

The magazine for families with disabled children
and all those who work with them

contact a family
for families with disabled children

Spring 2009

connected



Competition highlights

Your stories, films and pictures

New survey

What makes your
family stronger?

Our support group

Why one mum
wanted to do more

Mortgage interest payment help

New rules explained

Contact a Family

209-211 City Road, London EC1V 1JN
Tel: 020 7608 8700
Fax: 020 7608 8701
e-mail: info@cafamily.org.uk

Contact a Family Northern Ireland

The Bridge Community Centre, Railway Street
Lisburn BT28 1XP
Tel/Fax 028 9262 7552
e-mail: nireland.office@cafamily.org.uk

Contact a Family Scotland

Craigmillar Social Enterprise & Arts Centre
11/9 Harewood Road, Edinburgh EH16 4NT
Tel: 0131 659 2930
e-mail: scotland.office@cafamily.org.uk

Contact a Family Cymru

33-35 Cathedral Road, Cardiff CF11 9HB
Tel: 029 2039 6624
Fax: 029 2039 6625
e-mail: wales.office@cafamily.org.uk

Contact a Family North East England Region

The Dene Centre, Castle Farm Road
Newcastle upon Tyne NE3 1PH
Tel/Fax: 0191 213 6300
e-mail: northeast.office@cafamily.org.uk

Contact a Family North West England Region

6th Floor, St. James House
Pendleton Way, Salford, M6 5FW
Tel: 0161 743 0700
Fax: 0161 743 0711
e-mail: northwest.office@cafamily.org.uk

Contact a Family West Midlands Region

Prospect Hall, 12 College Walk
Selly Oak, Birmingham B29 6LE
Tel: 0121 415 4624
Fax: 0121 415 4922
e-mail: westmids.office@cafamily.org.uk

Contact a Family Ealing

Room 3, 1st Floor, St. Andrews Church Centre
Mount Park Road, London W5 2RS
Tel: 020 8810 8151
e-mail: ealing.office@cafamily.org.uk

Contact a Family Lambeth

c/o Weir Link Children's Centre, Weir Estate
33 Weir Road, London, SW12 0NU
Tel: 020 8675 8081
e-mail: lambeth.office@cafamily.org.uk

Contact a Family Lewisham

1 Forman House, Frensbury Road
London SE4 2LB
Tel: 020 7635 6333
Fax: 020 7732 8494
e-mail: lewisham.office@cafamily.org.uk

Contact a Family Southall

St. Georges Community Centre
8-12 Lancaster Road, Southall UB1 1NW
Tel: 020 8571 6381
Fax: 020 8571 6400
e-mail: southall.office@cafamily.org.uk

Contact a Family Southwark

54 Camberwell Road, London SE5 0EN
Tel: 020 7277 4436
Fax: 020 7703 6449
e-mail: southwark.office@cafamily.org.uk

Contact a Family Sutton and Merton

Hill House, St Hellier Community Association
Bishopsford Road, Morden SM4 6BL
Tel: 020 8640 5525
Fax: 020 8640 7799
e-mail: suttonmerton.office@cafamily.org.uk

Contact a Family Wandsworth

1 Sivard Road, London SW17 0LA
Tel: 020 8947 5260
Fax: 020 8947 9506
e-mail: wandsworth.office@cafamily.org.uk
www.cafamily.org.uk
Helpline: 0808 808 3555



4 Take part in our survey



8 Support group story



14 My daughter, Susie-Jo

From our Chief Executive

3 **Srabani Sen:** Springing into summer

Contact a Family

- 4 **What makes your family stronger:** Take part in our new survey
- 4 **Good luck to our Marathon runners:** Fundraising for Contact a Family
- 5 **Parent participation:** Helping groups to develop participation
- 5 **Children's centre and family information services:** Update
- 6 **Looking forward to summer:** Family fun events
- 7 **Contact a Family news in brief:** Quick roundup of our latest news

Support groups

8 **Life is a journey:** One support group's inspiring story

Other news

- 10 **News in brief:** Roundup of the latest news
- 11 **Mortgage interest payment help:** How the new rules work

Me and my disabled child

- 12 **Your stories:** Introducing this edition's theme
- 12 **Winning videos:** Your video entries to our recent competition
- 13 **Jo Trevett:** Coming to terms with her son's loss of sight
- 14 **Susie-Jo:** Mike Walker on his daughter's "endless giggles"
- 16 **Fabulous photos:** A selection of your photo entries
- 16 **The Beginning:** Poem by one parent who entered our competition
- 17 **Bethany:** The joys and challenges of bringing up children

Resources

- 18 **Book reviews**
- 19 **Find your local volunteer parent rep and family worker**

Connected information

Edited by: Karin Beeler, Elaine Bennett, Natalie Ridgway and Yvonne McGahren
e-mail: library.team@cafamily.org.uk **Design and layout by:** Natalie Ridgway

Note: Although great care has been taken in the compilation and preparation of this magazine to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.

© Contact a Family 2009

Next issue: The summer edition of Connected will be published in May. We are always interested in stories, especially from parents. If you would like to contribute, please submit articles of up to 750 words. e-mail: library.team@cafamily.org.uk The deadline is 14th April 2009.



Springing into summer

Srabani Sen, Chief Executive at Contact a Family, introduces the spring edition of Connected magazine and looks forward to a hopefully sunny summer and positive news for families with disabled children

Welcome to the spring edition of Connected, the magazine for families with disabled children and all those who work with them.

Firstly, a happy New Year to you all! The holiday season seems a long time ago now, and I can't believe it's nearly spring again. Walking to my various meetings I can see the blossom coming out and a few brave flowers, heralding, I hope, a much better summer than last, so we can get out and about and enjoy the timetable of summer activities we put on for families. You'll see the kind of things we get up to later on in the magazine.

"Your stories, pictures and videos were immensely moving, thought provoking and funny and give a wonderful insight into the joys and challenges of bringing up a disabled child"

Competition

Last year we ran a competition, 'Me and my disabled child' asking you to tell your own story by making a video, writing a story or poem or taking pictures.

We were so touched by the number of parents who took time out of their busy lives to write in and enter the competition, and delighted by the high standard of the entries.

Your stories, pictures and videos were immensely moving, thought provoking and funny and give a wonderful insight into the joys and challenges of bringing up a disabled child. You can read some of the winning entries in this edition. We'll be putting them on our website and Youtube channel and hope that by hearing your voices, we can raise awareness of the issues parents face to the general public and policy makers alike.

New strategy on Child Health in England

Talking of policy, the government has been promising the publication of a new strategy on Child Health in England. It's been delayed by several months, and we are lobbying the government hard to make sure it's published soon.

As well as the fact that we're expecting the strategy to address issues related to children with disabilities and complex health needs, an announcement was promised alongside the strategy about the amount of money that was given to primary care trusts for short breaks.

The Centre for Excellence and Outcomes (C4EO) are carrying out two strands of work which will affect families with disabled children, one is around disability and one around poverty. I'm delighted to report that I sit on the advisory group for both of these strands of work, so your voices will be heard loud and clear.

As we know from our research it costs three times more to bring up a disabled child, and many of our families are really struggling financially, particularly in the 'credit crunch' as you told us in our

'Counting the costs' survey. The C4EO will be gathering information about what works in practice to support disabled children, and children living in poverty.

The idea is to pass on this information to encourage local authorities and primary care trusts to adopt this good practice.

Here at Contact a Family we've also been working hard to develop our work plans for 2009/10. One of our big challenges is to continue to find funding to develop our services for families with disabled children.

Raising awareness

We're also looking at how we can raise awareness and get the issues our families face across to the wider public, to help reduce the stigma and isolation you tell us about in your daily lives.

We're seeing a quiet revolution on our Youtube and Facebook sites, with not only parents but members of the general public watching at our videos and asking questions about disability. This has allowed us to reach a much wider audience and is going from strength to strength.

Wishing you all the best from all our staff, volunteers and trustees. We hope we can make a difference for you in 2009.

