

connected

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



Celebrating achievements

– NO MATTER HOW BIG OR SMALL

WHAT YOU NEED TO KNOW ABOUT UNIVERSAL CREDIT

Our expert welfare
rights team explains

LOVE, LIFE, LAUGHTER

Our exhibition with award-
winning photographer
Rebecca Lee

JOIN OUR CAMPAIGN ON SCHOOL TRANSPORT

We need your views
to put to government

In this issue...

WELCOME

- 3 Update from our Chief Executive, Amanda Batten**

NEWS

- 4 Policy news**
by Una Summerson
- 5 What you need to know about Universal Credit**
Derek Sinclair, our welfare rights expert, explains
- 6 Parent carer participation**
Influencing local services in England
- 7 News from Wales and Northern Ireland**
- 8 Love, life, laughter**
Our Scotland office photo exhibition



CELEBRATING ACHIEVEMENTS

- 11 The little things**
Marijka tells us about accepting her son's autism



- 12 A perfect picnic**
Alice celebrates a fabulous day
- 14 On the right track**
Oliver follows his dream to work on the railways
- 15 A dream come true**
Tammy arranges a surprise visit to Chelsea for her son
- 16 A challenge like no other**
Shirley takes on a 100k walk
- 18 Spotlight on siblings**
Suzy talks about life growing up with her sister
- 19 Practice makes perfect**
The move to secondary school

FEATURES

- 20 Holiday with no limits**
Fun and games on an activity holiday
- 22 Dealing with sensory issues**
Mary talks about supporting her son
- 23 Tell it like it is**
Tips on claiming DLA
- 24 Ask the expert**
What is mindfulness and how you can benefit
- 26 Education**
Our experts answer your questions on school transport
- 28 Fundraising news**
Join our Marathon team!



LOCAL GROUPS NETWORK

- 30 New local parent support groups you can join**

contact a family
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Celebrating positives

Update from our Chief Executive Officer
Amanda Batten



At Contact a Family we hear a lot about when things going 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 – our helpline is there to support you to find a way through, and this won't change.

“The positive message that families can take away, is a sense that there's a community of people committed to a better world for families with disabled children”

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 this Winter we want to celebrate, and have launched the first Contact a Family awards. Turn to page 10 to find out more. And we thought what better theme for this edition of Connected. I hope you enjoy reading our amazing stories.

I must thank the colleagues and trustees who did the Thames Path Challenge (a fundraising walk) with me. In case you are wondering, it was really hard! Shirley tells us more on page 16. We are a charity reliant on fundraised income, whether that's supporters doing cycling challenges or dinosaur day activities. The message is that everyone can get involved and help other families to get the support they need. Moreover, it can be fun and feel good.

The positive message that families can take away, is a sense that there's a community of people committed to a better world for families with disabled children. People prepared to get blisters, be a bit saddle sore, whatever... a community of people on your side. And ultimately that's what Contact a Family is.

Amanda

connected magazine

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Is school transport an issue for you?

School transport is one of the top issues that Contact a Family's helpline gets calls about. In fact, calls on the subject have doubled this summer compared to the same period last year. So this November we launched a call for evidence on school transport as part of a cross-party Parliamentary Inquiry. We would like to give families across the UK the opportunity to tell us more about their experiences of school transport across all the age ranges, from early years to post 16. This will help us all to understand the scale of those affected, and most importantly identify the solutions.

What you can do

- Respond to our call to evidence at www.cafamily.org.uk
- If you have been refused school transport or want to find out about your rights to school transport, please call our helpline for advice. Read their answers to common questions on page 26.

We think access to home to school transport is an integral part of a child's education. If a disabled child can't get to school, or has a stressful experience getting there, they are not able to learn and take part in the school day like other children.

Submit your views at www.cafamily.org.uk/school-transport-inquiry

ASK THE HEALTH SECRETARY TO PRIORITISE MENTAL HEALTH

Contact a Family is calling on the health secretary, Jeremy Hunt MP, to make mental health support for families with disabled children and young people a top priority. Our *Waiting Times* research shows that despite having a referral – which can be a battle in itself – a third of disabled children are waiting more than a year to access mental health support.

For many children, accessing child and adolescent mental health services is often the first step in getting a diagnosis for conditions such as autism and attention deficit hyperactivity disorder. The Government pledged to put mental health on an equal footing to physical health, but this remains a long way off being achieved. To date, disabled children have not even been mentioned in the debate. Join us in changing that, by signing our letter to health secretary Jeremy Hunt MP.

You can sign our e-action by going to www.cafamily.org.uk/campaigning



Join our e-campaigner network

By being part of our network you'll be part of a movement demanding the best for families with disabled children. You'll have the opportunity to take action and make a real difference. Join up at www.cafamily.org.uk/campaigns

What you need to know about Universal Credit

The government is gradually introducing the full Universal Credit service to an increasing number of postcode areas. Our benefits expert **Derek Sinclair** looks at what this means for families with a disabled child

What is Universal Credit?

Universal Credit is a new benefit for people of working age. It can be paid both to people who are out of work and to those in employment. It is replacing Income Support, income-based Jobseeker's Allowance, income-related Employment and Support Allowance, Housing Benefit and tax credits.

What is the full Universal Credit service?

In most parts of the UK strict 'gateway conditions' mean families caring for a disabled child can't currently be asked to claim Universal Credit.

However in some areas, where the Government has introduced the full Universal Credit service, no gateway conditions exist. This means that a family with a disabled child in these postcodes can be asked to claim Universal Credit – but only if they try to make a new claim for one of the means-tested benefits or tax credits that Universal Credit is replacing.

For example: Tina is a lone parent and lives in an area where the full Universal Credit service applies. She loses her job and tries to claim Income Support as a carer. Because new claims for Income Support are no longer accepted in her area she has to claim Universal Credit instead. This new Universal Credit award also then replaces her

existing tax credit and Housing Benefit payments.

What about existing Universal Credit claimants who don't have a change of circumstances?

For the time being, existing claimants who do not try to make a new claim for one of the benefits Universal Credit is replacing will not be affected, even if they live in a full service area. However, between July 2019 and March 2022 the government intends to move all existing claimants of means tested benefits and tax credits onto Universal Credit.

How do I know if the full Universal Credit service is in my area?

The Government is slowly rolling out the full service to a small number of Jobcentre areas each month. For instance, during December it will be rolled out to Hartlepool, Hastings, Fulham, Shepherds Bush, Stratford-upon-Avon and Swindon Jobcentre areas.

Visit www.universalcreditinfo.net to find out whether the full service applies in your area. From July 2017 the full Universal Credit service will be extended to 30 additional Jobcentres each month, until it covers the whole of the UK by September 2018.

Will I be worse off on Universal Credit?

It is likely that many families with disabled children will be worse off on Universal Credit. This is particularly likely if you are out of work and your disabled child doesn't qualify for the highest rate of Disability Living Allowance care component or the daily living component of PIP at the enhanced rate.

This is due to a cut in the basic disabled child premium under Universal Credit. Families with a disabled child who is in residential accommodation and who has 'looked after' status are also likely to be much worse off. Some working families may find they are better off on Universal Credit but this is now less likely as a result of cuts to Universal Credit work allowances.

For information on Universal Credit see our website www.cafamily.org.uk or call our helpline on 0808 808 3555



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



Zara talks to BBC Breakfast News about SEN support

08:18

Parent carer on Breakfast News

In July, steering group member and parent carer Zara Bowden appeared on the BBC Breakfast News sofa. She was responding to a report suggesting teachers are not being adequately trained or supported to support children with special educational needs in the classroom.

Talking about her daughter, Zarah said "She is a child first and foremost. What we need to do is to put education and support around her to complement the person that she is and to enable her to be the best person that she can be. Parents who don't feel that that is there need to contact the parent carer forum in their area, who are supported by the Department of Education to ensure they are engaging with their local authorities, engaging with their schools to have these conversations and to be brutally honest about the challenges that they're facing, so there's that transparency and everyone can feel as supported as they need to be."

Watch Zara's interview: www.facebook.com/bbcbreakfast/videos/1340636352617166

Get animated!

Family Voice Surrey have created a short animation called **Power in numbers**. The idea was to have a short, powerful film that communicates the concept of co-production, persuading parent carers to come together for the good of all.

They have made it available for all forums to use, either as it is, or by re-badging it with your own logo, which you can do by paying the animator a small fee.

