand how hard it is to be made to feel that I am somehow responsible for my son’s difficulties, and to be pushed from person to person in search of answers. I know from bitter experience the pain and sheer exhaustion. When no one seems to listen and no one understands the frustration of not knowing how best to help your child.

For a long time our family dealt with these issues alone, but hopefully now others don’t have to. We don’t have all the answers, or a magic wand. But you’d be amazed at how much it helps.

ADHD West Cumbria is a support group for children with ADHD, autism and special educational needs and their families www.adhdcumbria.org.uk



Harrison and his brother

Helping us help each other

Gloucester mum Leonie tells us how joining her local parent carer forum helped her feel less isolated, and gave her the opportunity to help other families with disabled children in her community.

When my son Harrison was diagnosed with Down syndrome it was a total shock. Although I'd worked as a paediatric nurse for 15 years I struggled to come to terms with his diagnosis and what the future might hold.

I joined my local parent carer forum in South Gloucestershire soon after Harrison was born, to get out of the house and meet people. I'd lost a lot of confidence but wanted to challenge myself by making a difference and giving something back. I was very nervous at that first meeting, but I needn't have worried – the eight parents there were very welcoming.

Five years later, and I now help recruit and look after our volunteers for the forum. Our volunteers are local parents of disabled children, who help spread the word about the forum, and encourage other parents to get involved in any way they can.

From little acorns...

Numbers at meetings varied at first, between 2 and 15 parents. Sometimes I felt deflated if not many people attended, but I persevered and our numbers have steadily grown! Over 100 people attended our last annual conference, where another eight people approached our volunteer stall wanting to be actively involved.

Our parent volunteer numbers have grown from 12 in 2013, to 50 active volunteers today. Having a dedicated person to support volunteers and provide training helps people's confidence. And we emphasise that being part of a forum really can help parents' mental health and wellbeing. Being able to give something back – and not just focus on your own child – can really help you cope.

An army of ambassadors

Parents who can only offer a little bit of time can still help us by acting as ambassadors. The idea for the role came from thinking there must be lots of people like my husband, Steve, taking a child to pre-school or church, who could give other parents information and let them know we are there for them.

Steve says: "The news of Harrison's diagnosis came as a complete shock. However, as time has gone by, I wouldn't change the way he is. He is our ray of sunlight. Along the way I've had help from others and now I feel I want to give something back. I have lots of contact with other parents as my job involves going into people's houses. This gives me the perfect opportunity to carry out my ambassador role."

Some parents end up becoming friends outside of the forum. We aim to provide a community feel for parent carers because having a good network in place can help everyone feel less isolated.

Together we stand

Aicha fled from violence with her daughter, who has autism, and joined our team of parent champions – all parents of disabled children who volunteer to tell other parents about help available. She tells her harrowing story here

First, I don't see myself as a champion, but a loving mother who is passionate and proactive in raising my child. My belief that my daughter has the right to live like every other child is my drive to work harder and keep looking for ways to enable her fulfil her potential.

I moved to the UK from Morocco in January 2008 to be with my husband. I couldn't speak English, and had no family or friends in the UK. My daughter was born in August that year. By the time she was one, she wasn't showing normal baby behaviour, so I found a 'chatter box' group in the children's centre I used to go to. They referred her to the child development centre. I got an appointment in June 2010, and was told immediately that she's autistic and has severe learning difficulties.

Her dad reacted negatively to her diagnosis. Worse, his brother lived with us at the time, so I wasn't allowed to cry, because her dad didn't want him to know – or anyone else. I was blamed for everything. I started to go out and look for possible help anywhere, but the situation at home was escalating,, and in February 2012 I fled from violence to a refuge.

Finding my feet

The journey wasn't smooth, between court hearings, appointments and no childcare, and being a stranger with no British passport. I had to still be positive and find happiness. My daughter was completely silent at that time, all she did was scream, she still used nappies and a buggy. The first

refuge was busy, unfriendly and the ladies couldn't understand my daughter's situation. The schools didn't want to have her. I was alone most of the time, and I used to look for families of verbal autistic girls – which aren't many – just to listen to them and find how my daughter's voice could sound. Without many charities, I wouldn't be here... maybe I would have killed myself.