Srabani Sen

What makes your family stronger?



Your views can help us campaign for better lives for families with disabled children

Claire Pimm, Contact a Family's Director of Communications and Policy, said: "We know from our work with families with disabled children that they want to lead ordinary lives.

"Living without fear of debt and poverty, the opportunity to work, the chance to enjoy leisure activities as a family, getting an education to meet a child's needs and the importance of a good night's rest are essential to making any family stronger.

"The results from Contact a Family's What Makes My Family Stronger survey, will form new research and will help us campaign for better lives for all families with disabled children. We will also use the findings to raise awareness of what

life is like raising a disabled child."

If you are a parent or another family member caring for a disabled child please take the time to complete our What Makes My Family Stronger survey, which can be found on the Contact a Family website at Web: <http://www.cafamily.org.uk/surveys/strongersurvey.html>

The What Makes My Family research is part of Contact a Family's 30th anniversary celebrations. Later this year there will be a series of events, campaigns and a competition for families to enjoy to help us mark our 30 years of working with and supporting families with disabled children.

Contact a Family wants to know what makes families with disabled children stronger. We want to hear from parents and other family members caring for a disabled child about their biggest priorities to strengthen their family practically, socially and emotionally.

We have compiled an online survey to find out families' current experience and to ask what they would wish for if more help and support were available.

Good luck to our fantastic runners

Support our runners, raising valuable funds for Contact a Family

490 BC

Pheidippides, a messenger in Ancient Greece runs 26 miles from Marathon to Athens to tell the Athenians not to surrender to the Persian fleet.

1896 AD

A 25 mile race from Marathon to Athens, is included in the first modern Olympic Games in Athens to commemorate Pheidippides. As a result the Marathon challenge was born!

2009 AD

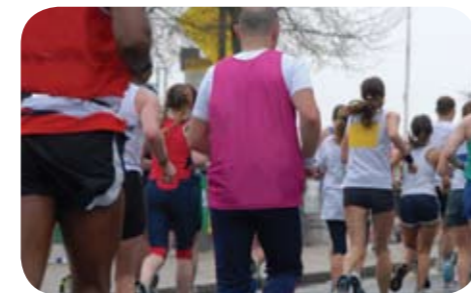
Contact a Family – in it's 30th Anniversary year – has 15 'Pheidippidesians' running in the London Marathon on Sunday 26th April 2009. The London Marathon is now the most prestigious marathon race in the world.

Each Contact a Family runner has a minimum fundraising target and when this is reached they will have raised at least £21,000 to support our work.

Our marathon team is motivated to run 26.2 miles and have chosen Contact a Family to benefit for a variety of reasons. As one of our runners said, "After many years of saying I would run the Flora London Marathon, I have finally bitten the bullet and entered! I have been fortunate to have been given a guaranteed place through Contact a Family, the charity that provides families caring for disabled children with support and advice, whatever the child's condition or disability."

Two of our team are brothers, Jason and Jonathon Pascoe who said, "Having secured golden bond guaranteed places from Contact a Family, we intend to complete it in memory of our brother who fell asleep at the age of 24. He suffered from Microcephaly and fought daily for normality."

"Our chosen charity, Contact a Family, offers not only assistance to disabled children, but to the parents and carers



who until recent years have been up against the system and so called 'red tape' that comes with it."

Contact a Family offers guaranteed places in the London Marathon and other running events that take place throughout the year. We support all our runners with tips on training and fundraising.

If you wish to join one of our teams or take part in one of our other exciting fundraising challenges visit our website, or contact our fundraising team at e-mail: fr.team@cafamily.org.uk

Parent participation takes off

Helping parent groups to develop participation across England

Parent groups in 97% of English local authority areas have now been allocated funding to help them have a say in planning and shaping disabled children's services.

In just two months, parents with disabled children in 145 of the 150 local authority areas were successful in bidding for grants to help them get involved in local decision making.

Over the next year, a further £1.5 million is available to parent groups to develop participation activity across England, as part of the Aiming High for Disabled Children (AHDC) programme. Together for Disabled Children (TDC) (a partnership between Contact a Family and Serco Education and

Children's Services, with responsibility for developing parent participation forums under AHDC) is delighted with this positive response from groups.

"Parents with disabled children, in 145 of the 150 local authority areas, were successful in bidding for grants"

Liz Ranger, participation manager for TDC, said: "This response shows the enthusiasm and commitment of parents with disabled children to making real improvements to services which will

directly affect them and their children. Parents with disabled children are experts in their child's needs and can collectively transform services for all children and families.

"Over the next few months there will be a number of events taking place across England to encourage parents to get involved in local decision making. We would urge parents who are not already involved to take part and have their say."

For further information on what's happening in your local area or to find out more about the next phase of grants available to groups, contact the TDC administrator on Tel: 020 7608 8783 or visit the TDC website Web: <http://www.togetherfdc.org>

Children's centre and family information services update

How can services be improved to make sure families don't miss out?

The children's centre team at Contact a Family provides dedicated support to children's centres and family information services (FISs) across England.

Although we don't have a comprehensive picture of what children's centres are providing for disabled children and their families, we have been hearing about and visiting centres that are providing some excellent services and help. These range from giving a room for support groups to meet, to having dedicated disability workers. Many are investing in equipment such as suitable changing and toilet facilities, while others have ensured all staff receive disability training.

Reaching out to families

However, many children's centres do not have contact with local families with disabled children and are not making attempts to reach out to these families. Parents themselves tell us they do

not think children's centre services are aimed at them, don't think their needs will be understood or met and others are worried about the attitude of others using the centre, particularly if the child has challenging or different behaviour.

Nearly a year on from the new duties placed on FISs, we have been asking them how they are helping families with disabled children who are struggling to find good quality childcare. The response was varied but included providing advice on funding to help pay for childcare; helping childcare providers access disability training; introducing parents to different types of childcare and working with providers to include disabled children.

However for many, childcare for disabled children is not available locally and they have had to record unmet needs.

Along with extra help around finding

childcare, parents with disabled children who contact their local FIS should also expect to receive information on a range of services, facilities and publications of particular benefit to them such as details of short breaks, support groups and health services. Some are confident they can provide this information, while others have to refer parents on to other organisations. However, they do recognise this and they would like to improve their information provision.

Contact a Family is working hard to improve the situation in children's centres and FISs. We are pleased that over 400 children's centres have signed up to the online version of the Contact a Family Directory. Our resource pack of parent guides is also proving very popular.

For more information, please visit our website or call Una Summerson on Tel: 020 7608 8742.

Looking forward to summer

Some of our offices regularly organise family fun events – find out what's on offer and how you can be eligible for a place

Every year, Contact a Family offices help over 1,000 families access a wide range of day trips and family events to a host of fantastic and fun destinations.

For some families, these are the only days out they get to enjoy as a whole family. For all, they offer family-inclusive quality time, giving parents, carers, siblings and grandparents the chance to enjoy leisure and recreational opportunities many people take for granted.

Our London projects organise a timetable of summer events. Some of the more imaginative destinations have included visits to Hindleap Warren, The Enchanted Forest, Moore's Valley Park,

Regent's Park Open Air Theatre, Windsor and Deal Castle. We've also been to Brighton and other seaside locations, farm fruit picking, as well as Legoland, Thorpe Park and Chessington World of Adventures.

And that's not all. We've organised Thames River Cruises, Duck Tours, boating in Shadwell Basin, flights on the London Eye, visits to London attractions and museums, climbing walls, go-karting and ten pin bowling. Plus summer parties, discos, and parent-only trips to local restaurants, and a whole range of family activities in parks and local leisure facilities.

Meeting other families

Families get the opportunity to meet other people from similar locations and circumstances and share experiences. We hope to encourage people to access local opportunities, which they can replicate according to their needs and preferences. You can also chat to our staff and volunteers about anything and everything. We can match volunteers to families if they need an extra pair of hands. This can be extremely rewarding and fun – for everyone involved.

In Wales we get families together for free film showings and wheelchair training weekends.