You can view it at www.familyvoicesurrey.org

Find out how you can have your own animation:
email Fran Morgan at fran.m@familyvoicesurrey.org



Just like everyone else



Kingston and Richmond SEND Family Voices and Achieving for Children have produced a great guide to reasonable adjustments in educational settings. Working with schools, parents and young people the guide explores best practice. It includes real life examples offered by teachers, children and young people and their families around mobility, sensory issues, getting school work done, school trips and sports days, rewards and sanctions.

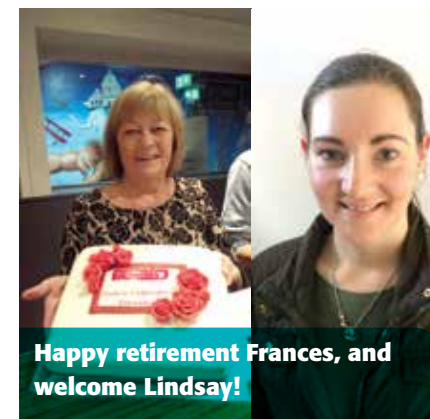
Download the guide and a three minute film about reasonable adjustments, made jointly with Achieving for Children and the local authority:
www.sendfamilyvoices.org/useful-documents/

All change in NI

It is a time of change for Contact a Family in Northern Ireland.

We say many many thanks and best wishes to Frances on her retirement, and welcome our new manager Lindsay, who has been Information Officer for the past three years. All the very best to Lindsay in her new role.

You can contact our Northern Ireland team at www.cafamily.org.uk/northernireland



Happy retirement Frances, and welcome Lindsay!

What is a parent carer forum?

A parent carer forum is a group of parents and carers of disabled children. Their aim is to make sure the services in their area meet the needs of disabled children and families. To do this they work with local authorities, health providers, a range of education settings and other providers. Parents or carers of a child with any type of additional need or disability are welcome to join.

For more information see www.cafamily.org.uk/parentcarerparticipation



Families get together for a forest walk in Wales

Moving on up (and out) in Wales

Contact a Family Cymru has a great history of providing workshops and social events for families in Wales. We are pleased to launch our Early Years Support Project, **If only I had found you sooner...** We will be running early years workshops for families of children under five in Wales, and developing our early years resources.

From 2012 to 2016, our **Lights, Camera, Connected** programme focused on running film show events, where families are able to join us at their local cinema to watch a family blockbuster, followed by lunch and a chat. We were delighted to find that last year 92% of the families that attended our events said they felt less isolated afterwards. We will now be working with Film Hub Cymru and some of the cinemas in Wales to advise and help them run a programme of disability and family-friendly film shows during 2016 and 2017.

When we invited families to share their views on our events this year, the majority of you were really interested in attending outdoor events – going on walks and rides, joining in nature activities, and taking part in camp-craft games. So we've applied to BBC Children in Need for funding to run a programme of outdoor events from 2017 onwards. Keep your fingers crossed and get those wellies ready!

To sign up to our Wales newsletter for regular updates please visit www.cafamily.org.uk/wales





Matthew

"Matthew is a truly amazing resilient person. He needs constant care and life isn't always plain sailing. He's charming, challenging, articulate and (so his brothers say) sometimes annoying!" says Mum, Judith.



Benjamin and Miriam

"My beautiful, wonderful, complex, autistic children. They are kind, empathetic and sassy. They love structure, stories and cuddles with family members. I will spend my last breath defending them against the ignorance of others. This is who they are, and they need no apology," says mum Karen.

Love, life, laughter

In May our Scottish office held a photography exhibition, ***My Family: love, life, laughter*** – a beautiful and uplifting collection that captures everyday life for families with disabled children across Scotland.

Award-winning photographer Rebecca Lee spent time getting to know two families: Matthew and his family, and siblings Miriam and Benjamin. Rebecca's images portray a day in their lives and capture the shared joy, exuberance and quiet reflection that all families can relate to. Parents across Scotland also shared their precious moments.



Alex

"Alex, our wonderful boy, is seven. He was diagnosed with severe autism at the age of three. Light, noises and smells adversely affect him – until we get back to nature."



Harry

"Harry is very musical, he's a good drummer and loves to sing! Harry has Tourette's syndrome. He is good fun and likes to have a laugh with his friends and family."

Dougie, left

"If people had more understanding they would be more accepting of Dougie the way he is – which in my eyes is perfect. He's the most wonderful, fun and caring little boy."

Melissa

"For ten years we have lived with the highs and lows of Smith Magenis Syndrome. We recently welcomed Luca into our lives – four legs and fluff! It's hard to describe the impact he has had."



Duncan

"My seven year old son Duncan has autism. He is my special wee man and life without him would be dull."

Celebrating achievements

At Contact a Family, we often hear from parents who have overcome huge obstacles getting the right health, social, and education support for their child. And sometimes the thing that makes them proudest is the simplest sign, or a word, or a smile from their child – at whatever age.

With this in mind, our Autumn/Winter edition celebrates parents', children's, and young people's achievements – or proudest moments – no matter how big or small.

And to go with the celebratory mood, this Autumn we launched our first ever Contact a Family Awards – to help us 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, which closed at the end of October.

We will be holding an awards ceremony and reception at the State Rooms in Speaker's House in January 2017. We know families love visiting Parliament and getting a chance to speak to MPs and Peers directly. We can't wait until January! We'll have lots of stories and photos to share from the event in the next edition.

(big & small)

The little things...

Marijka lives in Norfolk, mum to two lively boys: one on the spectrum and one not. Here she shares her experiences

I believe in miracles

We experience them every day. Things that people take for granted. It could be a prolonged period of eye contact, appropriately timed laughter at a joke, or funny situation. A full night's sleep. A clean trip to the toilet or a new food tasted.

One will never, ever realise just how much the tiniest little things can be so extremely important until they're not there anymore. Stanley said "mama" once and the odd beginnings of a word. But soon word dropped (that's a technical term) and he hasn't spoken since.

I believe in acceptance

It took me a long time to 'accept' Stanley's autism. On his eighth birthday last summer my husband and I, as a birthday treat, travelled to Chessington World of Adventures, staying overnight in the hotel. I remember the build up, we prepared as well as we could... symbols and social stories. We were looking forward to a 'normal' family weekend away.

We arrived. We left. Total waste of a four-hour journey. It was simply too much for Stanley. Sensory overload. Too busy, too loud and despite obtaining queue-jump wristbands we were still waiting longer than what Stanley (and us) could cope with. We were gutted, and after two rides and an hour's 'fight' to get him to stay (we had our youngest Buddy with us too) Stanley, using his PECs, communicated "I want help home."

So we checked out and we left. I think I cried all the way home to Norfolk.

The next day we went to the beach just five minutes down the road from where we live. We walked along the sea edge, climbed rocks, and enjoyed a picnic of prawn cocktail crisps, Haribo, and fruit shoots. Stanley had the best time and was so happy and calm. This was a turning point for me. It taught me that I have to accept that Stanley's expectations of a good time are not going to be the same as ours. Things that may excite children of the same age that don't have autism, won't excite him. And that a walk down the beach and a packet of his favourite crisps is enough. And finally, as sad as it is, to leave visiting such places to days when Stanley is in respite so Buddy doesn't miss out, and not to feel guilty for doing so!

I believe in gratitude

We accept we have to take each day as it comes. We are grateful for every opportunity or situation that brings us laughter – it's priceless. Those unique little traits Stanley has, and his pleasure in the little things.

I believe in celebration

I promise to celebrate the differences, not just in our child, but in us as parents. Celebrate the little things – because we know really, they are big things!

For better or worse we have grown, adapted, educated, and become better people for it, and, I hope... better parents.



