

# contact a family

for families with disabled children

## In Touch April 2010

### Contact a Family - Northern Ireland Bi Monthly newsletter

In Touch is issued every two months and aims to bring you up to date news, details of training courses, group information and new resources available from within Contact a Family and from other organisations. We hope the information is useful and helps you and your family.

We value your feedback on this and all our services and publications. Please forward you comments to the e mail address below.

For right up to date information on events, consultations, local groups our most recent Newsletter and more see our webpage at [www.cafamily.org.uk/inyourarea/nireland.html](http://www.cafamily.org.uk/inyourarea/nireland.html) bookmark this page and then you can access it quickly!

Our next Regional newsletter is due out mid June 2010

We are available to help with any issues that affect the disabled child or young person, parents, families and professionals.

Contact us at 028 92627552 or e mail [nireland.office@cafamily.org.uk](mailto:nireland.office@cafamily.org.uk)

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# Money issues .....

## Budget news!!!

**Child Benefit**.....There are two separate amounts currently paid for child benefit, with a higher amount for the eldest, or only, child.

The payment stands at £20 a week for the eldest child and £13.20 a week for each other child. These payments will go up to £20.30 and £13.40 respectively.

**DLA**.....Similarly the increase in benefits payments will only be marginal, with the highest rate of the care component of the disability allowance going up by 71p to £71.06.

### **a. Changes in carers benefits rules will help more families with disabled children claim**

From 12th April 2010 Carer's Allowance, the only state benefit specifically aimed at carers, will be made available to a greater number of those who are working.

Carer's Allowance cannot be paid to a carer if they work and earn more than a set amount. The government has announced that this earnings limit will be raised from £95 to £100 after tax deductions - the first time it has been changed since 2007.

For working families caring for a disabled child, the Carer's Allowance rules allow certain childcare costs to be deducted from earnings, so some may qualify even though they are earning slightly more than £100 per week.

From April, Carer's Allowance will also rise from £53.10 per week to £53.90.

Srabani Sen, Chief Executive of Contact a Family: "It's good news for working families with disabled children who provide 35 hours a week of care but are just missing out on Carer's Allowance.

"Working families with disabled children are under enormous pressure juggling their employment and caring responsibilities. It is vital that they ensure they are getting all the financial support available to them."

Contact a Family's free Helpline can advise families with disabled children who want to know if the change in the rules will help them claim Carer's Allowance. Call 0808 808 3555.

To qualify for Carers Allowance you must meet the following criteria:

- Be aged at least 16 years old
- Provide at least 35 hours per week care to someone who gets either Disability Living Allowance at the middle or highest rate or Attendance Allowance

- Not be studying on a course involving 21 hours or more supervised study
- Meet certain residence and immigration conditions
- Have weekly earnings below the earnings limit

## **b. 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.

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."

Go to [www.cafamily.org.uk](http://www.cafamily.org.uk) and follow the link in "Whats happening" - deadline for completion is the 30<sup>th</sup> April 2010.

## **c. Launch of Moneymadeclear money guidance service**

Following the successful pathfinder project, the FSA, in partnership with Government, today launched the national money guidance service, Moneymadeclear.

Moneymadeclear is an impartial, sales and jargon-free service providing consumers with information and guidance on how to manage their money now and in the future. The service is available over the telephone, in face-to-face sessions or via the Moneymadeclear website. The face-to-face service is being phased in over the coming months and will be fully operational by late 2010.

Moneymadeclear is available on 0300 500 5000 and online at [www.moneymadeclear.fsa.gov.uk](http://www.moneymadeclear.fsa.gov.uk)

## **d. CEA Card Scheme .....saving on cinema visits**

The Cinema Exhibitors' Association. This is a national card that can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema. Terms and Condition of use apply.

The scheme, which is open to anyone claiming Disability Living Allowance or who is registered blind, has been in existence since 2004. Set up to bring greater consistency to a wide range of disability-related schemes run by the sector, it now involves the majority of UK cinema companies.

To apply for the card, you will need to meet one or more of the following criteria:

- a) Be in receipt of the disability living allowance or attendance allowance.
- b) Be a registered blind person.

The card is valid for 1 years from the date of issue for cards issued since March 2009.

Application forms are available from cinemas across the UK supporting this card. Or are downloadable from [www.ceacard.co.uk](http://www.ceacard.co.uk)

Cinemas in N Ireland that are participating in this scheme are listed below

Movie House Cinemas Yorkgate  
Yorkgate Leisure Complex, 100-150 York Street, Belfast, , BT15 1WA  
028 9075 5000  
[www.moviehouse.co.uk](http://www.moviehouse.co.uk)

Playhouse Cinema  
47 Main Street, Portrush, Northern Ireland, , BT56 8BL  
01256 823 472

St Canice's Hall  
90 Main Street, Co Derry, Northern Ireland, , BT47 4LG  
028 777 41492

Queen's Film Theatre  
20 University Square, Belfast, Northern Ireland, , BT7 1PA  
02890 272 610

Odeon Belfast  
No. 1 Victoria Square, Unit 13SF, Belfast, , BT1 4QG  
0871 22 44 007  
[www.odeon.co.uk](http://www.odeon.co.uk)

## 2. Getting support.....

### a. MakingContact.org.....linking families through Contact a Family

*"I searched for ages to find someone with the same condition as my son. When I found someone through MakingContact.org who knew what I was going through - I was so happy, I cried."*

*Mother, Northern Ireland*

When you or your family is affected by disability or a medical condition, it can sometimes be an isolating experience. Often being able to contact someone who knows what you are going through can be the biggest help but how do you find those people?

