

24<sup>TH</sup> JANUARY 2017 IN THE STATE ROOMS OF THE SPEAKER OF THE HOUSE  
OF COMMONS, JOHN BERCOW MP, AT THE PALACE OF WESTMINSTER

CONTACT  
A FAMILY  
Awards  
2017

**contact** a family  
for families with disabled children



# FOREWORD

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*from the Speaker of the House of Commons,  
John Bercow, MP*

I'm delighted to be able to offer the State Rooms of Speaker's House to celebrate the wonderful achievements of families with disabled children and those who support them, at Contact a Family's first ever Awards.

Contact a Family established these awards to recognise the countless and often unseen things families do when caring for disabled children. In this booklet you'll be able to read the inspiring stories of the 21 shortlisted finalists. It's clear from the stories they've shared that families with disabled children give back to our community and economy in so many different ways we don't recognise.

It is a pleasure to be able to welcome all of the families to Parliament and celebrate with them in such a unique way.



# WELCOME

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*by Amanda Batten, CEO of Contact a Family*

At Contact a Family we hear a lot about when things go wrong for families. It might be the challenges involved in getting the right services and support in place for your child, public attitudes to disability or pressures on relationships. This isn't surprising, as to a large extent this is what we are here for.

However, it is important for all of us to recognise the things that go right too, and all the positives that come with being a family with a disabled child. So we wanted to celebrate by launching the first ever Contact a Family Awards – to shine a well-deserved spotlight on families with disabled children. We want the awards to be a celebration of the countless things UK families do when caring for their disabled child. We have been absolutely overwhelmed by the nominations, and I must admit the judging panel were often moved to tears reading about the wonderful things families do for each other and have achieved.

Contact a Family is all about families with disabled children, and we want our awards to truly celebrate their lives and the contributions they make. This fantastic opportunity to give someone special in your family's life the recognition they truly deserve is not only for the winners in each category, it's for all families, a community of people on your side. And ultimately that's what Contact a Family is.

Amanda Batten was one of three judges to shortlist from more than 100 nominations.  
We would like to thank our other judges, Gill Ackers and Charlotte Warner

# SHORTLISTED NOMINATIONS

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## *Parent Carer Award:*

Alexis Gilmour from Kirkcaldy  
Charles Wilk from Hertfordshire  
Philippa and Geoff Gretton from Hartlepool

## *Grandparents Award:*

Donna Taylor from Co Durham  
John and Catherine Kellaway from Barry  
Kara Powell from Bedfordshire

## *Proudest Moment Award:*

Calum McPherson from Stirling  
Hooriya Fida-Hussain from Wakefield  
Sid Page from Anglesey

## *Parent Power Award:*

Craig Mathieson from Cheshire  
Fiona Beard, National Network Parent  
Carer Forums Representative for Yorkshire &  
Humberside  
Jo and Ricci Hodgson of Spice support group  
from Berkshire

## *Sibling Award:*

Beatrice Kowalski from Cornwall  
Chloe Thomson from Anglesey  
Evelina Dolan from Newcastle  
Findlay James-Bruce from Aberdeenshire  
Kelsey Cawser from Tamworth  
Sophie Nesbitt from Stockport

## *Family Champion Award:*

Becki Plant from Walsall  
Kerrie Highcock from South Shields  
Suzanne Conway from Dundee

# PARENT CARER AWARD

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*Recognising the amazing things parent carers do to ensure their disabled children can take part in everyday life.*



*“Contact a Family has been a valuable source of information.”*

## ALEXIS GILMOUR

Kirkcaldy, Scotland

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Alexis was **nominated by her mum Vicky**. Alexis has four daughters, Riagan aged 9, Ashton aged 12, and her two 16 year old girls Mhairi and Wade, who have cerebral palsy. Vicky told us:

“Alexis has been a strong advocate on behalf of the girls in accessing the services they need to enhance their daily lives. Alexis founded the Funky Fifers Wheelchair Dancing group which has won several national awards. She also founded the KIDZ-U-NITE youth club with her girls. This is a youth club for secondary school age children with additional support needs and their families to have fun and socialise together. Alexis arranges outings so the group can go out together. There’s no stigma and no sense of being different at the club, unlike some mainstream youth clubs. Alexis has gone the extra mile and should be congratulated for what she has achieved.”