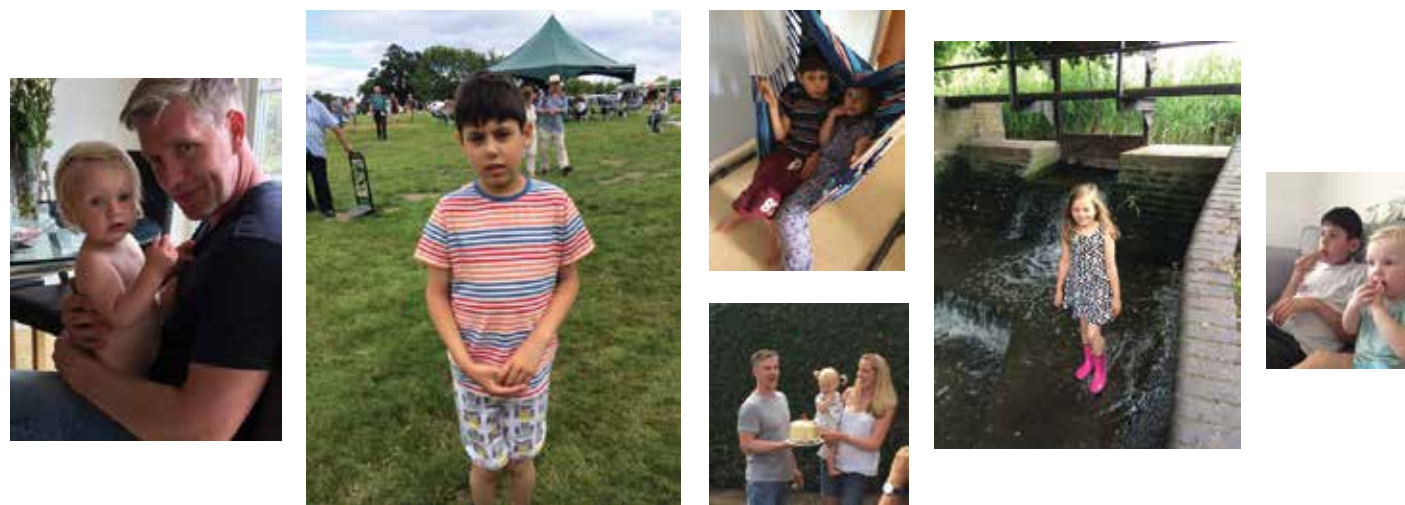
Marijka and Stanley

“Celebrate the little things – because we know really, they are the big things!”



A selfie with dad

Read more at Marijka's blog at: barberellablog.blogspot.co.uk



A perfect picnic

Alice describes a wonderful day at her son's short breaks centre, and tells us about the best buy of her life

I live in Hertfordshire with my three children, Jude 10, Elsa 7, Emmeline 12 months, and partner Joe, who is step-father to Jude and Elsa.

Today was a fabulous day. To start with, Jude, who has severe learning disabilities, decided he wanted to make his own toast for breakfast. Any sign of self-help in Jude is startling as he hates to try and do things himself as (I think) he is massively afraid of failing. This show of 'giving it a go' is a huge step for him and one I will definitely be encouraging.

I don't say it very often, but overall we've had a very positive weekend, and it has given me a great boost of enthusiasm. Yesterday Jude went out for a few hours with Jade (his support worker) and again late this morning. I'm amazed at how he comes out of himself when he's out with Jade and his other friends. It inspires me and shows me that my choice in encouraging him to have a support worker and to expose him to more social settings was the right thing.

A wonderful experience

So today was a special day. We went to meet Jude at Jubilee House as they were holding a family picnic event. I was so looking forward to being there with Jude to meet all his friends, the carers involved, and to just see the garden he talks about so much. It was such a wonderful experience. Jude was so proud and loved showing

us the sensory room, the garden, the sensory garden, and then later on when he needed the toilet, he told me he could go on his own and that

“ Jude decided he wanted to make his own toast for breakfast ”

I could wait in the hallway for him.

To see Jude be proud of something like this is truly wonderful. He behaved beautifully, smiled and chatted constantly, and even Elsa had a great time, running off to play with Jude or some of the other siblings (it also inspired me to arrange a siblings get together at some point!).

Time out for everyone

I cannot explain the feeling of constant activity that occurs when you have a disabled child, both within your mind and physically, from endlessly following them around the house/garden. You cannot rest, there is no chilling together on the couch and watching a film or playing games together. Centres like this are a life-line – parents get a break and siblings are able to do things they cannot readily do.

The children are so happy here and I'm actually proud of myself for finding such a setting for Jude to gain further skills and to make some friends. It's wonderful.

The best purchase of my life

So it turns out Jude's "big swing" as he calls it, has been the single best purchase of my entire life! All day he has asked if he can go and play on it, and after repeated prolonged periods of absence by Jude, I kept finding him like this...



Jude's new fave place

Or this...



It's amazing!! My mum bought him a radio today as well so he has literally spent all day in his room and he's just so happy. He even said to me this morning "Look at all the lovely things in my room mummy. I love my room". He never says that much or anything that meaningful, I was genuinely shocked, but thrilled he is so happy with it all.

He has been loathe to let Elsa anywhere near his room (he doesn't like her in there at the best of times), but remarkably, this afternoon... this happened...



MIRACLE!!! Harmony reigns in our house and the children are even being nice to each other. So thank you Family Fund for creating this amity and togetherness, by means of a hammock chair.

Need help to buy aids and equipment?

contact a family
for families with disabled children

It can be a struggle financially, emotionally and physically for families raising a disabled or seriously ill child. Our guide to **Aids, equipment and adaptations** has information on how to get equipment and mobility aids your child may be legally entitled to. You will also find information on equipment for play and leisure, borrowing equipment, buying second hand equipment, financial help, VAT relief and useful contacts for specialist support. There are also a number of grant-making trusts that help families with funds for items not supplied by statutory services. Call our helpline and ask for your free copy of our guide. You can also ask for our list of grants for families with disabled children to be sent to you.

The Family Fund is one of the largest grant-making charities for families with disabled children. They will look at any grant request that relates to the needs of a disabled or seriously ill child or young person. This might be furniture, clothing, bedding, sensory toys, computers or tablets, or a family break. For more information see the *How to apply* pages at www.familyfund.org.uk.

Our freephone helpline can help with any aspect of raising a disabled child. Contact them on **0808 808 3555** or email **helpline@cafamilly.org.uk**

You can read more about life with Jude on Alice's blog, livingwithajude.co.uk

On the right track

Oliver's life-long passion for transport and trains pays off. Proud mum Carol tells us how her son followed his dream



My son Oliver left school this year. Oliver is deaf and partially sighted and, like other parents of children with additional needs or disabilities, we had been busy during his 14 school years. This included getting him a statement, ensuring the provision was adequate in a mainstream primary setting (and that it was actually provided), getting him funded to attend a secondary school for the deaf, and even going to tribunal to ensure that he received enough speech therapy.

Choices, choices

Over the years we have got used to doing these things, and knowing he is being supported and encouraged by professionals who understand about special educational needs. However, Oliver didn't want to go to university, and decided to look for an apprenticeship instead. We had to confront the reality that he would leave the security of the

education system at the age of 17 (as he wouldn't be 18 until the end of August) and join the real world.

Oliver didn't take any A levels as he chose to do a BTEC Extended Diploma in IT. He was thrilled that he would only be studying IT, and no other subjects! His time in sixth form passed peacefully without any issues, but by the start of 2016 his leaving date felt very close. It seems to be the case that apprenticeship schemes don't recruit until quite close to their start date. This is

“ We are so proud of Oliver for getting through a lengthy application process, an interview and an assessment ”

difficult for anxious parents who want certainty about what their young person will be doing in September!

All aboard!

As a train and transport enthusiastic, Oliver had been busy keeping a keen eye on the Transport for London website, and in particular the information about their apprenticeships. Applications opened in January, which is much earlier than many other organisations, and Oliver submitted his straight away. He made it through that stage, and two more



“ He is enjoying the work, and coping with the long commute to London ”

online stages, and then he was invited to a half-day assessment and interview at the end of March. He found out a couple of days later that he had been offered an apprenticeship, starting in September 2016.

Going well so far...

It's difficult to describe how delighted we felt. We are so proud of Oliver. Transport for London offered him additional support during the selection process, and has procedures in place for disabled staff. He will also be supported by Access to Work. It's a relief to us that Oliver has had a smooth transition from education into the world of work. We're delighted that he has been able to follow his interests in transport and computing, and that it is all going well so far – he is enjoying the work, and coping with the long commute into London every day. His longer term plan is to move to London, but I'm not even going to think about that yet...!

A DREAM COME TRUE

Tammy arranges a surprise visit for her son Louie

On 8 October I gave birth to a beautiful little boy called Louie. Our journey didn't start out like many others as Louie was diagnosed with Holt-oram syndrome.

Holt-oram syndrome is the name given to the association of heart defect and upper limb abnormalities caused by the mutations (changes) in the TBX5 gene. Approximately 1 in 100,000 births.