Finally, I managed to find room in the Greenwich refuge, and my life started from there. I got a house in April 2013 and my daughter started school a few months later. The school is great, she started to say "mummy," and a year later stopped the buggy and gradually reduced the nappies.

in girls is vital to me. I'm looking for answers to questions like: Would my daughter understand that she is a girl? Would she behave like one? Will she ever understand what Mother's Day is? Some of the best help I've ever received has been from fellow parents, who have been very honest with me. The best advice I was given? Hard – all of them! But I'll pick one – don't try to change your daughter , accept her as she is!

Give unto others...

When I interact with other mothers, I see myself in every woman who's struggling with the English language. I see myself in every woman going through a violent relationship, or those

“ Some of the best help I've ever received has been from fellow parents... meeting families dealing with autism in girls is vital to me ”

It's important for parents of disabled children to get together to help each other – no one can know everything. We need to battle to make the world understand that making a place disability-friendly doesn't only mean having a ramp for a wheelchair user! And not every autistic child is Albert Einstein! More than that we need to build a system with the right support for our children. My daughter's world is still undiscovered for me, so meeting families dealing with autism

who are isolated and insecure. For these reasons becoming a parent champion seemed the perfect way I could give back to the community and support other parents as I have been supported.

It's hard when you are a young Muslim woman, a single parent, and without hijab... My impulse is driven by gratitude to every parent or person I've met who shared not only their experience and advice, but who have been a great inspiration.

FREE

contact a family
for families with disabled children

Resources for you and your family

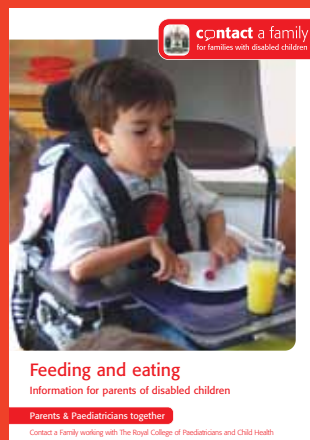
We have a range of guides to help with your child's behaviour



Understanding your child's behaviour

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. We look at:

- why children behave in different ways?
- behaviour as a form of communication
- setting the scene for good behaviour
- recognising triggers and finding strategies
- who can help and much more.



Feeding and eating

If a child refuses food or has difficulty with eating, it can leave parents feeling very anxious, helpless and frustrated. A disabled child can have difficulty feeding for several reasons. Perseverance and patience can often be needed so mealtimes do not become a battle ground. Our short guide, written with the The Royal College of Paediatricians and Child Health, lists some of the possible causes of problems, plus hints and tips around mealtimes and where to go for help.



Potty and toilet training

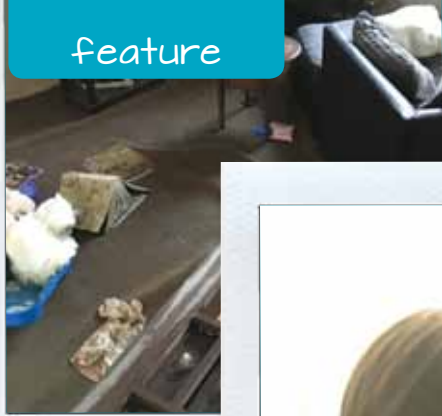
If your child has a physical or learning disability they may not be ready to start learning to use the potty or toilet until they are older. They may also need longer to learn to use it. Our guide for parents explains what we mean by toilet training and when you should start. It also has information for parents of children who find it hard to communicate and what to do if your child takes longer to learn to use the toilet, plus useful contacts.



Helping your child sleep

A child that doesn't sleep well affects the whole family. Exhaustion kicks in, you can't think clearly and brothers and sisters are also affected. Many parents say they feel caught in a vicious cycle struggling to cope – if you're experiencing difficulties, you're not alone. There are many reasons disabled children have difficulties with sleep, and there are different strategies and approaches to helping children sleep you can try. Our guide is packed with information and tips from parents and experts.