## CHARLES WILK

### Hertfordshire, England

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Charles was **nominated by his wife Hannah**. They have two boys with autism, Henry aged five and four-year-old William. Hannah says:

“Charles truly is the best father in the entire world. As soon as he comes home from work the children have 100% of his attention. He plays and watches whatever their obsessions are. In the five-and-a-half years of Henry’s life, he has only ever not put him to bed twice (when he had to work late!). Charles has convinced Henry to eat fruit and vegetables after he was terrified of them. Charles always puts the children first and deserves to be honoured for it.”



*“We have used Contact a Family’s online advice.”*



## PHILIPPA & GEOFF GRETTON

### Hartlepool, England

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Philippa and Geoff Gretton were **nominated by their daughter Sam**. Sam’s brother Ryan is 22 and has cerebral palsy and autism. Since 2010 he has been in and out of hospital due to health problems. Sam, 21, explains why she nominated her parents:

*“When Ryan was young, Contact a Family helped by setting up shared care arrangements.”*

“My mum always stays with Ryan however long his hospital stays are – the longest being 10 months! My dad works full time so he is backwards and forwards to hospital from work. Dad is lucky if he gets more than four hours sleep a night as Ryan is awake shouting as he’s in pain or needs his legs adjusting. They both rarely get any time to themselves and deserve some recognition for the stress and hard times they’ve had to go through - not only as Ryan’s parents but as his carers as well. He used to visit a family for a break, and those times were so precious to mum and dad, as they were for the family he visited.

“Both mum and dad aren’t in the best of health, yet all they are concerned about is Ryan and making sure he can go to all the shows, concerts and clubs he likes and that he is able to see his friends as much as possible. They are the most kind-hearted, funny and caring individuals I know, and I am both proud and lucky to have them as my mum and dad.”



# PROUDEST MOMENT AWARD

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*Recognising the challenges your disabled child has overcome that fill you with pride and make you smile.*



*“I have attended a Contact a Family workshop in Edinburgh regarding planning for Calum’s future which was very useful.”*

## CALUM MCPHERSON

Stirling, Scotland

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Calum, aged 10, has been **nominated by his mum Stacey**. Calum has a very rare genetic condition, De Novo Mutation of the CHAMP1 gene, which causes severe speech difficulties. Stacey explains why she nominated him:

“Our Proudest Moment was last year, when Calum started to use a new app on the Ipad. It turned him from a non-verbal, frustrated child to a little boy who was able to use a device that opens up his whole world.

“Finally everyone knew what he truly needed, and he was so happy (as were we). Some people were sceptical that he would be able to use the device correctly, but I never doubted my boy. He has continued to thrive using it at home and at school. Recently I downloaded the Scottish accent in the settings. He was overjoyed to hear him sounding just like his mummy and daddy when he pressed his words. I had tears in my eyes. I could list many proud moments, but nothing will compare to hearing your child be able to communicate.”



## HOORIYA FIDA-HUSSAIN

Wakefield, England

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Hooriya Fida-Hussain, aged 11, was **nominated by her mum Sarvat**. Hooriya was born profoundly deaf and is extremely shy. When Hooriya asked if she could join kickboxing sessions mum Sarvat had a difficult choice – Hooriya has a cochlea implant and contact sports are not recommended. Here she tells us why she nominated her daughter:

“I did not want to put her off, having always taught her that being deaf would not stop her from doing anything. I took her for the trial, not thinking she’d like it. But she stuck at it and trained for four years, achieving a black belt in kickboxing this year at the tender age of 11. This is an amazing feat given that Hooriya cannot access sounds during training sessions and relies on lip reading. She now teaches the younger members of the club. I feel immensely proud as she has really struggled and there have been tears along the way. I am proud not only of her achievement, but of her commitment to a challenging sport – she has not given up.”



