

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

incorporating  
**The Lady Hoare Trust**

in **contact**



**The newsletter of Contact a Family North East**

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

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### **New Tourette Syndrome NE Support Group**

Pictured left is Mayor of  
Morpeth, Cllr Ken Brown  
launching this new Support  
Group in January 2010  
Full details on page 7

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northern rock  
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# Wills & Trusts

Anyone who has to care for or provide for a family member with a learning disability needs to be aware that standard family wills may not work in this situation. This article, written by Helen Rowett from Irwin Mitchell covers some of the essential topics that families need to be aware of.

## Wills

It is essential to have the right sort of will when one of your beneficiaries has a learning disability. You must make plain to the solicitor drawing the will that you need to provide for a child or other relative with a learning disability. S/he needs to be aware of the complexities involved and if s/he doesn't show awareness of these, go elsewhere. If your child has a learning disability you first of all should consider their level of capacity to manage money, perhaps quite a substantial sum. If they do not have the capacity to manage their affairs, normally the Court of Protection will be involved and it makes sense to avoid it if you can.

Your child may be vulnerable to financial abuse if they do not appreciate the value of money. If your child is in receipt of means tested benefits, any large inheritance will disqualify them until the inheritance is reduced to the permitted level. This cannot be corrected after a death, as any variation would be treated as deliberate deprivation of assets, and the child will be means tested as if they still had the assets.

You DO need to be fair amongst all your children and balance competing interests. There may be good reasons why you do not treat all the children exactly alike, but you do need to give thought to the matter. You should always wrap your disabled child's inheritance in a trust within your will, or leave it to an already established trust such as the Mencap trust. DON'T just leave it informally to the others to look after for the disabled child – it may be lost in a divorce for example, and the disabled child would have no comeback.

As mentioned above, if there is no will, the intestacy rules operate and this can be a problem not only for your child but also for you. The current intestacy rules for a married couple, or in civil partnership, where there are children of the one who has died, are that the survivor receives what is called a statutory legacy of £250,000 and all the personal chattels (things) and a life interest in half the excess, and on the survivor's death it goes on to the children, whilst the other half of the excess goes in equal shares to the children outright at 18.

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## Wills & Trusts (cont.)

So a will gives you the chance to make proper provision for your children, to decide who administers your estate (executors and trustees), appoint guardians for any minor children, and express your own wishes about the distribution of your estate and the way things are dealt with.

### Trusts

There is a variety of trusts in use, but the type you need is called a Discretionary trust. (The Mencap trust is one of these). There is also a special trust for disabled people called an s89 trust for vulnerable beneficiaries. This can be useful on occasions, but normally we would choose a discretionary trust, as it does not affect a beneficiary's right to means tested benefits (income support and housing benefits, council tax benefit where relevant). So as long as the trustees pay bills on behalf of the disabled beneficiary, pay for treats, holidays etc, the beneficiary suffers no penalty.

A trust may be set up in your lifetimes and you and other family members can then leave money to it, or you can establish the appropriate trust in your will. It can be very convenient to have a lifetime trust in existence but it is very important that if you are using it as a recipient of legacies that you set it up and then leave its provisions unmodified. The service which Mencap offers can be really useful. You set up a trust with the Mencap Trust Company as trustee, you give them £5 to make the trust technically valid – it must have some assets in it – and you pay their set up charge, and the trust can lie dormant until your death, or of course it can receive legacies or funds from other family members in the meantime.

The trust is an excellent idea, particularly for families who need to ensure that someone will always be around to look after their child's inheritance in their best interests and who are worried about imposing on other family members. The trust pack is available from Mencap on request. More information can be found on their website at <http://www.mencap.org.uk/page.asp?id=10616> or give them a call on **0808 808 1111**

If you were not able to attend one of Mencap's recent Wills & Trusts seminars, would you be interested in attending a workshop to look at these issues in greater detail? If so, please let us know here at Contact a Family North East on 0191 213 6300 or email [northeast.office@cafamily.org.uk](mailto:northeast.office@cafamily.org.uk).