Louie has a complex congenital heart condition, and one of the most difficult to deal with (which is a single ventricle pumping circulation). He has undergone three open-heart surgeries, but this still means his heart and circulation will never be normal, and as he ages his heart will need increasing support. During Louie's last surgery he had a permanent internal pacemaker fitted to help with his heart.

Louie also has foreshortened arms with one hand attached just at his elbow. Both Louie's hands are flexed inwards with absence of both thumbs. So in our house we do high fours, not high fives!

Louie is a massive Chelsea FC supporter and over the years we've attended their Easter egg hunt and family fun day. However, I wanted to give Louie something special so I asked our local Contact a Family worker Charlotte Amison if she could help. She contacted Chelsea, then a lovely lady called Sally Mills, their charity administrator, wrote back to Charlotte to say myself and Louie were invited to watch Chelsea on their training day, with a chance to meet the players.

I was so excited, I kept it a surprise from Louie. When we arrived we got to sit in the players dug out and when I explained to Louie what was happening his face was priceless. To be within metres of the players and sitting in their seats was amazing. When the training session finished we waited in the tunnel and as the players came off the pitch, they signed his top and stopped to take some photos. It was an experience like no other and Louie was truly in his element.

This was an opportunity that wouldn't have happened without the help of Contact a Family, Charlotte, and Sally, and we thank them all so much. However, it didn't stop there as Sally then invited us back to watch Chelsea FC vs Bristol Rovers. This was Louie's first football match and he loved every second, chanting the whole way through. No words could thank them all for giving Louie these memories.



A challenge like no other

When Shirley decided to take on a mighty 100k walk for Contact a Family, it reminded her of other challenges she's faced, bringing up her daughter Felicity. Here she tells her story.

Saturday 10th September 9am. The grey, damp weather was in contrast to the bright jittery excitement of our team of 19 walkers – Contact a Family staff including Amanda our CEO, plus family and friends – waiting expectantly at Putney Bridge to start the 100k (62 mile) Thames Path Challenge.

I was panicking but it was far too late to turn back, and having a disabled child has given me useful life skills, such as how to keep going against all odds. I also knew the Contact a Family team would support me, and OK, this time it was just a fundraising walk, but it was something small I could do for Contact a Family so that they can afford to continue to support thousands of families like mine through all the challenges and fights that result from having a disabled child.

A different world

When Felicity was six months old she suddenly started having seizures and our world

stopped, wobbled and started again, but differently. Our daughter has severe learning difficulties, selective mutism, anxiety issues, and uncontrolled epilepsy.

A social worker said to me "You either will cope, or you won't". I know families in the disabled world who have broken, parents who have literally come to the end of their endurance levels and left their child at school. I know mums who have driven off and disappeared, families who have split up, and siblings who have gone off the rails. All of these families were begging for help that should have come automatically from their local authority, but until they broke, none was given.

Each fight is a journey

Felicity is 19 now, and has just started at Young Epilepsy, a brilliant specialist college in Surrey. It is the perfect place for her, but securing the right Education Health and Care plan, with the right named provision, was just the latest battle in 19 years of exhausting and draining challenges – challenges to get the right health care, welfare, respite, and support.

Each fight is a journey, not dissimilar to taking on a long non-stop hard walk. This one began well. The special educational needs team caseworker agreed with the teachers that a term time residential place would be the best provision. We took precautions – a solicitor came with us to the initial meeting. He emphasised the risk of sudden unexpected death due to epilepsy and Felicity's extreme vulnerability.

By law, the cut-off date for the completed plan was 31 March. This is so that parents have time to carefully prepare their children for a new experience.



Out and about with Felicity



Me, Natalie, Lawrence, Felicity, David, Beth

“ When Felicity was six months old she suddenly started having seizures and our world stopped, wobbled and started again... ”

On 29 May, eight weeks late, we got the Education, Health and Care plan through. The local authority agreed to fund a day placement at the college, but only because the local mainstream college (totally unsuitable) had refused to take her.

Proud to be a pushy parent

Having Felicity has taught us to be proud to be pushy parents. We fight to keep her needs at the centre of every single battle with the local authority. It was vital to her future independence that she had a residential term-time place.

I slept with Felicity every night so that when she had a seizure I could administer her medication immediately. It was exhausting and not very good for my marriage. The college has night staff and medical experts on hand. For the first time our daughter would be able to sleep in her own room. We had to fight on. We asked for her case to be heard at tribunal, and when we still hadn't heard anything a month before the start of the new term we asked for a judicial review of proceedings.

The thing about being a parent is that these fights have to be picked up at the end of a normal working day. They require endless letters, phone

calls, lobbying, and legal advice. They are extremely stressful. Felicity is incredibly sensitive to atmospheres and because she can't articulate anxiety, her behaviour deteriorates. Our family was caught in a tightening spiral of distress.

We did it

We were lucky. Suddenly, three weeks before the college started, our solicitor rang. His counterpart in our local authority had looked at the paperwork and decided they had no case. Our daughter had her placement. Just like that, it was over.

Felicity started college at the beginning of September. She is very happy and already is talking more, going out more, making friends, just like her sisters and brother did when they started University.

We miss her, but luckily her first weekend coincided with the 100k walk. The walk kept me occupied, there were funny moments, stunning views, aching legs and blisters, and times when I thought I would not be able to move another step. But The Contact a Family team were there and we crossed the finish line hand in hand. We did it. Thank you.



SPOTLIGHT ON... SIBLINGS

Shirley's daughter Suzy tells us what it was like growing up with her sister Felicity

Tell us about your family

We live in Surrey, and there's seven of us including mum and dad. I'm the eldest of five, four girls and my brother in the middle. We're all in our twenties now other than Felicity, my sister, who has epileptic seizures and learning difficulties.

How did you find out Felicity needed support?

We were told fairly quickly and nothing was ever hidden. Felicity was just a baby when she started having seizures. I was only eight and the others in between. Soon after the seizures started somebody – a doctor, I think – told my mum that Felicity would be bed bound, that she'd never walk or talk. Fortunately my mum wasn't having any of that, and as a result Felicity can do all of these things and more.

How did this affect your family life?

At the time, we all just got on with it. My parents didn't know what was going on for a long time, so there was a sense of uncertainty, but they always told us what was going on, so Felicity being in and out of hospital with my mum all the time became normal. We've always supported each other and it's made us very close. Looking back, I was incredibly lucky to feel so secure, but I think it was due to my parents being so open and supportive.

How have other people reacted to your situation?

It's got easier as Flissy's grown up, because she's become more independent. There's a tendency to view the situation either as if we're martyrs, or as if Felicity is, which is silly. We're all just people getting on with it, regardless of our abilities. We can all be wonderful, and we can all be nightmares!

What are your hopes and dreams for yours and Felicity's future?

I'm an actress, writer, and I run a theatre company now! Over the past few years Felicity has started to read which has been brilliant. She loves to go shopping for notepads and pens, and write. She loves it when we're all together. I hope that Felicity will be happy and safe, however that turns out.



SUZY'S TOP TIPS

Don't be afraid to ask for help if you're finding things tough. It is hard, and it can be scary, especially when the adults around you don't know what's going on either.

It's helped me to see difficult or upsetting situations as challenges. This keeps me feeling much more positive about any situation, even when I'm scared or worried about what the outcome might be.

I also try to take every day as it comes and just do my best on that day, because you never know what the next one may bring.

It's so, so, so important that you have fun! Go out and see your friends and laugh as much as possible! Fun should be made compulsory.

It's OK to get upset about things like homework, or exams, or arguments with friends. It might feel sometimes as if you can't be upset about those things because other things to do with your sibling might seem more important, but whatever you feel is OK.

The most important thing is to find people you feel safe talking to about how you feel. And never feel guilty, or bad, if sometimes you just need a break.

Practice makes perfect

Starting a new school can be a real concern for parents, but sometimes our children cope better than we think. One mum shares her experiences

Our 11 year-old-daughter is on the autism spectrum and has just started Year 7 at a mainstream high school. She was not diagnosed with autism until she was eight, so we had many years of wondering why she was different to other children. We thought we were useless parents because she did not do things that children her age managed with no bother, such as using the toilet, or joining in play with others – and she had to be read **Goldilocks and the Three Bears** every single night for three years.

Falling through the net

When the diagnosis came through, and the psychologist told the Year 4 teacher that our daughter had autism, she replied "I find that hard to believe" because "she can speak"! We knew we'd struggle to get any support from her. The psychologist recommended School Action Plus and we didn't find out until the end of year that the teacher never implemented it. We took the strategic decision not to go to battle with her and waited for a new start with the Year 5 teacher.