 All our publications are free to family members who call our helpline **0808 808 3555**
They are free to download from **www.cafamily.org.uk/publicationslist**



Saskia and me, Saskia with a chocolatey smile



The flood



Skye and me



Skye, 17, and Saskia on her 16th



Terry.

Swept away

Rachael and her daughter Saskia were overwhelmed by help from strangers when 47 years of life in their flat was destroyed by Hurricane Desmond. Read their inspiring story here

How time flies – Saskia is now 17! I had downsized and moved due to the bedroom tax, and the next hurdle was getting Saskia's Personal Independence Payment. I gave them loads of information, but they still sent out an assessor. The assessor said she didn't know why they had sent her out as there was definitely enough information on the form. To cut a long story short, Saskia became excited that we had a visitor and pinned me to the floor. The assessor turned round and said she had seen enough and promptly left! Within two weeks I received a letter saying that Saskia had got the highest rate and the car.

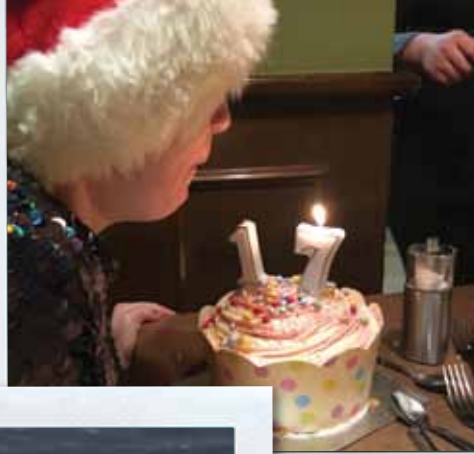
December 5 I had a phone call. Hurricane Desmond had happened and my flat was under 4ft of water. Because I was on the ground floor I had

lost everything: white goods, furniture, clothes, shoes, designer dresses, paper work, passport, birth certificates and marriage and divorce certificates. Years of Saskia's documents. 47 years of life. At least I still had my children alive and well and I still had my car!

I went in to clear out the property the next day. Total devastation, everywhere was dark and dingy and the smell was just horrendous. The fridge had been upended and had nearly blocked the kitchen door, the couch had been lifted and the cabinet that had housed all my photos had fallen over too, destroying almost everything inside. I had no idea where to start, so my friends put out an appeal for help and strangers turned up – it was amazing the help that was offered. People were so generous and



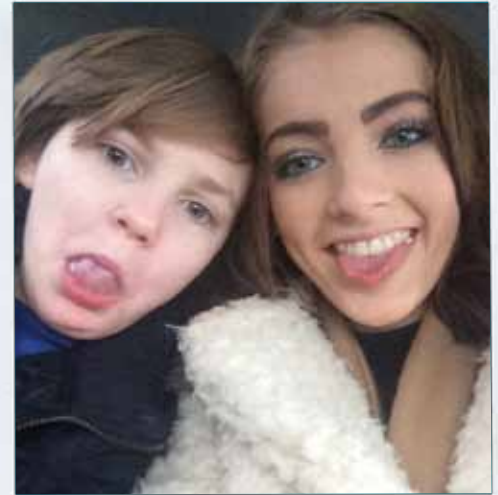
Saskia dancing and looking like an angel!



my boyfriend and Saskia



Hannah, my second child, and her children at the beach



Skye and Saskia trying to stick their tongues out

kind, especially my local support groups. A kind photographer dried out my photos for me and managed to save some – I cried whilst sifting through them! I couldn't even afford the insurance and thought that because flood defences were in place that they would hold. I ignored that little voice in my head telling me otherwise.

I lived in a hotel for six weeks while Saskia stayed with carers. On Christmas Eve we were offered an apartment at Gosforth Hall. It was hard work as Saskia often flooded the bathroom and there wasn't a cooker. For those weeks I was literally storing things in hotels, in my car and in my mate's garage!