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# Money Issues

## Cash Counts

Contact a Family has recently launched **Cash Counts**, a new online service dedicated to ensuring families with disabled children are getting all the financial help they are entitled to. Cash Counts includes:

- An online benefits calculator, allowing families to work out how much they are entitled to
- A top tips guide on the benefits available to families with disabled children written by the Contact a Family helpline
- A frequently asked questions page to help families navigate the complex benefits system



Visit Cash Counts at <http://www.cafamily.org.uk/cashcounts>. Alternatively, please give our national freephone helpline a call on **0808 808 3555** to make sure you are receiving all the financial help you are entitled to.

## Counting the Costs – how are your finances in 2010?

Finances can be a major concern for families with disabled children. In 2008, Contact a Family asked families about their finances and the results were shocking: with one in six families reporting that they were going without food and heating.

Now, two years on, we would like to ask families about their finances again so that we are able to demonstrate if and how things have changed. There is a lot of talk that the economy has turned a corner and things are beginning to improve, but we would like to know what the experience of families with disabled children is.

Counting the Costs 2010, a Contact a Family survey of families with disabled children's finances will help us to raise awareness of the money worries specific to the families we support and to campaign for change. Srabani Sen, Chief Executive of Contact a Family, said: "In these recent turbulent economic times everyone has been struggling. But it costs three times more to raise a child with a disability and families with caring responsibilities have greater difficulty working, so are more likely to be living in poverty. Please take the time to fill out our short online survey, which will take no longer than five minutes to complete."

Counting the Costs 2010 survey: <http://www.surveymonkey.com/s/T2S2ZZF>

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# Regional Events

## North East Regional Parent Partnership Services 2010 Annual Parents Conference on Special Educational Needs

This year's conference is taking place on Wednesday 9th June from 9.30am to 2.45pm at Ushaw College, Durham

The conference is free to parents and carers of children with special educational needs from across the North East. Professionals are welcome to attend at a cost of £50. The day includes workshops to help you to support and understand your child's learning difficulties such as the SEN Code of Practice, Disability Discrimination, Inclusion, Support provided in schools and more. There will also be a number of information stands there on the day.

Refreshments, lunch and a crèche are also provided and transport for parent/carers from around the region can also be provided.

For further details or to book your place, please contact Ann Connor from Durham Parent Partnership Service on **0191 5873541** or send an email to **ann.connor@durham.gov.uk**

## Advocating for your Child, Are You Being Heard?

A free Afasic training day for parent/carers of children and young people with speech, language & communication impairments. The programme will look at what is meant by advocacy and how to be an effective advocate for the needs of children and young people. Topics include establishing a case, methods of communication, participation and boundaries, and possible scenarios.

Parents and carers will be their children's best and most consistent advocates. Don't let words, procedures and policies bamboozle you! If you would like to learn more, or brush up on your skills and knowledge, then this training is for you.

Choose from either **Tuesday 23rd March 2010** at **Marriott Hotel, Gateshead** OR **Saturday 24th April 2010** at **Blackwell Grange, Darlington** from 9.45am-2.15pm  
Lunch and refreshments will be included. Places must be booked in advance through Janine Curd at Afasic. A £10.00 refundable deposit is required for each place booked. Call Janine on **01287 209882** or e-mail her at **jc.afasic@hotmail.co.uk** for more information or to book your places.

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# Local News

## Funky World



A world of multi-sensory learning and play for all the family has opened in Hartlepool. Funky World is a unique centre in Teesside, providing a wide range of well-equipped facilities in a relaxed environment for children of all ages and abilities and their families.

Funky World encourages children to interact and helps to increase confidence and learning potential through sensory stimulation, relaxation and play. Children and their families can explore and enjoy a fully enclosed soft play area, sensory cave, two well-equipped sensory studios and a large screen Nintendo Wii. They have also recently received funding to install an interactive cinema.

Funky World caters for the whole family. The bistro overlooks the soft play area, allowing carers to enjoy a coffee whilst supervising the children. There are no age or height restrictions. Individuals and groups are equally welcome, and they also take bookings for children's birthday parties.

Funky World is accessible for wheelchairs and there is a fully equipped changing place. They are also able to provide transport to & from the centre in their 16-seater wheelchair-accessible minibus.