*“I am in close contact with Contact a Family Wales, who have always been available to call on.”*

## SID PAGE

Anglesey, Wales

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Sid, aged 18, was **nominated by mum Kerry**. He has severe learning difficulties and ADHD. Mum Kerry endures severe migraines as a carrier of Fragile X syndrome. She told us her proudest moment was when Sid saved the day when she collapsed at home:

“Sid’s anxieties and stress levels are very high. He struggles to use the phone and dial the numbers, as he doesn’t know his numbers. When Sid found me collapsed on the kitchen floor, he knew to get the phone for me to ring 999. He told the operator our address, unlocked the door, and waited for the ambulance men to come and showed them in. He coped brilliantly and did exactly what he should. I did not even know he could do that, so he truly surprised and amazed me. He is a real superhero.”

# SIBLING AWARD

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*Celebrating the often unseen but great things siblings do for their disabled brothers and sisters.*



*“Contact a Family gave me the opportunity to campaign in Parliament to work towards better childcare for working parent carers. And the information they provide online is invaluable.”*

## BEATRICE KOWALSKI

Cornwall, England

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Beatrice, aged eight, was **nominated by her mum Katherine** for helping save her brother Lawrence’s life. Lawrence had an epileptic seizure and had stopped breathing. Beatrice heard Lawrence’s seizure start when he was in bed and alerted her mum. She helped to keep Lawrence breathing while her mum phoned for an ambulance. Beatrice then let the ambulance crew in because her mum couldn’t leave her brother, then bravely went next-door to sleep at the neighbours’ as the rest of her family rushed off in the ambulance.

Beatrice was only six years old when this happened. Mum Katherine told us:

“Beatrice has overcome significant anxiety and continues to do well at school, all the while every day helping at home with Lawrence – entertaining him, reading to him, feeding and changing him. He is unable to do anything for himself. Beatrice always thinks of Lawrence first, and what he would enjoy, before thinking of herself. She is growing up to be a kind, considerate and generous little girl who always looks out for people who need help, or are less able than her.”



*“Contact a Family has always been there for me and my other friends with disabled children.”*

## CHLOE THOMSON

Anglesey, Wales

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Chloe, aged 13, was **nominated by mum Catherine Bennett** for being such a brilliant step-sister. Mum Catherine says:

“Five years ago she had never met my stepson Tim and had never experienced a severely autistic child. But at the age of nine she took everything in her stride, including Tim’s biting, shouting, and taking some of her precious possessions and ripping them up. Now they are as thick as thieves, and although Tim is non-verbal she has him saying and singing all sorts and they make videos together. Chloe has also taught him how to swim and how to colour. She is so patient with him, and Tim (who is now 21 years old) adores his little sister.”

## EVELINA DOLAN

Newcastle upon Tyne, England

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Evelina, aged eight, was **nominated by mum Katja**. Despite her young age, Evelina is always thinking about the future. She has told her parents that she is going to buy the house next door when she is grown up, just so she can look after her brother Lucas, who is seven. Mum Katja told us:

“Evelina helps Lucas get dressed, gives him drinks, gets his nappies and helps mum and dad whenever she can. She plays with Lucas, reads him stories and helps him with Makaton. Evelina understands her little brother on a different level to everyone else and is able to teach him lots of things. At the moment she is teaching him to match pictures and letters and how to draw. Evelina knows that different textures are important to Lucas as well as smells and tastes so she is always encouraging him to try something new. Last weekend it was lovely to watch her when she took his hand to touch a branch. They have a special bond and we are very proud of them both.”



*“Just knowing Contact a Family is there for us is helpful.”*



## FINDLAY JAMES-BRUCE

Aberdeenshire, Scotland

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Findlay, aged seven, was **nominated by his mum's friend Laura Hawcroft**. Both Findlay and his younger sister Iona have a very rare chromosome condition called Trisomy 12q. They need a lot of specialist equipment and adaptations to help them take part in basic daily activities such as sitting, standing, and bathing.

Findlay is an amazing little boy who has never lost his sense of humour, despite everything that life has put him through, Laura told us:

"I am nominating Findlay specifically for the support that he has shown to his sister Iona and his parents Charlotte James and Dave Bruce when Iona was in hospital with sepsis, viral infections, and a meningococcal infection between January and March 2016. Findlay was by his sister's side constantly, reading to her, playing with her, trying to lift her spirits and just holding her hand through the cot bars. He even helped the doctors and nurses, because he understands his and his sister's disabilities so much. He is an inspirational child. Despite being just as disabled and only a little older, Findlay is a caring brother to his precious sister. He really is fantastic!"