In January we were given temporary accommodation eight miles from Cockermouth in a two bedroom bungalow. The neighbours are lovely, but the place is way too quiet, too small and too far away from amenities – but hey, I have a home! It is isolating, but I still have my car and wonderful friends who have supported me throughout. I am liaising with the powers that be to make sure that the flat is flood resilient when we move back. "Going back?" you shout? Yes, because it's the best

“ I had no idea where to start, so my friends put out an appeal for help and strangers turned up - it was amazing the help that was offered. ”

place for Saskia and the community spirit is awesome. The local hotel loves Saskia as we recently had to stay there for a few days. I volunteer now with some of the very people that helped me, the Eden flood volunteers. They recently won an award, and quite rightly so! Oh, and there is fabulous news: my son's wife gave birth to twin girls, and they are thriving!

Better for a break

Getting away with a disabled child can be a challenge, but if you can get organised and access funding it's well worth the effort. Here **Elizabeth** shares her holiday adventures with her son, Happy





“ Happy loves Thomas the Tank Engine, and seeing it live was his greatest experience ever. ”

In this short story, I would like to share with you three of our numerous holidays where I have accompanied Happy. A seven day holiday to Crete and four nights' holiday in York were funded by Family Fund, and a three night break at Kielder was funded by the local authority in conjunction with the Carers Association.

Crete

The seven night holiday in Crete was the most enjoyable time we have ever had. We planned to take the holiday in May, which is the beginning of the island's summer season. A wonderful lady at Thomas Cook booked us on an 'All Inclusive' tickets for two which cost us £495.00.

What worked well for us is that Thomas Cook provides buses to take tourists from the airport to the hotel, and staff who are very helpful while you are on the island. The island is rich with a vast array of blue beaches and great warm weather, as seen in the pictures. The hotel room was clean and facing the pool and Happy enjoyed swimming every day.

York

Planning to visit York was easy as we did everything on the computer using a Travel by Inspire money card provided by Family Fund. Just like most people, we both loved the experience and freedom of staying in a private house. The holiday home was clean and well equipped and suited our budget. The house was located closer to the York City Walls, York Railway Museum and the cathedral and Metropolitan Church of St Peter in York.

We began by touring the walls, and later spent most of our first day at the railway displays. Happy loves Thomas the Tank Engine, and seeing it live was his greatest experience ever. Naturally, he loves all trains and he enjoyed watching both massive and small trains. We also visited the cathedral and attended a church service. We forgot the iPad charger and we could not take more photos. Next time we will have to make sure we have do not leave chargers behind.

Kielder

Planning and making a booking at Kielder was not a problem as we had been allocated days by the local authority, therefore we were not involved in planning the date. We were not comfortable with the dates allocated, which fell in March. But, to our surprise, it turned out to be warm and sunny. Happy enjoyed a number of outdoor activities including crossing the bridge on a rope.

Holiday advice for parents

All the above-mentioned holidays, and a number of others we have enjoyed over the years need a lot of research, especially for wheelchair users. Our son Happy uses a wheelchair because of his heart condition, which causes him to get tired quicker, and the first thing we look for in a holiday is accessibility. When flying, we make sure we request a seat which is near the window, because he likes looking outside if we fly during the day. Because he is autistic, he also likes his space and we also request a seat that gives him space to stretch his feet, and also easily accessible when he wants to use the bathroom. We also ask for a special diet as there are certain foods he doesn't like.



Family Fund is the UK's largest grant-giving charity for families raising disabled or seriously ill children. They provide grants for a wide range of items, including family breaks. To find out if you might qualify

for a grant or to discuss your situation please contact them. See the 'How to Apply' pages at www.familyfund.org.uk

Making friends with 'challenging' behaviour



Christopher's birthday outing

Adele Meader tells us how understanding her 22 year old son's behaviour has helped her family make his world theirs too

My son's behaviour has often challenged me. But over time I've learnt that his behaviours are a like a friendship. They come for a reason and can last a season – or a lifetime!

With no speech, he communicates through actions. And although the majority of people's communication is made up of non-verbal things like body language and tone of voice, my son can't use these. What he does have, though, are his behaviours.

While many might describe this as 'challenging', I can honestly say the only 'challenging' bit was trying to get services to support me with the expertise I didn't have.