Funky World is a Community Interest Company, a not-for-profit organisation, all payments they receive are used to cover running costs and improvements to the centre. It is advisable to book in advance, so contact Funky World for further information and for prices. Funky World CIC, The Parity Centre, Durham Street, Headland, Hartlepool, TS24 0HQ.

See their website at [www.fwcic.com](http://www.fwcic.com), email them at [info@fwcic.com](mailto:info@fwcic.com) or give them a call on **01429 860700**



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# Local Support Groups

## Tourette Syndrome North East Support Group

As featured on the front cover, the Tourette Syndrome North East Support Group was launched on 30 January 2010. The Group is run by and for people in the North East affected by Tourette Syndrome.



Tourette Syndrome is a complex and much misunderstood brain disorder. Many people associate Tourettes with compulsive swearing. But in fact only 10% of people with Tourettes have this symptom.

The Tourette Syndrome North East Support Group offers people with Tourettes and their families a unique opportunity to meet regularly with others who understand. Meetings are friendly and informal, and enable those with the condition and their families to share experiences, find out about treatments and therapies, sources of further information and advice, and, most importantly, to support each other with friendship.

For half of the young people attending the first Support Group meeting in January, it was the first time they had ever met another person with the same condition as them. Now they have new friends who they can call, text, and have fun with at meetings. And so have their parents!

Meetings in 2010 will be held on Sat 22 May, 17 July and 27 Nov for Children and Families and on Sat 29 May and 25 Sept for Adults and children aged over 16 only. For further information please email [jac.campbell@homecall.co.uk](mailto:jac.campbell@homecall.co.uk) or phone **07501 620200**. For more information about Tourette Syndrome, visit [www.tourettes-action.org.uk](http://www.tourettes-action.org.uk)

## Support Group for families who have children with Neurological Conditions

A support group for parents and carers of children who have neurological conditions meets on the second Thursday of each month at the Nunsmoor Centre, Fenham, Newcastle from 10.00am-12.00pm. For more information about the group, please call Nadia Conway, Paediatric Neurology Nurse Specialist on **0191 2829834** (Mon to Thurs 8.30am-3.30pm).

If you are interested in attending but the venue is too far away from you, please give Nadia a call as they may be able to arrange meetings closer to where you live, depending on demand.

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# Publications Update

## Contact a Family Publications

A number of Contact a Family publications have been revised and updated and we have also expanded the number of podcasts available too. Some of our publications are now available as web downloads only from our website at <http://www.cafamily.org.uk/publications.html>. Recent additions include web guides on Community Care Grants and a Tax Credit Guide for Self Employed parents.

If you are unable to access these from our website or would like a full list of publications available, please just contact the North East office.

## Contact a Family North East & Cumbria Local Contacts

### Family Support Worker for Cumbria

**Debbie Armstrong** is our Family Support Worker in Cumbria. Debbie can provide one to one support & help with lots of information about local services etc. You can contact her on **01228 550069** or by email at [debbie.armstrong@cafamily.org.uk](mailto:debbie.armstrong@cafamily.org.uk)

### Volunteer Parent Representative

**Bob Mitchell** is in Northumberland and is happy to help local parents & professionals who would like more information about Contact a Family. You can contact him on **07532450218** or by email at [bob.mitchell@cafamily.org.uk](mailto:bob.mitchell@cafamily.org.uk)

### National Freephone Number - 0808 808 3555

Contact a Family's **National Freephone Helpline** for parents of disabled children is open from Monday to Friday 10.00 a.m. to 4.00 p.m. (& 5.30 - 7.30 p.m. Monday) The text phone number is **0808 808 3556** and Language Line is available for parents whose first language is not English

If you did not receive this newsletter at your own address and would like to be added to our mailing list please give us a call or write to us at Contact a Family, The Dene Centre, Castle Farm Road, Gosforth, Newcastle upon Tyne NE3 1PH.

Tel/Fax - 0191 213 6300

E-mail - [northeast.office@cafamily.org.uk](mailto:northeast.office@cafamily.org.uk) Website - [www.cafamily.org.uk/northeast](http://www.cafamily.org.uk/northeast)

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