Year 5 was a dream! The Year 5 teacher put her on the special needs register, set her some 'soft' targets to pay attention, organise her work and not panic when she doesn't understand. He even arranged adaptations on her chair to help her sit still.

Unfortunately, when we met the high school SENCO, we found out that our daughter had not been on the special needs register list sent over to the high school. If we had not been proactive in making an appointment with the SENCO, the school would not have known our daughter had autism! We had great anxiety about the transition to high school and worried how she would manage the change of setting with different teachers for each lesson. As always our children will surprise us!

Organisation is key

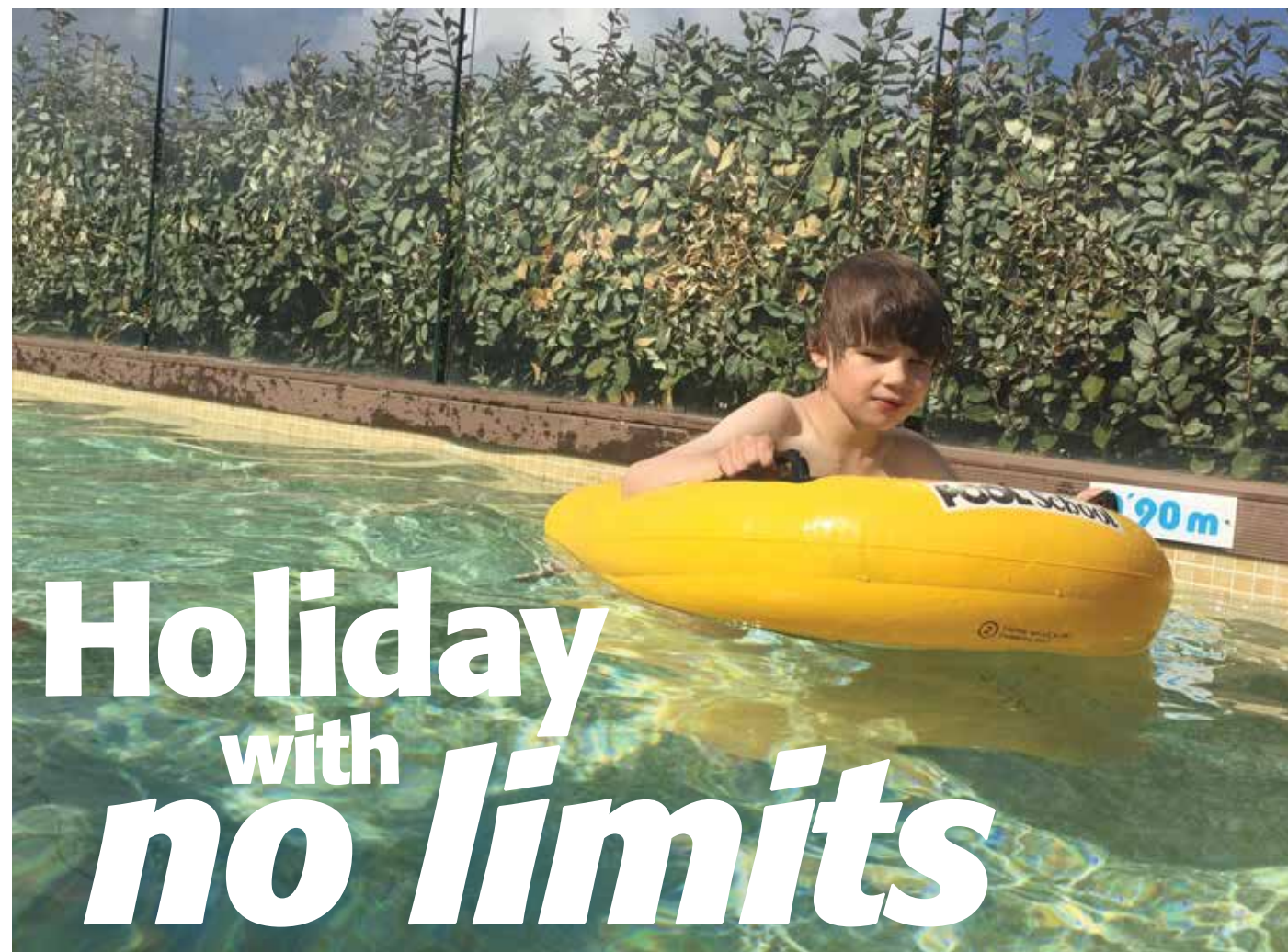
She has enjoyed high school from day one. She makes lists of things to remember, keeps notes in her diary of homework deadlines and insists on going to school for 8am every morning to make sure she's ready and knows where she needs to be for that day. She also came up with the idea to practice wearing the new uniform every day over the six weeks holidays so she had time to get used to the feel of it and figure out any sensory issues before September.

At lunch time she brings a packed lunch to avoid the stress of queueing and deciding what to eat. The first few days, she spent lunchtime in the school library to give herself time to de-stress and get centred again before afternoon lessons, but has now started to spend some of break time with other children.

“ We are really proud of how she has managed to figure out her own strategies, and are hopeful that she'll continue to find the school a positive experience ”

We are really proud of how she has managed to figure out her own strategies, and are hopeful that she'll continue to find the school a positive experience.

Our daughter will never get an Education, Health and Care plan because she achieves academically, but she needs support for the social aspects of school life. We have found that being positive, politely persistent, gritting our teeth and not falling out with the teachers has worked best in getting the support our daughter needs.



Wendy tells us about the fun and games on an activity holiday with her children

The car was packed to the brim with teddies and meerkats and us: myself, Chloe, 8, and brother Josh, 6, who has Norrie disease and is blind. We set off to East Sussex, all set for a fun-packed PGL Activity Family Weekend superbly organised by VICTA, a charity for blind and partially sighted children, young people and their families. We had no idea of what to expect and as we got lost en-route I was trying to banish those 'oh no what have I done now?' and 'Is this such a good idea?' thoughts...

As soon as we arrived, we were greeted by a sea of lovely and very cheery VICTA staff and volunteers. The families who had already arrived seemed settled, relaxed and very friendly. The welcome sound and sight of canes gently clapping away could be heard and that feeling of 'everything's going to be OK' settled in. We were introduced to Daz, one of Josh's helpers and a wonderfully

energetic member of the team who helped us transport our car load of totally unnecessary paraphernalia to our room.

The three of us were sleeping in a room with three bunk-beds – yeah no need to argue over top or bottom... or so you would think. We all trotted off to bed at 9.30pm having had a lovely evening of introduction games and singing. Chloe could have gone on til midnight.

Let the fun and games commence!

Saturday morning was when the real fun and games started and this lasted for three whole days – yipppeeee! As I said goodbye to the children for their first drop off with their groups, I couldn't help but take a sneaky peek over my shoulder as they departed and wonder what on earth was going to happen to them over the next three hours and would they need me? Well the answer was



absolutely not. In fact, I'd only have cramped their style.

Between them, Chloe and Josh conquered the climbing tower, they scaled a rock climbing wall, they roved around in pitch black underground tunnels (I think Josh had a distinct advantage here), made rafts, plunged themselves into icy cold water and scaled a ridiculously tall totem pole – the goal being to stand on a piece of wood on the top the size of a pizza box – whatever next?!

In full swing

On one occasion I could hear shouts of 'meerkat' echoing round the grounds. And sure enough there was Josh gently swinging from his hoist, half way up the climbing tower, having far too much fun bouncing off the walls yelling 'meerkat' down to his helpers below, who presumably were shouting 'meerkat' to encourage him to go just a little bit higher... but no, why would he change a thing when he could swing where no one could reach him whilst making them call out his favourite thing in the whole world? He's not daft you know!

Stuck in a tunnel

Then it was the adults' turn to do all the things their little treasures had done. No problem, easy as pie... right? Ok, not to go into too much detail but scaling the totem pole and balancing on a pizza box with two dads was the most terrifying thing I've done after childbirth (not a great comparison, sorry!). I loved my team, they were wonderful people and we laughed so much – rediscovering that we never did have a

particular skills at netball but we were good at getting stuck in tunnels whilst trying to escape the rats that we were told were down there. The 'rats' were in fact ten children that Alex lovingly let loose in the tunnels once all four adults were firmly stuck, wedged and lost in the tunnels. Terrifying.

Until next time!