## KELSEY CAWSER

Staffordshire, England

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Kelsey, aged 11, was **nominated by her mum Fiona**. Kelsey has anxiety but she puts this to one side while helping her brothers who have autism and specific learning difficulties. Fiona told us how brave Kelsey is when supporting them:

“Kelsey has been so grown up with helping her brothers Aiden, 13 and Harry, 7. She’s always on hand to fetch her younger brother drinks or his toys because he has a muscle weakness that makes him feel very tired. Kelsey also supports her brother Harry at school. Because of his condition, Harry finds it difficult to communicate but Kelsey sacrifices her lunchtime play with friends to help him. On four occasions, she has alerted staff when Harry’s become injured and needed medical attention. Without Kelsey, he wouldn’t have been able to tell anyone that he was hurt. Kelsey always puts others’ feelings before her own – she is so thoughtful and selfless that I feel she deserves a little recognition. When I heard about these awards I just knew I had to nominate Kelsey – she is an absolute credit to our family!”



*“Contact a Family have given us advice on various issues.”*



*“Contact a Family has put me in touch with others in my situation, which helped me realise that I’m not on my own. Sophie even campaigned for her school to choose Contact a Family as their chosen charity.”*

## SOPHIE NESBITT

Stockport, England

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Sophie, aged ten, was **nominated by mum Tina**. Her mum says Sophie is the most fantastic big sister to her brother Jack. Jack has a myelin deficiency in his brain, which causes global development delay. He also had severe reflux which meant he was a very noisy baby. Mum, Tina, told us:

“This did not faze Sophie and she persevered in playing with him, cuddling him and trying to cheer him up. Later, when Jack learnt to smile and eventually laugh, Sophie would take it upon herself to ensure that he cracked at least one smile before she left for school. Sophie has explained Jack’s disability, feeding tube and equipment to her school friends. When Sophie gets home from school, she will read Jack a story and give him an uncontrollable fit of the giggles. They are the very best of friends and Sophie is extremely proud and protective of him. Sophie completely accepts Jack for who he is – no more, no less – and I absolutely adore her for it.”



# GRANDPARENT AWARD

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*Recognising all the wonderful and everyday things grandparents do.*



*“Contact a Family has shown me I’m not alone, and for that alone, I am forever grateful.”*

## **DONNA TAYLOR**

**Co Durham, England**

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Donna was **nominated by her daughter Kirsty**. Kirsty says her mum has been there from day one, giving her fantastic support. Here she tells us why:

“I have been a single mum from day one, with five-year-old twins, Brooke and Callum. My daughter Brooke is disabled and it’s not been an easy journey so far. My mum has been not just my rock, but our family rock. She is the glue that holds this family together. She helps us every day, and is at every hospital appointment and every school event. I would not be the woman, or mum I am today if it wasn’t for her. My twins idolise her and she is my hero. Without her we’d be lost – she is phenomenal.”



## JOHN & CATHERINE KELLAWAY

Barry, Wales

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John and Catherine Kellaway were **nominated by daughter Emma** because they have helped her with every aspect of her family's life including having them to stay with them for four months while their house was adapted for their son Sebastian's needs. Emma told us why she nominated them:

"My parents are both retired now, and I don't know what I'd do without them. My dad John and my son Sebastian are best friends, he really makes sure Sebastian doesn't miss out on anything. My mum Catherine can't do more for us – helping with washing, ironing and generally keeping our house in order. They look after Sebastian every Friday so Alex, my husband, and I can have some time together and relax, and even come on holiday with us to help us take care of him. They are simply the best grandparents in the world and I can't thank them enough. I want to take the opportunity to let them know how amazing I think they are!"