The film showings happen at various locations throughout Wales – mainly Swansea and Galeri in North Wales. At the films we run different workshops, for example art workshops, to give children

who find it difficult to sit through a whole film an opportunity to come out and do something different and then perhaps return when they are ready. The workshops go on after the film while the parents have an opportunity to chat and have a cuppa. Our next trip to the cinema will be to see Madagascar – Escape to Africa.

Our wheelchair events have been held for the last five years and give families the opportunity to come together and get wheelchair training skills. Wheelchair Children bring along enough wheelchairs for all the family to have a go. This gives siblings and parents the opportunity to experience a weekend in a wheelchair and the problems this may present. We always have a good turn out and have the opportunity to go swimming and bowling at the centre, making for a very sociable weekend.

Getting a place

If you'd like to attend our events, you'll need to be registered with your local Contact a Family office to be eligible for places. They can also tell you what's happening this summer.

Due to demand on places, we can't publicise these activities to everyone and, because they are heavily subsidised by local fundraising initiatives we have to adopt an allocation process, which allows as many people as possible to access the events. You can find out if your local office offers events by contacting them via the details listed on page two.



Wheelchair training



At the London Eye



London park visit

Feedback from families

- "The staff are always so pleasant and helpful, they make you feel there are people out there who care after all."
- "Thank you for the opportunity you gave our children to have one of their best summer holidays. They cannot stop talking about all the places we visited."
- "Contact a Family trips enable children to make friends and socialise in a relaxed and supported environment – once again thanks!"
- "The best part was allowing my child to roam freely without a worry."
- "I think events like this are really good. We can see there are other dads with a disabled child in the same position."
- "The worry of a child crying or behaving inappropriately just wasn't there – it was only after I got home that I realised I hadn't been stressed and none of the other families seemed stressed either. I'm sure this rubbed off on the children. It was a real treat for the whole family."

Contact a Family news in brief

Helping to improve lives of Scotland's disabled children

For Scotland's Disabled Children (FSDC), which Contact a Family Scotland is part of, has appointed a policy manager to secure rights and justice for disabled children, young people and their families in Scotland.

Ellenor Anwyl, Chair of FSDC and Director of Contact a Family Scotland, said: "FSDC recognises there has been positive policy progress in Scotland in recent years but wants to encourage politicians and policy-makers to make good the commitment to get it right for every child. Services for disabled children and their families have been under-funded for far too long."

For more information contact Ellenor Anwyl on Tel: 0131 659 2930.

Contact a Family on Twitter
Twitter is an increasingly popular

online messaging service that allows you to send out short messages (known as 'tweets'). Follow us at Web: <http://twitter.com/contactafamily> and join the conversation.

New report on Disabled Facilities Grants launched

Contact a Family Wales, along with Shelter Cymru, have launched a new report on Disabled Facilities Grants (DFGs). The report looks at parents' experiences of getting DFGs, a grant which is intended to help all parents make their homes suitable for their disabled children. To read the report visit our website.

Keith Bowen, Director of Contact a Family Wales said: "This research has shown that delivery of Disabled Facilities Grants is not consistent across Wales. The Welsh Assembly Government and local authorities must continue to lead the way on improving

access to suitable accommodation for disabled children in Wales."

Take part in one of our podcasts

Contact a Family is looking for families to take part in our podcast series on what it is like for families affected by rare disorders. We would like to interview families about their experiences of a disorder or having a child/children with a rare disorder. We are interested in hearing about any rare condition, or from any family whose condition is in our Directory. Families whose children have very rare disorders often don't have a support group to turn to or access to other parents to share their experiences, so hearing the stories of other families can be a great source of support. For more information contact Sasha Henriques, Tel: 020 7608 8714 e-mail: sasha.henriques@cafamily.org.uk

contact a family
for families with disabled children

Information for families with disabled children

Contact a Family produces a range of publications for families with disabled children, available from our helpline



Guides

Free guides on a wide range of issues, including different benefits, rights and entitlements and relationships.

Titles include 'A guide to claiming Disability Living Allowance for children,' 'Dealing with debt,' 'Help with council tax bills,' 'Holidays, play and leisure,' 'Preparing for adult life and transition,' 'Relationships and caring for a disabled child,' 'The winter guide - help with fuel bills and keeping warm,' 'Working,' 'Siblings,' 'Grandparents,' and 'Benefits, Tax Credits and other financial help.'



Connected magazine

- news and articles
 - parent stories
 - published quarterly
 - yearly subscriptions
- £10 from Contact a Family.



When your child has additional needs

General guide for parents with a disabled child helping you to find all the information you may need and where to go for further help.

Helpline **0808 808 3555**

www.cafamily.org.uk

Incorporating **The Lady Hoare Trust**

Life is a journey

Through our local parent support group network scheme, Contact a Family is in touch with hundreds of parent support groups. The Aldershot Garrison Special Needs group is a member and here, co-founder, Patricia Robson shares her experiences

There's an old, simple saying which happens to be one of my favourites and one which is known to most, it is coined 'Life is a journey'. I tend to wholeheartedly agree.

Being the parent of a severely disabled child has to be one of the biggest journeys and life-changing experiences you are ever likely to embark on. It seems to throw a variety of emotions at you, some when you least expect them. But having said that, it also happens to be one of the most rewarding, life enriching journeys a person is ever likely to undertake.

My journey of a lifetime began in the delivery suite in September 1994, with the arrival of our much longed for, first child – a beautiful baby boy we named Thomas.

I relished my new role as a mummy, along with the overwhelming love and pride that a parent feels for their child. The weeks and months seemed to fly by and before we knew it, Thomas was six months old and seemingly appeared to be a healthy, happy little boy.

As my husband was a serving soldier, he was posted in April 1995 from Germany to Aldershot in Hampshire. Within weeks of arriving in Aldershot, Tom was seen by the local health visitor and GP who carried out routine development checks on him. It soon became apparent that Thomas did not appear to be developing both physically and mentally as he should have been.

Getting a diagnosis

Finally, after months of hospital tests and assessments, Thomas was seen by

three consultants at the local children's hospital and diagnosed with severe learning difficulties. I remember feeling bewildered and confused. "What on earth does severe learning difficulties mean?" I thought to myself. I could tell by the solemn and grim facial expressions of the doctors that this was serious stuff.

I was told he would never be able to walk and would require care and support for the rest of his life; my perfect little boy whom we had so many dreams, plans and aspirations for. It didn't seem real. "It had to be wrong," I was screaming inside. I found myself unable to look at my beloved son for two weeks after receiving such earth-shattering news.

"Being the parent of a severely disabled child has to be one of the biggest journeys and life-changing experiences you are ever likely to embark on"

Looking back, I was unable to come to terms with Tom's diagnosis and went into shock.

Telling the news to my husband was the hardest thing. To see the 'rock' of our family, a soldier, suddenly crack, crumble and breakdown was simply heartbreaking.

From that moment onwards our lives changed forever and became very different, the continuous 'uphill'

struggle began on that day in 1995 and continues to this day some thirteen years later. Having to fight for our son soon became our priority in life, from claiming Disability Living Allowance to respite care, incontinence supplies, to specialist equipment, it went on and on. The isolation also became an issue.

Some years later, I met Bev Fletcher, another Army wife. Bev was also going through similar circumstances, trying to bring up a disabled child whilst being married to a serving soldier, having no family close to hand to offer support with her husband always away on operational tours of duty.

We decided that rather than sit on our laurels we wanted to use the experience of raising our disabled children in a positive way and to help others in similar circumstances, as well as raising awareness of disability.

Setting up the group

As a result we set up The Aldershot Garrison Special Needs Group on a voluntary basis in 2002 and it became a flagship, being the first of its kind within the British Army. Subsequently other Garrison's have taken a leaf out of our book and have gone on to set up similar groups up and down the country.

The British Army have an outstanding welfare support system, one which my family had accessed with regards to Thomas; however the group has allowed parents the opportunity to talk to one another about caring for a disabled child first-hand.