When it was time to say goodbye I said a big thank you to Daz and the other volunteers and Daz's reply was one that will stay with me. He said "Thank you for trusting us with your blind son and letting me throw him off a 40 foot climbing tower! I've never worked with a completely blind child before".

Well thank you Daz as Josh has never had the opportunity before to work with a volunteer who would chuck him off a 40 foot tower!!!

One of the biggest messages I took home from the activity break is that there is really no stopping and no limits for our visually impaired children.

“ Would they need me?
Well the answer was
absolutely not. In fact,
I'd only have cramped
their style ”



Dealing with sensory issues

Many disabled children need help to deal with an often overwhelming world. Here, Mary talks about supporting her son

Our son Alex 'flapped' from a very young age. We've got lots of pictures of him in his pram, arms and legs moving wildly as he became excited. We didn't know what it meant at the time and dealt with other issues as he developed, prioritising his speech, language and physical needs. We also had to cope with him stopping eating and got support from specialists at Great Ormond Street Hospital for that. It's all part of his sensory profile.

Hidden senses

We all know about touch, hearing, sight, smell, and taste, but you may not know that there are two more sensory systems: proprioception – knowing where your body is in space, and vestibular – relating to posture, bilateral sequencing (moving the two sides of the body in a coordinated manner), visual field, arousal levels and attention.

Alex is affected in most of these systems and it affects all aspects of his life. For example, his difficulties regulating vestibular feedback means he can fluctuate between seeking behaviours (such as rocking, waving his arms or fingers) or becoming over stimulated. His poor proprioceptive processing is seen through sensory seeking behaviours such as squeezing others and jumping.

You can read more about sensory issues and behaviour in our guide *Understanding your child's behaviour*, available free to parents who contact our freephone helpline on 0808 808 3555, email helpline@cafamilly.org.uk or download it at www.cafamilly.org.uk



He needs support to regulate his sensory needs. When he's under-aroused he can seem tired and lethargic and needs alerting activities such as using a swing or riding a trike. When he is over-aroused he can laugh a lot and become upset. Then he needs calming activities like wearing his weighted vest or using ear defenders. All of this is written up in Alex's 'sensory diet', and the aim is to support him to remain calm and alert.

It's been a very difficult journey for us as a family because these needs were largely not recognised or accepted in our local area. It felt like if they didn't identify his needs or support us they would simply go away. In the end we had to get private assessments and go to tribunal to get his needs recognised and met.

Children like Alex need people who understand them, a flexible curriculum and a sensory diet to maintain a calm, alert state. When that doesn't happen or people don't understand him he'll get more upset. This contributed to his breakdown at school a few years ago and he had to stay at home for a year and a half. Fortunately his current school provides the specialist occupational therapy input he needs.

TOP TIPS

Understand the different needs of your child – although sensory issues can and do affect behaviour and emotions, we see these sensory needs for what they are and respond to them through the 'sensory diet'.

Remain calm at all times and know what works to help your child remain calm and alert otherwise they'll pick up on your stress and it will become worse.

Have the right aids to help in the right way and at the right time – weighted vest, theraputty, weighted blanket, ear defenders etc.

Tasks can also help, such as carrying objects or deep pressure by pressing hands on shoulders. Not all aids have to be purchased, some can use physical support or swings at home or in the park.

If you child has vestibular issues and likes to rock say, think carefully about your furniture choices. As our children get older furniture strength is very important.

Tell it like it is

Claiming Disability Living Allowance for your child can be daunting, but with the right guidance you can make a successful claim. Sue shares her tips and experiences

My son, Freddie, was diagnosed with autism when he was three years eight months old, after suspicions that he was not meeting his milestones by the age of two.

I cannot recall if I was told about Disability Living Allowance (DLA) at the time of Fred's diagnosis and it did not sink in, or I was not told at all. Anyway, after two or three years I did know about it, and did a little research into what needed to be done. The general advice was that you never say "but", and that it is "all the time, every day"!

When I received those very extensive forms that daunt us all, I took a very firm view that I could easily tackle this, because, as it goes, and as sad as it may be, I love a form!!

The very small boxes that they provide you with to complete questions such as 'Does your child have communication problems, if so for how many minutes of every day...' did not sit well with me. I added 'see Appendix 1', which ended up being two A4 pages long on all the communication problems that he had, with so many varied examples of how they affect him that it would bore anyone senseless.

I did, in fact, do this with every question. This amalgamated into a very long application, which would have taken the most enthusiastic reader a fair amount of time to get through.

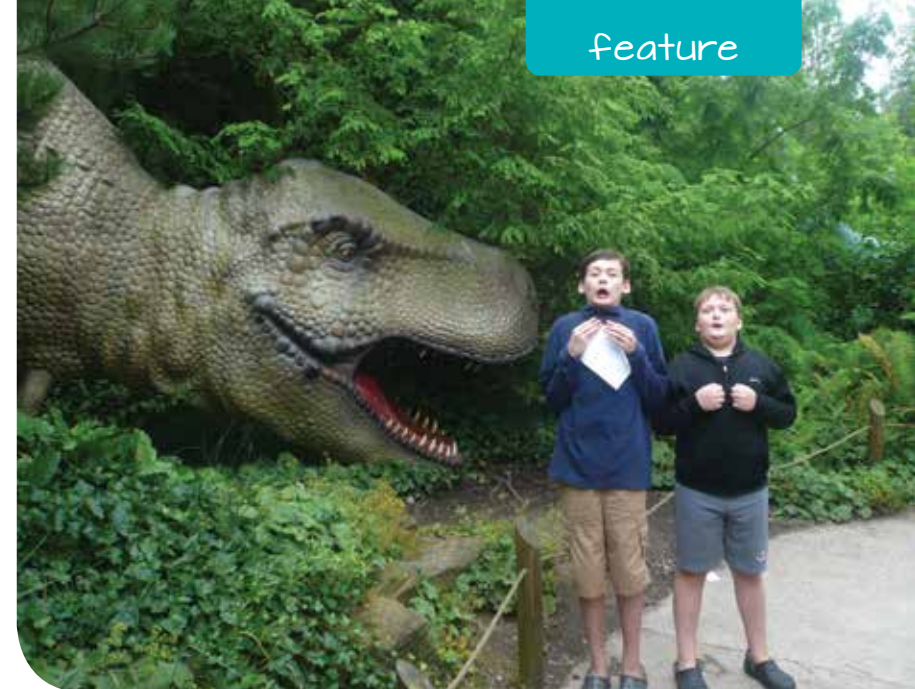
When you have a child with autism (or in fact with any disability) certain things, such as communication or sensory issues, are fairly consistent

throughout their lives. If my son has communication problems then he has problems communicating all of the time and, this is what I added to my form. If my son does not have a sense of danger where he would talk to anyone, believe anyone, walk away with anyone, step out into the road without looking or wander off without a word, I would say that he never has a sense of danger, and this happens "all of the time", "every minute of every day".

During the course of my work I have spoken to quite a few parents of children with additional needs who have not even thought of these things. Even if they have neuro-typical children without additional needs, it is not obvious to them that they are providing extra support. They are simply looking after their vulnerable child.

My son is in receipt of DLA up until he is 16, when this will stop and then we have Personal Independence Payment to deal with. I do know that this will be a challenge, but one that I am ready to take.

Freddie has a great sense of humour and is a very funny, affectionate and loving young man. Because of Freddie, I have a job with Lewisham Parent Carers Forum which I thoroughly enjoy – I have met some wonderful people, many of whom have become good friends. I am more confident, more outspoken and more knowledgeable about disability than I ever thought possible. Most of all, I am a kinder more patient person, I think! I am so lucky.



You can find out more about claiming Disability Living Allowance, the main benefit for disabled children, in our guide *Claiming Disability Living Allowance for children*. It has helpful tips on filling out all the questions on the form. For a free copy, contact our freephone helpline on 0808 808 3555, helpline@cafamilly.org.uk or download it from our website.

If you live in Lewisham get in touch with Lewisham parent and carers forum for local news and info www.lewishamparentcarer.org.uk

Step into the moment



What is 'mindfulness' and how can it help families with disabled children?
Dean Wilson of relationships charity One plus One explains

Mindfulness is a moment-to-moment awareness of thoughts and feelings. It has become a popular way for people to let go of their stress, and to 'find' themselves in the midst of their daily (and often very busy) lives.

If you are the parent of a disabled child, you might benefit from practicing mindfulness in:

- your relationship with your partner
- your role as a parent.