*"Contact a Family hosted a special film viewing for families with disabled children in Wales. They all felt very comfortable and loved the experience. There were no judgemental people or stares - they thought it was fabulous."*

## KARA POWELL

Bedfordshire, England

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Kara was **nominated by her sister Melissa** for her tireless work looking after her grandson Shayne, aged four, and keeping the rest of the family together. Melissa explains:

"Kara's daughter Kirstie is epileptic and fell pregnant on Epilim, an anti-convulsant medicine. This caused her grandson Shayne to be born with fetal valproate syndrome, a rare, severely disabling condition. Kara is Shayne's main carer. Shayne needs round the clock care and spends a huge amount of time at Great Ormond Street or Bedford hospitals, where she is always by his side.

"As well as this, her youngest daughter Stacie (12) was recently diagnosed with diabetes and her husband Les is also diabetic. How she holds the family together is beyond me. Yet she still balances everything.

"On top of that, she is also still there for me and my children. She's first to offer help and stretches herself without breaking. To be honest grandparent award isn't enough, she deserves them all."



*"Kara uses Contact a Family as a support network."*



# PARENT POWER AWARD

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*For an individual parent carer, local parent group, or local parent carer forum who have campaigned to make life better for families with disabled children.*



*“The Supreme Court’s judgement and the Government’s subsequent action on the matter was only made possible by the support of Contact a Family. They put Craig in touch with lawyers specialising in Human Rights issues. They arranged media coverage of the case and kept in touch with Craig and his family with encouragement and great sensitivity from the moment they became involved, and indeed, they have continued to remain in touch with the family which has been so much appreciated.”*

## CRAIG MATHIESON

Warrington, England

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**Craig was nominated by his parents, James and Sandy Mathieson.**

In 2015, the Supreme Court unanimously ruled that taking Disability Living Allowance from Craig’s disabled son Cameron after he had been in hospital for more than 84 days was in breach of his human rights, and unlawful. Cameron spent more than two years in hospital with life-limiting disabilities before he died in 2012. Craig was determined to fight on to leave a lasting legacy on Cameron’s behalf, so that other families might not have to endure the financial hardship experienced by his own family. James and Sandy told us:

“Throughout the five year long legal process Craig really had to put his own life on hold. There were many times when we felt that he was fighting a losing battle and we worried for his own health, not least when he had to attend a court hearing in London less than three months after Cameron’s death. But throughout all the setbacks and hurdles along the way, Craig remained resolute that the 84 day rule was unjust and needed to be changed, and he worked tirelessly to achieve his aim. To challenge a Government department is a huge undertaking but for Craig, knowing that he had the chance to make a difference for other families not only in his own community but throughout the country, made it all worthwhile.”



*“I use the Contact a Family website for any help I need and to be reassured it’s not just me, it’s a community. Keep up the good work!”*

## JO AND RICCI HODGSON

SPICE (Special People in Ice) local parent carer support group in Berkshire, England

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Jo and Ricci Hodgson were **nominated by Helen Gregory Osborne**, whose disabled daughter attends SPICE.

SPICE was set up by this husband and wife team who, with a group of helpers, make it possible for disabled children and adults to ice skate. Helen describes the difference they make:

“My little girl, who has cerebral palsy, lives her dream every Sunday morning when she attends SPICE. The disabled synchronised skating team have won awards, as have the disabled ice hockey. Recently, they fought tooth and nail for a temporary ice rink whilst the one used is being refurbished. And after everyone saying they couldn’t do it... last week the council agreed to a full size temporary ice rink. The Hodgson family really are tirelessly amazing!”

## FIONA BEARD

National Network of Parent Carer Forums’ representative for Yorkshire & Humberside

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Fiona has been **nominated by Sara Smithson**, who is a parent carer also involved in shaping and improving local services for disabled children through the local parent carer forum. Here Sara tells us why she felt she had to nominate Fiona:

“Fiona works tirelessly to champion parent carers, not only locally but at all levels – from her local parent carer forum, regional forum and role on the National Network of Parent Carer Forums as the regional representative. Fiona promotes inclusion, partnership working and is solution-focussed. She spends days and weeks away from home to represent us at national levels, yet is still in touch with the families in her area. Fiona really goes above and beyond her role devoting a lot of her free time to making a difference, and I cannot think of a more deserving nominee to win this award.”