The group is open every week on Tuesday and Friday mornings, 10am-12.30pm. The group is entirely self-funded and we rely heavily on donations and fundraising to exist, but we still manage to organise major events and outings for the families and young people.

There is no charge to attend and the group offers advice, support, and friendship. There is also no age limit as disabled children do eventually grow up into adults and their parents and families should still be and need to be supported in every possible way. We are located within Union Buildings in Aldershot Garrison and all parents are welcome. The group is still going strong. We were



The inviting looking Aldershot Garrison Special Needs group meeting space

given our own fantastic permanent base over four years ago, thanks to the overwhelming generosity of Aldershot Garrison and the Garrison Commander. One of our most recent highlights concerning the group was receiving the much respected Army Families Federation Community Award two years ago, by HRH the Duchess of Gloucester in light of our voluntary work.

"Rather than sit on our laurels we wanted to use the experience of raising our disabled children in a positive way"

As for our beloved son Thomas, he is now a cheeky, mischievous teenager. He also now has a little nine year old sister Katie, who always wants to help mum with the care of Tom. Tom's severe learning difficulties remain the same, he is also mute, profoundly Autistic with extreme challenging behaviour and pica, amongst other things.

Tom will indeed require one-to-one care for the rest of his life, as the doctors had mentioned years earlier, but he did

eventually learn to walk aged six years.

Both Bev and I agree that we both feel hugely privileged and special to have gone on this unique journey, along with our amazing children and families. It may not have been our chosen or preferred destination in life, but we would not change it for the world, and we are all the richer spiritually and emotionally for having done so.

Our children's progress and achievements may be painfully slow, if at all, but the sense of pride that we feel is truly immeasurable. Hence why the phrase 'life is a journey' could not be more apt.

Contact Aldershot Garrison Special Needs group

Tel: 01252 343753 or 01252 327752
e-mail: specialneeds.aldershotgarrison@googlemail.com
Web: www.aldershotspecialneedsgroup.hampshire.org.uk

Support for groups

For more information about how Contact a Family could help your group and for more information about setting up a group visit Web: <http://www.cafamily.org.uk/families/supportinggroups.html>



Patricia with her son, Thomas, and her daughter, Katie

News in brief

Changes to the NHS complaints system

On 1st April 2009, the government is introducing a new process for dealing with patients' complaints about NHS healthcare. Following public feedback, they are streamlining it from a three-stage to a two-stage process, to make it quicker and easier for a complainant to have their concern dealt with. The Healthcare Commission will no longer be involved in dealing with patients' complaints about the NHS as they will cease to exist on 31st March 2009 and the Health Service Ombudsman will take over.

Web: <http://tinyurl.com/cwcpmt>

Better access to childcare for families with disabled children in London

Families with disabled children in London are to get extra financial assistance help with childcare costs. The government has announced a childcare affordability pilot scheme that will pay an increased level of Working Tax Credit to parents of disabled children in London. Eligible low income families in London with a disabled child are set to receive £215 per week and families with a severely disabled child £300 per week. These limits will be further increased if childcare costs are claimed for more than one child.

Improving the quality of life for children and young people affected by neurological conditions

Cerebra is a charity set up to help improve the lives of children with brain related conditions through researching, educating and directly supporting children and their carers. Their grant scheme offers direct and practical assistance. If your child is aged 16 or under and the equipment or resource that would benefit your child is not available from statutory agencies, such as social services or the NHS, then contact their Grants Co-ordinator, Debbie Godsave on Tel: 01267 244 216 or e-mail: debbieg@cerebra.org.uk

They will also be running the speech

and language therapy (SALT) voucher scheme again to help children who need therapy but are not getting it. The voucher is worth up to £500 of speech and language therapy.

And, after a successful scheme in 2007, Cerebra will continue the wills and trust voucher scheme in 2009. The voucher is worth up to £350 towards the cost of a solicitor or professional will writing service to prepare a will and discretionary trust, to make provision for your child's future. For an application or more information on the voucher scheme or the wills and trusts scheme, contact Alex Elsaesser on Tel: 0800 328 1159, e-mail: alex@cerebra.org.uk

Kidz exhibition dates announced

Kidz exhibition events allow disabled children, their families and professionals to try the latest disability equipment and products and talk to the specialists who supply them. Events are free to attend.

There will be three Kidz exhibitions in 2009. Disabled Living, organisers of the events, have expanded their programme this year to include the Midlands.

Kidz in the Middle will be held on 12th March at the Ricoh Arena, Coventry. Kidz South will be held on 18th June at Rivermead Leisure Complex in Reading. And Kidz Up North will be held on 20th November at the Reebok Stadium, Bolton. For free tickets or more information, please contact Disabled Living on Tel: 0161 214 5962 or e-mail: info@disabledliving.co.uk

Family Fund increases age limit in England

The Family Fund is a national charity which gives grants to families with disabled children. They have recently increased the age limit of children they can help in England to include 17 year olds, providing the application is received before the young person's 18th birthday. This brings it in line with the eligibility criteria for Wales. In

Northern Ireland and Scotland the age limit of children and young people they can help is 16 years of age or under, providing the application is received before the 17th birthday. Also, you can now check the progress of your grant application online.

For further information see Web: <http://www.familyfund.org.uk>

Working parents who care for a disabled child now protected against discrimination

Contact a Family has welcomed a ruling by the Employment Tribunal protecting parents who combine work with caring for a disabled child against harassment and discrimination in the workplace. The ruling means that parent carers have the right to claim against employers who treat them unfairly "by association with disability". Working parents of disabled children are now protected in law against discrimination such as a refusal to offer flexible working. The decision follows a parent carer's legal victory in the European Court of Justice. Sharon Coleman claimed that she was discriminated against and harassed because she had a disabled son. The ruling paves the way for parents with disabled children in England and Wales to make immediate claims against their employers if they are treated unfairly.

NHS websites merged

Previously, the NHS had two national websites – NHS Choices and NHS Direct. Now both these websites have been combined into one – NHS Choices – making online information about health and health services available from one site. The site will include popular features such as the self help guide, a health encyclopaedia and the online enquiry service. There will be directories of services, comparative hospital performance data and guides to common long-term conditions, with translations available.

The new combined site is available at Web: <http://www.nhs.uk>

Mortgage interest – new rules

Derek Sinclair, Parent Adviser at Contact a Family, explains how to get help with mortgage interest via the benefits system

If you claim Income Support, Income based Jobseeker's Allowance, Pension Credit (Guarantee credit) or income-related Employment and Support Allowance, it is possible to get help towards your mortgage interest payments.

Unless you are aged 60 or above, there is normally a "waiting period" before a claimant receives help. Previously the length of the waiting period depended on your personal circumstances and when your mortgage was taken out. Most claimants had to wait 39 weeks before they got help with their mortgage interest, although some people including carers, could get help with half of their mortgage interest after eight weeks and all of their eligible interest after 26 weeks.

However, on the 5th January 2009, the government introduced new rules allowing many claimants to get all of their eligible interest taken into account after 13 weeks. In addition the government has increased the maximum amount of loan that they will meet from £100,000 to £200,000. These new rules apply to most new claims. It will also apply to some claims made before 5th January.

The government has described these new more generous rules as a "temporary measure", without saying how long they are likely to remain in place. If you have a mortgage and were previously refused one of the means tested benefits mentioned above call our free helpline to check whether these new rules will now help you to qualify for help.

Alongside these changes, the government has also announced for a temporary period, that the amount of help you get with mortgage interest will be calculated using a fixed standard rate of 6.08%, rather than being calculated in line with the Bank of England rate.

On a less positive note it was also announced that new Jobseeker's Allowance claimants will only get help with mortgage interest for a maximum of two years. This time limit will not apply to anyone whose claim started before 5th January 2009.

For further advice on getting help with mortgage interest (and certain other housing costs) call our free helpline Tel: 0808 808 3555.