Who can help me?

With his hair pulling or dropping to the floor? Raspberry blowing? Please? Anyone?

I found out about a free workshop to help carers develop 'diversion, diffusion and de-escalation skills'. Two tactics I learned changed my life:

1 Hair pulling (my seasonal friend!). Simply peel away the little finger of the offending hand. This was my son's way of telling us he wanted someone else's food when he'd finished his. We sorted it by first giving him a small portion, then seconds (and sometimes thirds). Identifying the trigger and knowing how to prise his hand away helped us manage it.

2 Dropping to the floor (a friend for life!). Stand behind the person on the floor and simply cup their elbows and nudge upwards. He drops to the floor when he doesn't want to go out or come in.

The incessant day and night raspberry blowing caused us most difficulty. Was he under-stimulated? Perhaps he was in pain. I asked for a home assessment. A behavioural team couldn't help. An overnight carer would cost too much. How much is too much before we have a mental breakdown?

After five years of this, an independent reviewing officer suggested a residential school and, as an act of desperation, I saw no other solution.

If only I knew then what I know now...

Sadly I didn't. But perhaps I can help others.

- Don't get caught in the trap of describing your child through their condition. 'He's autistic'. No he's not.

He has autism and it's part of the person he is.

- Always make time for you. Without my weekly yoga sessions, I dread to think how my body would have coped with all the lifting and handling I've had to do!
- Use your support networks to hunt down information. Look out for training. Share what you learn. Lots of great resources exist but they won't just land on your doorstep. Buy yourself a folder for all the 'stuff' you discover.
- You can't know what you don't know. Turns out his raspberry blowing was feeding his 'gustatory oral needs.' Now I know this, I love his raspberry blowing! If you're told your child has a sensory need or sensory disorder – or whatever the buzz word is – explore what this actually means.

There's an old adage that says you can't fit a square peg into a round hole. This is so true for our children. Step into their shoes and make their world your world too.

Cheering the London Marathon



🔗 [The National Autistic Society has great information about understanding sensory needs: www.autism.org.uk/about/behaviour/sensory-world.aspx](http://www.autism.org.uk/about/behaviour/sensory-world.aspx)

🔗 [The Challenging Behaviour Foundation supports families with children who have severe learning disabilities whose behaviour challenges. www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

Confused about education in England?



Jill Davies and Carmel McDermott from our Education Advice Service answer some common questions

It's nearly two years since the Children and Families Act came into force in England, bringing about the biggest change to the SEN system in 30 years. Our education helpline advisers continue to answer many enquiries from families wanting to know about a system which is still new and sometimes confusing.

Many queries are from parents whose children still have statements under the 'old' law and have not yet transferred over to the new system. Below we answer some of the most common questions we are asked:

What's the difference between a statement and an Education, Health and Care (EHC) plan?

Like a statement, the EHC plan is a legal document describing your child's special educational needs and the extra help (special educational provision) which will be given to them. The EHC plan has sections covering health and social care needs. It is more 'person centred' than the statement, as it describes what you and your child want for their life, and what the extra help will enable them to achieve.

I'm happy with everything in my child's statement – do we have to change to an EHC Plan?

All statements will end by April 2018, and so your child will be transferred at some point. It's understandable that you are worried about letting go of a 'good' statement – especially if it took a long time to get. However, if your child's special educational needs have not changed they will continue to receive the same help and support through the EHC Plan.

Information from my child's statement has just been copied into the new EHC plan – is this right?

No – there should be no shortcuts. The transfer process must involve an EHC needs assessment.

This includes looking in detail at all the existing information about your child, seeking new advice from professionals and inviting you and your child to a meeting to contribute to the review.

The transfer process is taking a really long time – how long should it take?


It's a legal process, and there are timescales and deadlines. The local authority must write to you at least two weeks before the transfer review starts. From that point until the issue of the final plan must take no more than 20 weeks.


Will my child definitely get an EHC plan at the end of the process?

The local authority may refuse to issue an EHC plan if, for example, they think that your child has made enough progress, or they believe that a school or college can give them the help they need without additional funding. If your local authority decide not to issue an EHC plan they must write to you with reasons. You can appeal this decision.