*“If it wasn’t for Contact a Family, thousands of parent carers wouldn’t be involved in local and national decision making. They have helped set up local parent carer forums all across England and support the National Network of Parent Carer Forums.”*

# FAMILY CHAMPION AWARD

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*For professionals, politicians or government officials who have gone the extra mile to champion the causes of families with disabled children.*

## **BECKI PLANT**

**SENCO at Brownhills School in Walsall, England**

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Becki was **nominated by Victoria Bird**, the parent of a young man with autism who attends Brownhills School in Walsall, where Becki teaches. Victoria tells us why Becki is one of a kind, and is always there for all her students:

“Becki is always there for all students with special educational needs and goes above and beyond to help. She is there before school starts, during all school hours including breaks and dinner times, and also after school to help my son with his homework. I have never met such a fantastic SENCO!”

“My son, who has high functioning autism and other problems, would never have settled into the mayhem of mainstream senior school without her support. I just cannot thank her enough. As a single mum of three children – two of whom are disabled – you are such an important service! Thank you for all you do.”



*“Contact a Family helps such a lot with the worries over budget cuts and benefits, it’s been very reassuring, you go out of your way to write down the facts in a way that is easy to understand. You make it seem easy.”*



## KERRIE HIGHCOCK

Family Development Manager, South Shields, England

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Kerrie is from the North East Autism Society and was **nominated by her colleague and friend Lisa Taylor** because of the lifeline she offers so many families living with autism across the North East. Lisa says:

“Kerrie runs our toddler groups, parents workshops, autism training and family support groups. She really does go above and beyond for our families. She supports parents day or night if they post questions on the local online parent carers’ Facebook group, offering them comfort during difficult times. She always has a big smile on her face and is happy to help anyone.”

*“Kerrie works closely with Contact a Family’s North East team, supporting families, distributing our regional newsletters and signposting families to the services Contact a Family offers.”*

## SUZANNE CONWAY

Short Breaks Team Leader, Dundee, Scotland

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Suzanne was **nominated by Paula Brown**, the parent of a disabled child. Paula tells us why she nominated Suzanne, who she says always goes the extra mile:

“My eight-year-old daughter Gracie is severely disabled. Suzanne is the team leader of Cornerstone, an organisation that provides short breaks services and support for children like Gracie and their families across Scotland. As a mum who has nearly lost her daughter and faced many difficult times, I am extremely anxious when it comes to letting others care for Gracie. But Suzanne has worked with me, respecting my anxiousness and issues at all times. It’s taken four years but now Gracie goes to respite for two nights a month. Gracie loves this and has learned to cope without me all the time – she has tried different things and is much more confident and sociable. I still struggle to the point I can become unwell, but Suzanne is always there to reassure and support me, and as a working mum I am slowly beginning to enjoy a break.”



*“I have only recently come across Contact a Family, but now I know you are there I will be using you for future support and advice.”*

# HOW WE HELP

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Contact a Family exists to support families with disabled children – whatever their condition, wherever they are in the UK, whenever they need us. All too often families don't know where to turn. We act as their first port of call, helping them see a way forward, and connecting families with each other and the services they need.

Our freephone helpline gives advice about any aspect of raising a disabled child, including help with finances, education, emotional and practical support.

**0808 808 3555 [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)**

## HELP US REACH MORE FAMILIES

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Contact a Family reaches 20% of families caring for a disabled child in the UK. We know there are thousands more families who need our support, which is why our aim is simple – to reach more families, and reach them sooner.

The need for our services is growing, but with your help we can change this. You can transform the lives of families with disabled children by supporting our work.

Your support could be life changing. As an individual donor, Charitable Trust, Company, or through the Contact Collective, our Young Philanthropy Network, which hosts fun, sociable, engaging events, raising critical funds and awareness for Contact a Family.

Please speak to us about how you can make a vital impact on the families we support by contacting Sinead Lynch on 020 7608 8756, or email [sinead.lynch@cafamily.org.uk](mailto:sinead.lynch@cafamily.org.uk)

You can visit our website for more information on how we support the thousands of families caring for a disabled child across the UK or make a donation online, and be there for families when they need it most.

**[www.cafamily.org.uk](http://www.cafamily.org.uk)**