Studies have shown that practicing mindfulness helps foster positive feelings like contentment, self-awareness, empathy and self-control. It soothes the parts of the brain that produce stress hormones and builds those areas that lift mood.

The practice of mindfulness can be a guided process – there are a number of exercises that can be used by everyone – you don't need to attend a class. But you can also practice mindfulness simply by concentrating on your own breathing, or what you are doing at each moment – for example walking down the street and paying full attention to everything around you, or peeling the potatoes!

There are many mobile apps that have guided processes for mindfulness. They can be a helpful option because they can introduce you to the concepts of mindfulness and they can sit in your pocket for the opportune moment. Even if you only have time for 5–10 minutes it can still be very beneficial. It's worth doing a bit of research to find an app that you enjoy using as the practice of mindfulness becomes more powerful when it becomes a daily habit.

Your relationship with your partner

We all face stressful, difficult and challenging situations, and our relationships would probably be a lot stronger without them. But it's far too idealistic to expect stressful moments will completely go away; they are a fact of life in any relationship. Families with disabled children have to cope with significant emotional, social, physical and financial pressures, and everyone has different coping styles. Mindfulness can help us with our reaction to stressful events. By mentally preparing the mind and the body, we can be less controlled by situations when they occur, and we can handle conflict better. By

“ Mindfulness helped me to deal with my problems and anxieties. It taught me to live in the here and now and to breath into my problems ”

being truly 'present' with our partners, we can become better listeners and focus on how to improve the problems we face. This creates some space for us to be the best versions of ourselves for our partners.

Your role as a parent

In a study that was carried out on mothers with disabled children, mindfulness led to 'significant improvements' in:

- stress
- depression and anxiety
- sleep quality
- life satisfaction.

So why not try out some mindfulness today? Search for 'mindfulness apps' to find information about free and paid apps, plus reviews for them.

Charity One plus One has a site for couples on relationships help at thecoupleconnection.net



Resources

Mindfulness Techniques for Children and Young People: A Practical Guide by Stan Godek

Published by Children in Scotland
£16.99 ISBN: 978-1-901589-92-4



This unique book by Stan Godek, one of Children in Scotland's regular trainers and a renowned expert in mindfulness techniques, gives us an invaluable insight into how children think and feel. Based on scientific and psychological research, it gives parents the tools to help them develop positive life-skills and self-calming techniques.

Chapter One takes us through a history of mindfulness, from its origins in early eastern philosophy to its more recent use in the fields of mainstream medicine and mental health. However, as Godek says, 'mindfulness work with children is not about teaching them to meditate or to practice yoga. It involves the therapeutic use of particular breathing and meditative techniques but it is also about relaxation and enjoyment, imaginative thinking and having fun.'

The book has a useful explanation of what stress is, and what happens to the chemicals and hormones in our brains and bodies when we experience it. It gives examples of how to help children and young people who are experiencing stress or distress, plus ways to limit its effect.

Godek gives us a step-by-step guide to creating the right environment for practicing mindfulness, with simple instructions parents can follow to recreate the exercises in the book. The exercises help children reduce not just tension but pain (including chronic pain) and discomfort, and introduce them to the concept of 'inner strength' and their 'inner smile'. They have also been shown to reduce behaviour that challenges.

Written in a warm, straightforward style with a great sympathy for children and young people, I recommend this book to all parents. You will learn something new and valuable about yourself and your children.

Karin Beeler karin.beeler@cafamilly.org.uk

Royal Blind School students and staff in Scotland have produced a short film about mindfulness. Students with visual impairment and complex needs are learning soothing techniques to help them deal with the stresses of everyday life. Watch their film by going to Youtube and searching for 'Mindfulness Royal Blind'.



The wheels on the bus...

For many parents who call our education helpline, it's not school or college that's the problem, it's getting there and back. Our experts answer some commonly-asked questions

My 10 year old daughter is a wheelchair user - I've been told I can't get help with transport as we live within 3 miles of her school.

Incorrect. The law says that free transport help must be provided for eligible children of compulsory school age (5–16). Pupils who cannot be expected to walk to school because of a special educational need, disability or mobility problem are eligible for transport, whatever the distance between home and school.

My local authority says I must use my seven year old daughter's Disability Living Allowance to pay for transport.

The local authority must provide transport to the nearest suitable school for eligible children. It's not lawful to take Disability Living Allowance into consideration when making a decision to provide transport.

My 13 year old son gets transport to his special school but it's an hour long bus journey with several other children. He has sensory difficulties and arrives at school very stressed.

Transport needs to be suitable, and your child needs to arrive at school ready to learn. Some children may need individual transport arrangements: for example, an escort, an individual taxi or a mileage allowance if you want to use your own car. Discuss options with your local authority transport team.

My 15 year old daughter has autism and it's a struggle to get her to school on public transport. But my local authority says they only provide transport to pupils with physical disabilities.

Your daughter is eligible for transport if her special educational needs or disability would prevent her from walking to school – this is the only test that should be applied. It is unlawful for a local authority to have blanket policies which exclude particular groups. Beware statements such as 'We only provide transport to children with EHC plans/physical disabilities/children attending schools in this local authority'.

I want my son to go to primary school in the next village as they have a good reputation for special educational needs. But my local authority won't provide transport as it's not our nearest school.

The local authority only has to provide transport help to the nearest suitable school. They can refuse transport if they consider that a nearer school could also meet your son's needs.

My son has turned 16 and from next September the local authority are stopping his transport to school.

Transport for young people over compulsory school age is provided at the local authority's discretion and they can charge for this age group. However, local authorities do have a duty to ensure that young people can access education. Your local authority should assess your son's needs and provide transport help if required. Local authorities should provide transport to help disabled adult learners over 18 get to a college if needed.

TAKING ACTION

If you are not happy with a transport decision, check the local authority policy and appeal.

Every local authority must have a school transport policy and a separate policy for young people over 16. This should set out how decisions are made, and the appeal procedure and deadlines. In challenging a decision it's important to include supporting evidence of your child's need for transport.

If an appeal fails there may be further action you can take to resolve the situation.

Call the helpline on 0808 808 355 for advice.

contact a family
for families with disabled children

Personal Independence Payment and other benefits at 16

Information for parents of disabled children in England, Scotland and Wales



New guide for parents – Personal Independence Payment and other benefits at 16

Our new guide has advice and information for parents about Personal Independence Payment (PIP), the benefit that's replacing Disability Living Allowance for people aged 16–64. It looks at what tests are used to decide if someone gets PIP and explains how the points system works, including the often confusing terminology on the claim form. Plus other benefits and rights entitlements when a child reaches 16.

All our guides are free to family members who contact our freephone helpline on **0808 808 3555** email **helpline@cafamilly.org.uk** and are free to download from our website.

Palace fan gets on his bike

Our supporter Stephen Kingdom – a die-hard Crystal Palace FC fan and passionate cyclist – is taking on a huge challenge to raise money for Contact a Family.

Stephen will clock up a phenomenal 6,000 miles as he cycles to and from the 38 Eagles' matches during this Premier League season as he aims to raise at least £10,000 for Contact a Family.

Stephen kicked off his epic cycle adventure on 13 August and will finish on 21 May 2017 with the away match at Manchester United.

You can sponsor Stephen's cycle challenge by texting CPFC16 £5 (or your preferred amount) to 70070



Our North West team meet Stephen at Burnley FC

MISSED OUT ON A MARATHON PLACE?

We still have places! The Virgin London Marathon will take you through London's most iconic landmarks through thousands of cheering spectators. You will have a wonderful day soaking up the electric atmosphere.

Our fundraising team are on hand to offer you training and advice from the word go. We will be there on the day to cheer you on with our super cheering squad and provide cheer gear for your supporters. After the race you'll receive a goody bag to thank you for all your kind efforts in supporting families with disabled children.



How do I sign up?

We'd love to have you on our team! To express your interest in one of our marathon places contact our fundraising team at fundraising@cafamily.org.uk or call 020 7608 8786.



Our Thames Path Challenge crew

Help us keep you connected

Because we're a charity, we need to be sure you're happy for us to keep in touch. If you have recently received a letter or email from us, please give us your permission to stay in touch. This will ensure you'll keep hearing about the positive ways Contact a Family can help you!

Just go to www.cafamily.org.uk/here



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

ABERDEENSHIRE

Galaxy Group

Support, advice, and information for parents and carers around the transition process.