My child is already at college, will they be transferred to an EHC plan?

Young people who are already getting support in further education will not automatically transfer to the new system. You, or someone from the college, must start the process by making a formal request to the local authority for an EHC needs assessment. Your child can make their own request if they want to.

 If you have questions about this or anything else concerning your child's education contact our freephone helpline and speak to one of our education specialists on 0808 808 3555

 We also have a range of factsheets on our website explaining the new system in England at www.cafamily.org.uk/the-sen-process

GROUPS NEW TO OUR NETWORK

Parent support groups are a great way to meet other parents for practical and emotional support.

Most local support groups are set up and run by parents and carers of children with additional needs.

Groups generally offer friendship, activities such as a crèche for siblings or family days out, information and advice and much more.

Use our website to find your local support group:

🌐 www.cafamily.org.uk/supportgroups

To find out more contact our Local Groups Manager:

✉️ adele.meader@cafamily.org.uk

SOMERSET

Chill 'n' Spin Ilchester

Bev runs 'Chill 'n' Spill', a group for parents and carers of children with additional needs of any age. Come along for coffee, tea and cake. Meets 9.30–11.30am every Friday morning at the Tall Trees Community Centre.
01935 840 562

Rising Stars Bridgwater

Weekly stay and play group for 0–5 year olds with additional needs. 'Safe haven' where parents can have a coffee, learn about strategies and break the feelings of isolation. Meets every Monday term-time 1–2.30pm.
www.bridgewaterparentsupportgroup.com

Finding Your Way Chard

Jos, Irina, and Sue welcome all parents, carers and family members and professionals. Meets 10am–12pm first Wednesday of the month (term-time only). Everyone who joins Somerset Parent Carer Forum get a first hot drink free at every group. You can register on the day or online.
01460 68500 or kerry.leydon.spcf@outlook.com

Finding Your Way Yeovil

Claire runs this group at 'The Hub'. Meets during 10:00am–12:00pm on every second Friday of the month.
01278 699 397 or Help@SomersetParentCarerForum.org.uk

Finding Your Way Wells

All parents, carers and family members and professionals are welcome. Meet every first Thursday 7:30–9:30pm. Bring along homemade delights or nibbles!
Help@SomersetParentCarerForum.org.uk

Finding Your Way Wincanton

Kerry runs this group (with coffee and cake!) for parent carers who have a child with any additional need. Meets 10am–12pm on the third Friday of the month, during term time.
01963 31842

WALES

Serennu Centre Support Groups

Various support groups are available in Newport and surrounding areas:

Your Voice

For parents to share knowledge and support each other.
jenny.brenton-davies@wwutilities.co.uk

T:21 Dragons

Support group for parents of children with Down syndrome.
Fran 01633 748 013
Frances2708@gmail.com

Parents for change

Support and campaigning group for parents and carers.
Lisa.collins10@ntlworld.com

Newport Autism Support Group

For parents/carers/grandparents in Newport whose children have an autistic spectrum disorder.
Hilary Leadbetter 07899 906 344
nasgmembers@gmail.com

SMILE Coffee mornings

for parents and carers of a child living in South East Wales with an additional need.
Sue Williams
smilecoffeemornings@yahoo.co.uk

Hands up for Down's

For families who have children with Down syndrome in the Swansea and surrounding areas. Meet every second Sunday of the month at 1–4pm in Swansea Central Library.
07930 263 301
www.handsupfordowns.weebly.com

NORTH EAST

Hemichat

Local group offers peer support and opportunities to meet through leisure activities.
www.hemichat.org or www.facebook.com/hemichat

Tea Time Club

Relaxed and welcoming group to chat, share and receive advice and support. Children welcome. Meets at Newton Aycliffe One Point Children's Centre on the last Wednesday of every month from 2–5pm.

03000 263 666

rabindra.singh@durham.gov.uk

Rollercoaster

Runs on the third Wednesday of the month at the Acley Centre, for parents supporting a child or young person with a mental health issue.