Your experiences matter

Look out for new survey on disabled children's services

In spring the government will be sending a survey out to a sample of parents of disabled children to ask for their views on the services they receive. Parents answers will be used to develop a National Indicator for disabled children, which will measure the performance of each local authority's disabled children's services.

"Local areas will be able see how they are performing. Areas that perform badly will be expected to improve"

This is the first time there has been a specific indicator for disabled children's services. Local areas will be able to see how they are performing and compare with others. Areas that perform

badly will be expected to improve their services and are likely to channel money and resources into meeting National Indicators where they are underperforming.

What is a National Indicator?

In April 2008, a new system was introduced to measure and compare the performance of each local authority in England. Every local authority will now be measured against 198 National Indicators, including the Disabled Children's Services National Indicator to see how well they are serving their local community.

What difference have other National Indicators made?

One National Indicator says that patients should be referred to a health specialist within 18 weeks of being referred by a GP – the introduction of this National Indicator has significantly reduced patient waiting times.

If I receive a survey, why should I complete it?

The Disabled Children's Services National Indicator is a key tool to ensure services improve in your local area. It will focus education, health and social care's attention on services for disabled children in a way that hasn't been seen before. Your experiences are crucial in measuring local services for families of disabled children. The survey is a unique chance to have your say – if you get the opportunity to take part, please do, and encourage other parents to do the same. It will be initially sent to some parents in the spring and then to a larger sample in the summer. After that it will be sent out on a regular basis once a year.

If you, or anyone else you know about has any problems filling in the survey there will be a phone number clearly marked on the questionnaire that you can call to get assistance.

Me and my disabled child

Elaine Bennett, Media and Communications Officer, reflects on our recent competition which encouraged families with disabled children to talk about their experiences and to share their stories

Families with disabled children always say that the best source of information and support is from other parents. There is enormous value and benefit in speaking to and hearing from other families who have shared experiences.

Parents can give a reliable insight into what life is really like caring for a child with a particular disability or rare condition day-to-day. Parents are also often experts in the practical help and support networks that are available. Parent to parent contact either face to face, through written stories,

videos, e-mails or social networking sites continues to be a huge source of support for many families caring for a disabled child.

Last year Contact a Family launched a competition, Me and My Disabled Child, asking parents to share their stories about the joys and challenges of caring for a disabled child. We asked for entries to be submitted either as a home video, in writing or in images and were overwhelmed by the response to the competition and the quality of entries we received.

We are delighted to dedicate this edition of Connected to showcasing the winning entries and feature others which we particularly liked.

A huge thank you to all those families who entered the competition, the standard was incredibly high and we will look forward to using other entries on our website and other online channels such as Youtube and MySpace to raise public awareness of the everyday challenges families face raising a disabled child.

Winning videos

Your video entries gave a wonderful insight into what family life is like for families with disabled children



Finley at home with his family

Some of the entries to our competition used the medium of video to show what life is like in their family. We will be putting the winning videos onto our YouTube channel and on our website as they are a perfect way to help raise awareness of disability and to show other families that they are not alone.

The overall winner for our competition was Gareth Allen's entry, 'Fab Fin' about his son Finley who has Cerebral Palsy. The video shows Finley, a fun loving five



Stills from Gareth's film

year old, at home, with his family, singing and playing.

The other winning video entry was Stephen and Lisa Dinning's entry about their son Jamie, who has Down syndrome.

The video gives a real window into domestic life with a disabled child, showing Jamie as a baby, giggling over a musical card, running away in the park and sitting on the 'naughty step' at the bottom of their stairs.



Stills from Stephen and Lisa's film

Son's bravery and maturity during eye op – an inspiration to mum

Jo Trevett's written entry detailing her son's operation to fight eye cancer was one of the competition's runners up

March 10th 2008 and we are both sitting on the hospital ward, both of us aware of what is going to happen today but neither of us mentioning 'it'.

"One of us is asleep and another of us frantically thinks of things to do to pass the time. Text family and friends, let them know that everything is proceeding as planned"

Time goes faster now, down to theatre, more checking by nurses and then one of us is asleep and another of us frantically thinks of things to do to pass the time. Text family and friends, let them know that everything is proceeding as planned. Really easy on text, no-one worries.

Go to hospital shop; buy favourite drink. Wander around; play with phone just to look busy, no-one will start talking to you if you look busy on a phone.

Back to ward and finally awake, eye is very swollen and shut, that's okay the consultant told us that, relieved that this is to plan, that means everything else must have gone to plan. Not rational thoughts but comforting when you can't see what they have done.

We are both now being brave, can't get upset, that is not going to help anyone, need to be strong to support and protect my son.

He has had cancer of the eyes before; he fought it and won, no reason to believe that he won't win this time.

Four days later – son reports that he can only see black, he needs assurance that the eye is still swollen, it is not, but I 'buff' round that fact. Contact hospital, emergency appointment for next day.

My son tells me that it is just taking longer than the doctors said; he assures me that there is nothing to worry about, role reversal happening, feel guilty but have nothing to say to him.

Doctors tell us that his retina is detached and torn, there will never be any sight now, and my son will always live in the dark. Big regrets, I should have made sure he looked at all those important things before the procedure, his dad, sister, me, his grandparent...

"He has had cancer of the eyes before; he fought it and won, no reason to believe that he won't win this time"

Sighted guide, white cane, now I have to adjust how we all get around, I have to learn to be a sighted guide, good cane skills and to remember to describe what is around him, I have to reassure him and allow him time to see with his hands.

Need to ensure that expectations of the people and the world around him remains the same, it is so easy to lower these but much harder to maintain them.

His comment is, 'You can't always have what you want, but I am still the same.' I am taken aback, how can he be so mature and matter of fact at six years old, and yet I can't make sense out of any of it. Why? No-one can really answer that, it encompasses too much. Struggle on, smiling at his progress, at his attitude to make the best of it. My son is my strength, he is also my inspiration.

He is right, he has not changed.



Jo with her family

A different life, but one filled with laughter and giggles

Winner of written entries, Mike Walker, describes life with Susie-Jo

I had cut the cord and there I was, holding my newborn baby. Maybe they were born with their eyes closed like puppies. I didn't know. "Well is it a little boy or a little girl?" The midwife's voice jolted me back into the world. I hadn't even looked. She had. She squeezed my arm and told me she was just getting a doctor. I smiled bravely at my wife, the growing panic in her eyes twisting a knife in my heart as a massive storm cloud brewed on our horizon.

Funny thing, Latin. Many years ago they stopped using it in church services when it was decided the common people might actually benefit from understanding them. And yet the diagnosis of an impairment, news of such crushing enormity that we must be left in no doubt as to its most intricate implications is inevitably delivered to us in Latin. I can see the point, in a crowded chemist's, of asking for medication for your condylomata acuminata rather than your genital warts, but if I've got a clot on my lung I don't need to be told I'm suffering from a pulmonary embolism.

Breaking the news

The consultant who eventually arrived to diagnose our baby told us in an emotionless monotone, "Left socket micro-ophthalmic, right socket anophthalmic", he needed to be prompted by our anguished bewilderment to kindly continue, "Your child will have no useful vision." before stalking off into the deepening evening



Susie-Jo

gloom. I would've given him a little wave had my sense of humour not been a little blunted at that moment.

What next? The phone calls. The endless phone calls. I so wanted the people we loved to celebrate this new life with us. Our first child, a beautiful little girl. But I had to say it. "She's blind. She doesn't have any eyes". The words stuck in my throat. How did we expect people to react? What were they supposed to say? I felt for them as one excited voice after another was followed by an awkward silence.

"I ran along the sand dunes at our local beach shouting, "My child is blind! She'll never see this!" at the crimson globe of the setting sun"

A few weeks later I was summoned to another consultant's office as scans had revealed 'further abnormalities'. At least they were talking English. Now there's a surreal experience. Standing outside the headmaster's office multiplied by a million. I could walk in and he could tell me that my child was going to be fine but for some minor problems or he could tell me that she wasn't going to be with us for long and to go away and prepare for the worst. My entire life made or broken just by stepping through that door. Predictably there was much talk of 'septum pellucidum' and 'corpus callosum', 'hypotonia' and 'cerebral palsy', after which he basically said that he didn't have a clue to what extent she would be affected by these conditions and to go home and wait and see what happened.