07516 852 814

info@galaxygroup.org.uk

Rainbow Rogues

For families with children aged 0–5 who have additional needs and their siblings under school age. Meet every Tuesday and Thursday 9.30–11.30am term time.

rainbowrogues@outlook.com

07756410118

BERKSHIRE

Swings and Smiles

Meet every second Tuesday of the month 9.30–11.00am. Sessions aimed at under fives. Soft play Monday 9.30–11.00am. Lego club and sibling support. laura@swingsandsmiles.co.uk www.swingsandsmiles.co.uk

BUCKINGHAMSHIRE

National Autistic Society Milton Keynes Branch

Meets once a fortnight, Wednesdays 9.30–11.30am with a small play area for pre-school children. Evening social group meets monthly.

NASmiltonkeynesbranch@nas.org.uk

07827 662 052

www.facebook.com/NAS-Milton-Keynes-Branch

Rainbows Coffee Afternoon

New group for children aged 0–4 with additional needs in Aylesbury. Come to our coffee afternoon to discuss what the group is going to be about and meet other parents. Children welcome.

wstanley@Spurgeons.Org

CAMBRIDGESHIRE

ADHD Support Group

Meets once a fortnight during term time at The Queen Mary Centre, Wisbech.

Marlene.Hall@cambridgeshire.gov.uk

Big Journeys Begin With Small Steps

For parents of children with Down syndrome from birth up to school age and expectant parents in Huntingdon. Meets every Friday afternoon. Once a month meetings support school age children upwards. bjbwsmallsteps@gmail.com

Cambridge Baby and Toddler Down Syndrome Support

Meet on the first Saturday of every month (except Aug) from 10.30am–12.30pm. All children including siblings can play with toys. With outside safe play area. laura.parton@gmail.com

CHESHIRE

Autism Together Children and Family Services

Support to children and families affected by autism.

info@autismfamily.co.uk

www.wasfamily.co.uk/

CHAPS – Cheshire Autism Practical Support

Children's activities, support for adults on the spectrum and run the autism Attention Card in conjunction with Cheshire Police, NW Ambulance and Cheshire Fire.

admin@cheshireautism.org.uk

0844 850 8607

www.cheshireautism.org.uk

Cheshire and Warrington Carers Trust

Monthly parent carer support groups and coffee mornings around the county – Crewe, Poynton, Congleton, Northwich, Ellesmere Port and Macclesfield.

sarah@cheshireandwarringtoncarerscentre.org

www.carers.org.cheshire

CUMBRIA**Cerebral Palsy Support Group**

For parents, carers and individuals. Everyone welcome! Meet on Thursday mornings, 9.30–11.30am term time only at Wild Zucchini's. rachaelhdavies@hotmail.com **07515 596 262**

Cumbria Down Syndrome Support Group

For people with Down syndrome and their families and carers. Monthly meetings and regular social activities. cardowns@hotmail.co.uk **07966 659 238**

DORSET**Dorset Deaf Children's Society**

Information and support for hearing impaired children and their families. Education and benefits advice, meet other children and families. info@dorsetdcs.co.uk www.dorsetdcs.co.uk/

DURHAM**Dyspraxia Support Teesside**

Fortnightly meetings for young people affected by dyspraxia, to help them achieve their goals. prithjit@roseberrycommunityconsortium.org **07804368585** www.dyspraxiasupport.org

EAST SUSSEX**National Autistic Society Bexhill and Hastings Branch**

Parent/carer support group in Bexhill and Hastings meet during term time. All family members welcome. Family activities during

the school holidays.

bexhill@nas.org.uk
07920 254 569
www.nasbranch.org.uk/Bexhill

LONDON**Southwark ADHD parent and carer support group**

Parent and carer led group offering mutual support. Invite speakers on various topics. Monthly and bi-monthly meetings. southwarkadhd@gmail.com www.facebook.com/southwarkadhd

Waltham Forest Parent Carer Forum Support Groups

Two support groups held in cafés or community rooms around the borough once every half term, speakers often attend. Dads, Grandads, and general support group. **07528433640** walthamforestparentforum@live.co.uk www.walthamforestparentforum.com

GREATER MANCHESTER**Breaking Barriers**

Parent support groups are run throughout various venues in Bolton. **07717 434 840** breakbarriers3@gmail.com

Sensory Explorers

Support, sensory stimulation, social opportunities for parents/carers and youngsters with a visual impairment and complex needs. Meet fortnightly during term time. **07930259090** I.hoburn@lancasterian.manchester.sch.uk

HAMPSHIRE**New Forest Aspergers Support Group**

For parents of children, young people or adults with Asperger syndrome or higher functioning autism. Meets every second month from 7–9pm. sjtealconsultancy@gmail.com

HERTFORDSHIRE**Epilepsy Beat**

Runs once a month on a Saturday, 2–3pm from the children's outpatient department at Watford General Hospital with support from consultant Dr C Ramesh. tink78225@gmail.com **07713736497**

KENT**National Autistic Society Bexley Kent**

Activities and support including events, coffee mornings and talks/presentations. bexley@nas.org.uk **07826 950 496** www.autism.org.uk/directory/resources/123.aspx

MONMOUTHSHIRE**21 Plus - For Children with Down Syndrome**

Weekly free speech and language therapy group for pre-school children. Training for schools and families, group for pre-schoolers Wednesday morning term time. victoria.21plus@gmail.com www.21plus.org.uk

NEATH PORT TALBOT**Special Needs Activity Club Neath Port Talbot**

Indoor play area, sensory room, arts and crafts and more. Support network for parents from all areas

of South Wales.

info@snacwales.org.uk
www.snacwales.wordpress.com/

NORFOLK**Parent Support Group Earlham**

A support group for all, with or without a diagnosis, to discuss any concerns or ideas. Sensory room available. tmills57rn@nsix.org.uk

NORTHAMPTONSHIRE**Northamptonshire Deaf Children's Society**

Information, support and activities for families with deaf children and young people. Meets monthly on the last Saturday of the month. **07887 623 778** northamptonshire@ndcsgroup.org.uk

SENDS 4 Dad Northamptonshire

Support group for dads. Meets monthly at 7.30 pm at the Obelisk Centre in Northampton. Social events and support for dads/male carers. paul_meadows2@ntlworld.com **07900 442 077** www.sends4dad.org.uk

NORTHUMBERLAND**Education Centre for Children with Down syndrome**

Educational support to children with Down syndrome. Meets weekly for children up to 14 years of age. alison.wishart@eccds.org.uk www.eccds.org.uk

NOTTINGHAMSHIRE**Newark Support Group**

A chance to meet up with other parents for a cuppa and support. Toys are available for children. Meets one Friday each month between 10am–12pm. still.smiling.newark@gmail.com **07810803433**

POWYS**South and Mid Powys NAS Branch Powys**

Support and advice to families with children on the spectrum plus a monthly adults get-together social gathering session. southpowys@nas.org.uk **07435 785319**

SUFFOLK**Opportunity Group Haverhill**

Meets on Monday mornings between 10–11.30am. Open to parents who have a child with any additional need. karen.potter@suffolk.gov.uk **01440 760 500**

Parent Engagement Group in Stoke (PEGIS)

For parents/carers of children and young people with SEND up to the age of 25. Meets on the 1st Tuesday of each month for a couple of hours, term time only. pegis.stoke@hotmail.com **07935 557380**

WEST YORKSHIRE**Down Syndrome Training and Support Service**

Run by and for parents and carers of children who have Down syndrome. Support and training for parents and professionals.

office@downsyndromebradford.co.uk
www.downsupportbradford.btck.co.uk/

WILTSHIRE**Westbury Parent Carer Group**

For parent carers of children/young people with special educational needs and/or disabilities, meets monthly. starcarerpainter@outlook.com www.facebook.com/faithcareshare/

WREXHAM**Wrexham Family Friends for 5-11s**

Family education sessions, drop-in to help with forms, emotional support, IT etc, Family Fun Club during school holidays. familyfriends@lineone.net www.family-friends.co.uk

YORKSHIRE**Little Hiccups Yorkshire**

Stay and Play sessions, subsidized outings for all the family, outreach programme for families that aren't ready to come to one of our sessions. info@littlehiccups.co.uk **07831 230 741** www.littlehiccups.co.uk



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**

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for families with disabled children

 **020 7608 8700**

 **info@cafamily.org.uk**

 **www.cafamily.org.uk**

 **www.facebook.com/contactafamily**

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 **www.youtube.com/cafamily**