07415 380 040 or

wendy@success.coop

Meet, Talk, Play

For parent carers with activities on offer for children and young people of school age with additional needs. Every Thursday at The Memorial Hall, Longframlington, Morpeth from 6–8pm

01665 570 888

kmgpost@hotmail.co.uk

LD: North East Early Years Support Group

Activities and groups for pre-school children and their families. Contact them to find out meeting dates.

0191 262 2261 www.ldne.org.uk

ESSEX

Dyslexia Support Group

For parents of children affected by dyslexia and co-occurring difficulties. Monthly meetings at St Michael's Church Hall in Braintree with free resources and sometimes a guest speaker.

0751 3348 600 www.edsg.co.uk

NORTH WEST

St Helens Independent Support (SHIPS)

1:1 visits to parents in the comfort of their own homes, and can attend

meetings at school/LA with parents as support.

ships2015@outlook.com.

CUMBRIA

Kendal Family Drop-in Centre

Training days, regular drop-in to meet other parents Thursdays at 10am, help with forms.

07795 346 632

shirley-gilpin@sky.com

STAFFORDSHIRE

In It Together Tamworth

Monthly drop-in's with activities for children. 2nd Wednesday of the month at St Pauls Church, Coleshill Street, Fazeley from 9–11am and 3rd Tuesday at Sure Start Children's Centre, Hawsworth, Glascoate from 10am–12pm.

initttogether.tamworth@gmail.com

www.in-it-together.weebly.com

SNUG (Special Needs United Grandparents)

Help and advice for grandparents. Meet up term time once a month, for tea/coffee and chat and talks from professionals.

07471 178 128

snugstaffs@gmail.com

LONDON AND HOME COUNTIES

Centre for ADHD and Autism Support

Support individuals with ADHD or autism and their families. Information, training, practical help and support in Harrow, Hillingdon, Ealing and Brent and parts of Hertfordshire.

0208 429 1552 www.adhdandautism.org

SUFFOLK

Little Kingfishers Play Centre

Soft play centre that offers sessions

exclusively for children with a disability or learning difficulty and their siblings. Held on the first Thursday of the month from 4.30–6.30pm in Sudbury. Pre-booking is essential.

Tel 01787 375 656

www.littlekingfishers.co.uk

WEST SUSSEX

Autism Support Crawley

We meet to share information, advice and support in a relaxed, informal environment at Broadfield Children's Centre on the first Thursday of each month from 7.30–9.15pm. Professional speakers at some meetings.

For exact dates and more information see www.autismsupportcrawley.co.uk or call

07596737741.

NORFOLK

Slice of Advice Martham and Great Yarmouth

Support groups with regular guest speakers for parents and carers of children with an autistic spectrum condition or ADHD. No diagnosis needed. Come and chat with other parents every Tuesday 9.30–11.30am at Trinity Sure Start Children's Centre at Martham Primary School, or on Wednesday Gt Yarmouth Library, between 10.00am–1.00pm.

07773116515 sliceofadvice@hotmail.com



Need advice?

Call our freephone helpline, a 'one-stop-shop' for advice and information on any aspect of caring for a disabled child.

0808 808 3555

Open Monday to Friday, 9.30am–5pm

helpline@cafamily.org.uk

“ I always come back to the helpline for advice. People take their time to support me. ”

Our education advisers can help you with

- early years and preschool
- getting extra help in school
- statements and EHC plans
- bullying
- exclusion
- transport
- support for medical needs
- education after 16.

Our general advisers can help you with

- benefits or tax credits issues
- details of local and national support groups
- information about your child's condition
- how to get help with getting a break
- details of grant-giving charities
- any other aspect of caring for a disabled child.



“ Running the Marathon for Contact a Family is my way of thanking them for supporting Shola and me. ”

Help us support more families – you can fundraise by doing almost anything!

Call us today on 020 7608 8786 or email fundraising@cafamily.org.uk

contact a family
for families with disabled children

020 7608 8700

info@cafamily.org.uk

www.cafamily.org.uk

www.facebook.com/contactafamily

www.twitter.com/contactafamily

www.youtube.com/cafamily