Cerebral Palsy. Now there's a term for you. Cerebral Palsy, it means 'something

wrong with your brain'. We'd love that as a diagnosis wouldn't we? Yet get it in Latin and we gravely bow our heads and dutifully retire to come to terms with... we don't exactly know what.

Needless to say we sought, and found, solace and advice outside the medical profession. Thank God for support groups through which we met a mum who sent us the photos, a few weeks after Susie-Jo's diagnosis. They showed her daughter, also blind from birth, a grinning baby, a chortling toddler, a laughing, excited little girl, a happy teenager clearly loving life. They showed us then what now, with Matty and Herbie, Susie-Jo's two sighted brothers, we know to be true. That life really doesn't end with the diagnosis, even once you've understood it. But it is going to be very, very different.

Adjusting to all this is hard, especially in those early days. Some people never do. They might walk away from the relationship, feel unable to care for the child, convinced they can't cope with the new life ahead. Instinct, fear, prejudice or belief surface from the unconscious mind to take the place of rational thought.

Maybe it's a matter of gender. When the sabre-toothed tiger appeared at the mouth of the cave the women would immediately run to the back of the cave picking up the babies and hiding the young ones in secret recesses for protection. The men would grab flaming branches from the fire and run at the beast yelling and hurling the branches at its face to scare it away. Or I bet they did anyway. I'm just trying to understand the huge differences, in my experience, between men and women when it comes to having a child with a disability.

Following Susie-Jo's birth my wife went to the back of the cave and sought the solace of other women. She talked and talked for hours on end, giving vent to her feelings, seeking support and information. The reaffirming nature

of these actions led her to establish a support group for parents of blind children and ultimately into a career in the field, most often in the company of other women. I ran to the front of the cave. I needed to confront this thing alone. I ran along the sand dunes at our local beach shouting, "My child is blind! She'll never see this!" at the crimson globe of the setting sun sinking into the evening surf, rippling through the clouds above in a cruelly splendid vision blurred only by my tears. For me that sunset was the burning tail of the tiger as it sloped away, unable to do me any more harm. I turned back to get on with a new life.

Finding the right path

After all I was used to new lives. I'd spent years travelling. I'd soon find who to ask, where to go, what to do, what to avoid. Wouldn't take long before someone put us on the right road. And many tried. And like fools we believed them, stumbling along the path of parenthood as blindly as our daughter before finally realising that we are the experts in our children. We kept desperately believing that there were scores of professionals out there who would know. It's one thing acquiring a realisation of how your child's varying needs will best be met, indeed being passionately convinced about it, but it's quite another actually achieving it.

We had been advised that Braille was too complex for Susie-Jo and that she should try a simplified script known as moon. The decision was then made that nothing of much use was actually written in moon so she should go back to Braille. Then it was decided that, despite her evident glee over her ability to get a talking computer to read back a word she had successfully written, she was never going to be reading books in Braille and so less attention was paid to it.

Is this a problem of perspective? Professionals do not allow emotion to cloud their judgement. Indeed they make a virtue of this. They make objective decisions based on precedent and diagnoses to serve pragmatic ends. A health care professional sees a condition, an educationalist sees learning potential, a parent sees their child.

"Trailing clouds of glory do we come From God who is our home"

Parents see their children in these lines from Wordsworth. I don't see a blind girl



Susie-Jo with her brother, Matthew

in a wheelchair with Cerebral Palsy, I see my daughter. I hear her laughter and feel her tears, see the smiles of achievement and share her joy of praise, of being able to please. So I make decisions on very different grounds. I don't want Susie-Jo to continue with her Braille so she can read books. I want her to achieve something that brings her a sense of fulfilment. Leading a fulfilling life means being able to do something meaningful in your own terms and perhaps we all need reminding that our particular terms are not the only perspective from which human potential, indeed, human worth, can be viewed.

"I don't see a blind girl in a wheelchair with Cerebral Palsy, I see my daughter"

It's good to remind ourselves of this. It's easy to take a one dimensional view of progress and become depressed by the different planets of awareness her old school friends now inhabit. We look at her peers, if such is the right term for people of Susie-Jo's age, and could struggle with the concept of progress. They have hit puberty, they have formed their various cliques, they are obsessed by appearance, sulking, selfish, demanding. They have been exposed to all the material temptations around them, crave what they cannot have, huddle in conspiratorial groups giggling, scorning those who don't fit in.

Endless giggles

Susie-Jo giggles because the dog's wet nose has just brushed against her knee. She launches herself into a futile search for her and finally gives up saying, "I expect she'll come back when she's tired, won't she mum? Dad go 'ding-dong!'" This is Dad's cue to make a doorbell noise. It's Treeve Hodges, her imaginary Cornish friend to whom she listens with rapt attention and a broad grin and who is privy to secrets she would never tell her parents. She farts loudly and laughs till she cries when Mum shouts, "Susie!" It's at moments like these when I question the value of progress itself in its traditional sense.

And it's laughter, at the end of the day, that makes it all worthwhile. The laughter she gives us when she asks Princess Anne if she can smell her and if she has an ancillary. Or when she shouts, "He's behind you!" a propos of nothing except for the fact that she's at the pantomime, oblivious to the sea of faces turned towards her. The sense of humour you need when a school hearing specialist diagnoses severe hearing loss because she doesn't turn her head to see where the sound is coming from. Or when a kindly parent tells you how wonderful it is to have a "child like yours" at the school because, "It makes the other children realise how lucky they are!"

It makes us realise how lucky we are as Susie-Jo's endless giggles and trademark grin tell the tragic world she's fine thanks.

Your fabulous photos

Many of the entrants sent in some eye-catching snaps of their child – here's a selection



Top to bottom: Winning photo of Zak at school, sent in by his adoptive mum, Vanessa; Zak out and about; Daniel on the beach, sent in by his mum,

The Beginning

We received this poem from one parent as their entry to our competition

Please believe me when I tell you,
I'm sure this can't be right.
My son should not be feeding,
Two-hourly day and night.

He's loosing weight and crying.
He's looking gaunt and sick.
Please believe me when I tell you,
We need your help, now, quick.

I tried a bottle like you said.
It's helped a lot, it's true.
He's gaining weight and sleeping,
But it's given me a clue.

His suck is weak, he dribbles milk.
His muscle tone is poor.
Please believe me when I tell you,
I know there's something more.

He's floppier than he should be.
He should be sitting up.
He can't bounce in his bouncer,
Or drink out of a cup.

He doesn't crawl or build up bricks.
He's made no attempt to walk.
He doesn't even babble,
Let alone begin to talk.

"He'll do it when he's ready",
You think that I'm a pest.
But please believe me when I tell you,
I'm his mother, I know best.

Competition winners

Overall winner (Dell Laptop) – Gareth Allen. Runners up (Nikon 'Coolpix' digital camera) – Stephen and Lisa Dinning, Jo Trevett, Mike Walker, Vanessa Plant, Ruth Jackson

The prizes for the competition were donated by Hobbs the Printers.

Bethany – joys and challenges

Bringing up Bethany, who has Global Developmental Delay, is not without its moments – both good and bad – as mum Ruth explains



Bethany grinning for the camera

Bethany is the fourth child in a family of five children. She has one brother (a great play-mate) and three sisters. Nothing was detected at birth, and it only became gradually apparent that she wasn't developing at the usual rate. She didn't sit up until she was a year old and didn't walk until she was three. She has a learning disability, physical difficulties (can't jump, hop, run and easily loses her balance), is hyper extensive and communicates mostly using Makaton, a basic sign language. As she has no firm diagnosis, she is labelled as having Global Developmental Delay.

Those are the facts but they don't tell you the challenges and real joys in bringing up Bethany who is now five years old. In many ways they are similar to bringing up any child; you remember the lovely moments when they show affection, master a new skill, hurt themselves, or come out with a funny phrase or gesture. Yet with Bethany those joys and challenges seem more heightened. She has had more accidents than the others. She once cut her head badly just tripping and falling, but unable to react quick enough to break her fall it was a deep cut requiring stitches. Likewise, when she managed to blow a raspberry (she had been unable to blow, only suck, until very recently) the whole family were so excited. Another popular gesture is putting her hand across her mouth, with a suitable expression, as if to say, "oops what have I done!"

Bethany is very close to her siblings and good at organising them to do what she

wants. Although she can't talk she will take their hand and drag them to where she wants them to go, usually the slide or the trampoline. Bethany has blessed, and continues to bless our whole family. Her younger sister signs away to her and helps her with her coat quite naturally. Her eldest sister is twelve and Bethany is very attached to her, always giving her hugs and wanting piggy-backs. A dear friend of the family once said, "Your children were lovely but having Bethany has made them exceptional."

"Bethany is very close to her siblings and good at organising them to do what she wants"

Bethany would like to go to the park and swim everyday and can howl when you aren't able to. She was very quick to learn signs for important foods like biscuit, sweets, and crisps! She enjoys doing the animal signs and her favourite song at the moment is "Old MacDonald" as she likes signing the horns for a cow and can make a "mmm" sound for "moo." Another firm favourite is "Five little men in a flying saucer", so she will stick up five fingers and start turning round, which is our cue to burst into song wherever we are!

The trials are also more heightened. Most of them due to dealing with the education and health service. We were thrust into a stream of appointments, endless advice on what to do with her and assessments. Battling to get additional support when she started to attend school full-time was a challenge. Whenever funding has been reduced (which is at each review meeting) we battle it back up, get risk assessments done, additional reports written, and eventually get her hours re-instated. However the hours never get backdated. It's at stressful times like this that you give Bethany a hug and remember you are doing it for her safety and well-

being. And try to maintain your sense of humour when told by well-meaning officers that Bethany doesn't need one-to-one because the other children in her class can help her.

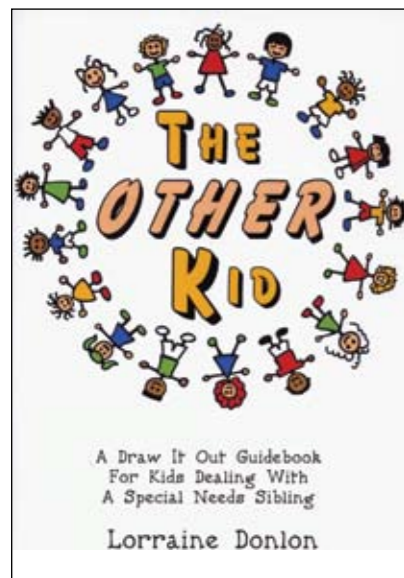
Practical challenges

There are practical challenges that regularly occur. All the other children ride round to the park on their scooters. Bethany clearly wants to join in but can't ride one. We have found we can just manage round to the park (it's not far) perching her on a scooter and a certain technique to push her on it whilst holding onto her in case she lets go of the handles! We can go on a cycle ride together now thanks to a trailer (and possibly a specialist trailer trike – to be test ridden soon).

The joys far outweigh the challenges, but you do need to remind yourself of that occasionally. Without Bethany we would never have been to London to see a specialist in connective tissue disorders, sent a urine sample by post to Scotland, met David Cameron MP, re-assessed what is really important for our family and learnt, and continue to learn, to take each day as it comes. We don't know what the future holds, I don't think I would want to know. We do know that as a family we will do our best for Bethany, for her security, happiness and well-being.



Bethany (centre) with her siblings



The Other Kid – A Draw It Out Guidebook For Kids Dealing With A Special Needs Sibling

Lorraine Donlon

This book is a wonderful idea for brothers and sisters of children with disabilities. It comes in a large A4 size so that children draw and write about their thoughts and feelings in it.

In simple words children can understand, the author explains how and why some children are born with disabilities and need lots of extra care and attention, and others aren't.

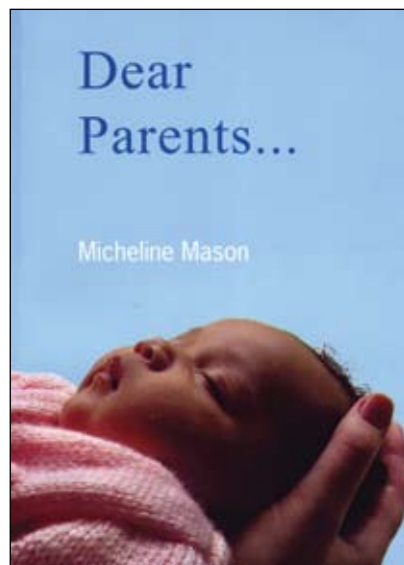
The author encourages the children to think and talk about their feelings in a way that aims to make them feel good about themselves. She doesn't gloss over difficult feelings like guilt, jealousy, sadness or feeling lonely. Instead she acknowledges and affirms for the child that these feelings are very real and

OK to have, and most importantly they matter. She encourages the child to think about any feelings and suggests solutions, like talking to someone they trust. They're invited to draw and write about their feelings on the page next to it.

The author's style is direct and very warm, giving lots of encouragement and support to the child, and letting them personalize the book to their situation. A lot of thought has gone into the text and making the 'other' kid feel as special, and deserving of love and attention as their disabled sibling appears to be. Reading it as an adult you can't help feeling that any child reading it will feel like they have the love, space and permission to be themselves. Highly recommended.

Karin Beeler
e-mail: karin.beeler@cafamilly.org.uk

Published by Llumina Kids
ISBN: 978 1 59526 780 1
Web: <http://www.llumina.com>



Dear Parents... Micheline Mason

This book looks at the relationship between disabled children and their parents. The author, Micheline Mason, has a disabled child and is also disabled herself. This allows Micheline a unique vantage point, being able to see both the needs of disabled children and parents. She has an innate understanding of what works and what doesn't.

All children are born expecting to be welcomed into the world, to have their needs met and to be loved. However, for disabled children, the job can sometimes be more confusing or difficult. Many parents may be deprived of vital information, either because they are not given it or because it is not available. For many, the expected welcome translates as disappointment, which the child themselves and people around them can pick up on. Micheline points out that all of these factors can have a damaging impact on the natural bond between a child and their family.

Throughout the book the case is made for switching to a more social model of disability, above the medical model. Through the childhood stories, which make up much of this book we read about the detrimental impact the medical model can have on a disabled child's well-being.

Clearly there is still a huge amount of work to be done to make lives better for disabled children, their parents and families. People who are there to help, including the medical profession, schools, and social workers also have their part to play.

This book is a great opportunity to step back for a moment to listen to the voices of disabled children, to understand the challenges and issues, and to hopefully move forward in a positive way.

Natalie Ridgway
e-mail: natalie.ridgway@cafamilly.org.uk

ISBN 0954635159
Price: £9.95
Published by Inclusive Solutions

Volunteer Parent Representatives

Contact a Family has a UK-wide team of Volunteer Parent Representatives who are parents of disabled children providing local information.

England

Birmingham North, South Asian Communities, Sonia Tooray, Tel: 0121 3311 248
Bradford - South Asian Communities, Nusrat Qureshi, Tel: 01274 743 224, e-mail: nusrat.queshi@cafamilly.org.uk
Buckinghamshire, Gail Walshe, Tel: 01296 713 138, e-mail: gail.walshe@cafamilly.org.uk
Cornwall, Anna Walker, Tel: 01209 315 661, e-mail: anna.walker@cafamilly.org.uk
Devon, East & South East, Margaret Ladbury, Tel: 01392 459720, e-mail: margaret.ladbury@cafamilly.org.uk
Devon, North, Julia Forrester, Tel: 01237 429 453, e-mail: julia.forrester@cafamilly.org.uk
Hampshire & Isle of Wight, Cay Byford, Tel: 01252 545 345, e-mail: cay.byford@cafamilly.org.uk
Morecambe, Kate Thompson, Tel: 07505 157 196, e-mail: kate.thompson@cafamilly.org.uk
Northamptonshire, Anja Sacké, Tel: 01933 359 623, e-mail: anja.sacke@cafamilly.org.uk
North Somerset and Bristol, Jan Seamer, Tel: 01275 461096, e-mail: jan.seamer@cafamilly.org.uk
Oxfordshire, Sophia Nicholls, Tel: 01491 836 765, e-mail: sophia.nicholls@cafamilly.org.uk
Ribble Valley Bridget Parkinson, Tel: 07527 875 978, e-mail: bridget.parkinson@cafamilly.org.uk
South Yorkshire, Elaine Doran, Tel: 01226 361 590, e-mail: elaine.doran@cafamilly.org.uk
St. Helens, Ruth Card, Tel: 01942 721 323, e-mail: ruth.card@cafamilly.org.uk
Suffolk, Sue Willgoss, Tel: 01502 513538, e-mail: sue.willgoss@cafamilly.org.uk
Surrey, Caroline Hunter, Tel: 01784 460842, e-mail: caroline.hunter@cafamilly.org.uk
Warwickshire, Rizwana Pathan, Tel: 024 7634 9612, e-mail: rizwana.pathan@cafamilly.org.uk

Scotland

Aberdeenshire, Carol McBride, Tel: 01651 891 468, e-mail: carol.mcbride@cafamilly.org.uk
Borders, Frances Teckkam, Tel: 01450 379 081, e-mail: frances.teckkam@cafamilly.org.uk
Dumfries & Galloway, Jacqui Law, Tel: 01387 263 563, e-mail: jacqui.law@cafamilly.org.uk

Fort William, Catriona Sillars, Tel: 01397 700 619, e-mail: catriona.sillars@cafamilly.org.uk
Orkney Trudy Marwick, Tel: 01856 761 835, e-mail: trudy.marwick@cafamilly.org.uk
North Lanarkshire, Elaine Glyn, Tel: 01236 840 049, e-mail: elaine.glyn@cafamilly.org.uk
South Lanarkshire, Elaine McKelvie, Tel: 01355 237 569, e-mail: elaine.mckelvie@cafamilly.org.uk
West Fife, Fiona Fisher, Tel: 01383 730 376, e-mail: fiona.fisher@cafamilly.org.uk
East Fife, Bernadette Bastiman, Tel: 01333 426 704, e-mail: bernadette.bastiman@cafamilly.org.uk

Family Workers

Contact a Family has a team of experienced Family Workers, covering different parts of the UK. Our staff help families to access services as well as offering support at times of particular need.

England

North Somerset, part Gloucestershire, Bobby Owen, Tel: 0117 914 0543, e-mail: bobby.owen@cafamilly.org.uk
South Birmingham, Wolverhampton & South Shropshire, Gaye Cowley, Tel: 01527 833 293, e-mail: gaye.cowley@cafamilly.org.uk
Blackpool & Lancashire, Corriena Tomkinson, Tel: 01772 812 294, e-mail: corriena.tomkinson@cafamilly.org.uk
Bradford for South Asian Communities, Rifaf Parveen, Tel: 01274 668 922, e-mail: rifaf.parveen@cafamilly.org.uk
Buckinghamshire, Gail Hanrahan, Tel: 0845 324 7542, e-mail: gail.hanrahan@cafamilly.org.uk
Cambridgeshire Adele Meader, Tel: 01799 543 043, e-mail: adele.meader@cafamilly.org.uk
West Cornwall, Janice Jenner, Tel: 01209 614 588 e-mail: janice.jenner@cafamilly.org.uk
North & East Cornwall, Liz Farmer, Tel: 07852 445 132, e-mail: liz.farmer@cafamilly.org.uk
Hampshire, Dorset, South Wiltshire & Isle of Wight, Debbie Ravensdale, Tel: 01489 895 501, e-mail: debbie.ravensdale@cafamilly.org.uk
Luton, For South Asian families with children under three years, Shuguftha Malik, Tel: 01582 548 106, e-mail: shuguftha.malik@cafamilly.org.uk
Oxfordshire, Valerie Reed, Tel: 01582 600 388, e-mail: valerie.reed@cafamilly.org.uk
Suffolk, Rachel Hill, Tel: 01473 422 539, e-mail: rachel.hill@cafamilly.org.uk

North and East Yorkshire and Humberside, Linda Legg, Tel: 01723 859 839, e-mail: linda.legg@cafamilly.org.uk
West & South Yorkshire, Judith Samways, Tel: 0114 250 8345, e-mail: judith.samways@cafamilly.org.uk

Scotland

Lothians, Borders & Fife, Joanne McIntosh, Tel: 01506 828 899, e-mail: joanne.mcintosh@cafamilly.org.uk
Highland and Morayshire Catherine Louttit, Tel: 01463 831 506, e-mail: catherine.louttit@cafamilly.org.uk

Wales

North West Wales, Jill Bartlett, Tel: 01248 670 965, e-mail: jill.bartlett@cafamilly.org.uk

Northern Ireland

Belfast, Co. Antrim, Co. Down & Co. Armagh Karen Patterson, Tel: 028 9262 7552, e-mail: karen.patterson@cafamilly.org.uk
Derry/Londonderry, Co.Tyrone & Fermanagh Patricia McAroe, Tel: 028 6863 2101, e-mail: patricia.mcaroe@cafamilly.org.uk
Northern Ireland Health and Social Services Trust, Virginia Maxwell, Tel: 028 9262 7552, e-mail: virginia.maxwell@cafamilly.org.uk

South West region & Cornwall

Contact a Family manages the local Parent Carers Council for Cornwall (PCCC).
Parent Carer Council Co-ordinator, Jane Jones, Tel: 01209 821 485, e-mail: jane.jones@cafamilly.org.uk
West, Ruthanne Lyne, Tel: 01326 221 025, e-mail: ruthanne.lyne@cafamilly.org.uk
East, Andria Roe, Tel: 01752 813358, e-mail: andria.roe@cafamilly.org.uk

Contact a Family and the PCCC manage the Parent Partnership Service for Cornwall - offering parents information, advice and support with the special educational needs process.
West, Adele Nankervis, Tel: 01736 752 826, e-mail: adele.nankervis@cafamilly.org.uk
East, Caroline Smith, Tel: 01579 363 671, e-mail: caroline.smith@cafamilly.org.uk

Connected

4 issues for £10 – subscribe today

The magazine for families with disabled children and all those who work with them

- Stay up-to-date on the issues that affect families with disabled children and help you may be entitled to
- Stories from other parents about their experiences of having a disabled child
- All the news across the organisation

Subscribe to Connected magazine

	Price	Qty	Total
Annual subscription (4 issues)	£10		
Additional subscriptions to the same address	£5		
Total			

Tel: 020 7608 8700
e-mail: info@cafamilly.org.uk

Payment

Pay by cheque or postal order

I enclose a cheque/postal order made payable to 'Contact a Family'

Please send my subscription to

Name _____

Address _____

Post code _____

Tel _____ Email _____

Parent support groups can receive Connected for free. Please call our helpline, Tel 0808 808 3555



Getting in contact with us

Contact a Family,
209-211 City Road,
London EC1V 1JN
Tel: 020 7608 8700
Fax: 020 7608 8701
e-mail: info@cafamily.org.uk

www.cafamily.org.uk
www.makingcontact.org

Ring the Contact a Family freephone helpline for advice and information on any aspect of caring for a disabled child.

Contact a Family is the only UK charity providing support and advice to parents whatever the medical condition or disability of their child. Our helpline is a 'one-stop-shop' for parents and families whenever they need answers.



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

Freephone helpline:

0808 808 3555

Textphone:

0808 808 3556

Open Mon-Fri, 10am-4pm & Mon, 5.30-7.30pm