Contact a Family has been putting families with disabled children in touch with each other for over 25 years. MakingContact.org complements our existing services and gives you the chance to safely and easily get in touch with others who are affected by the same or similar disabilities or medical conditions as you are.

With thousands of medical conditions and disabilities listed and thousands of people signed up and looking for contact, this site could help you find the people you are looking for. Your child doesn't even have to have a diagnosis, just enter undiagnosed. It's free\*, safe and easy to use.

\* Finding people, posting your details and replying to others is free. There is a nominal annual charge if you want to initiate contact with others.

full list of all conditions is available in either alphabetical or hierarchical forms. Note that there are over 2000 conditions and these lists may take a few seconds to display

You don't have to enter the full name of the condition, abbreviations, parts of the name & wildcards (\*) are acceptable.

There is also a message board facility where there are boards covering Education, Behaviour, Working, Growing up and Transition, Consultations, questionnaires and events and Share your Day.

All visitors to the site are able to read the forums and registered members MakingContact.org are able to post messages. The first 6 posts you make to the site will be moderated (read and approved before they are posted live on the site). After this initial moderation, posts will only be read after they have gone live.

MakingContact.org is available to a vast range of nationalities and communities and although Contact a Family are UK based we are aware that not everyone using this site will have English as their first language. Following financial support from the Department of Health they can offer much of the site in 4 additional languages, Arabic, Farsi Somali and Simplified Chinese

## **b. Osteopetrosis Support Group - grants**

The Osteopetrosis Support Group offers support to families whose children are affected by osteopetrosis. One of the ways they do this is by providing grants. If you are a parent of a child affected by this condition contact the group to find out more about accessing this money. Email Alison Gould <[http://alison@osteopetrosis.co.uk](mailto:alison@osteopetrosis.co.uk)> or telephone her on 01984 639416.

## **c. Unique - family weekends**

Unique <<http://rarechromo.org>> is holding a number of family weekends for families whose children are affected by specific rare chromosome disorders: 4q deletions; 9q34 deletions; 8p23.1 deletions; 2q37 deletions and Pallister Killian Syndrome.

For further information about when and where these events will be held, email Prisca Middlemiss <[http://prisca@rarechromo.org](mailto:prisca@rarechromo.org)> at Unique.

## **d. New! Lisburn support group off to flying start.....**

Sarah Hillis, mum of Luke, Hope and Imogen has set up an informal group to offer support to local families of children with complex needs and severe disability. The group may be small with about 8 families at present but hopes to reach out to as many families in the area as possible, offering support, a place to share your experiences and be listened to by like minded people. The group meets every 3<sup>rd</sup> Wednesday in the month over a coffee, to find out more and go along yourself contact Sarah on tel 07736467588 or 02892586180 alternatively e mail [keepsmling.sarah@googlemail.com](mailto:keepsmling.sarah@googlemail.com)

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# **3. Resources.....**

## **a. New! From Contact a Family**

**NEW!** The updated version on **Dealing with debt in N Ireland** is now available to download from <http://www.cafamily.org.uk/pdfs/debtNI.pdf>

**Transition** – please find local N Ireland information around the issues of transition and transition plans at [http://www.cafamily.org.uk/pdfs/transition\\_ni.pdf](http://www.cafamily.org.uk/pdfs/transition_ni.pdf) where there is a downloadable booklet.

.....**Community Care Grants** publication downloadable at <http://www.cafamily.org.uk/pdfs/CommunityCareGrants.pdf>  
and .....**Tax Credits for the self employed** is downloadable at <http://www.cafamily.org.uk/pdfs/TaxCreditsSelfemployed.pdf>

We have added some more podcasts to the library one as part of the cash counts project and one about Soto Syndrome. If you would be interested in being interviewed for a podcast, particularly if you have a child with a rare disorder, email Cheryl Lenny <[http://cheryl.lenny@cafamily.org.uk](mailto:cheryl.lenny@cafamily.org.uk)>

Contact a Family is working hard to raise awareness of the issues for families who are affected by rare disorders. Our press officer is always keen to hear from people who would be happy to share their experiences with the media to raise awareness of a particular disorder and/or a particular issue. If you are interested in finding out more, email Elaine Bennett [http://elaine.bennett@cafamily.org.uk](mailto:elaine.bennett@cafamily.org.uk) or call her on 020 7608 8741.

## **b. National Centre for Young People with Epilepsy (NCYPE) - seizure diary**

The NCYPE have produced a fabulous diary to help children with epilepsy to help children 5-10 to record their seizures in a fun way. This is a lovely book with fun pictures and cartoons and is available free of charge by calling 01342 832243 ext 296 or email <[http://info@ncpye.org.uk](mailto:info@ncpye.org.uk)> .

## **c. Cerebra Research Unit**

You may have heard about the Cerebra Research Unit (CRU), a new project made possible by funding from the UK charity Cerebra.

The CRU was founded to help establish what treatments and therapies improve the health and wellbeing of disabled children and their families.

As part of this work they have begun to produce a series of short reports to answer some questions about the evidence surrounding treatments and therapies that parents and carers have queried. The reports are called “What’s the evidence” and they are now available on their website <[http://sites.pcmd.ac.uk/cerebra/evidence\\_main.php](http://sites.pcmd.ac.uk/cerebra/evidence_main.php)>

So far they have produced three reports, and will continue to produce more in response to queries from parents and carers. So if there is a treatment or therapy that you would like them to produce a “What’s the evidence” report about, then please let them know. You can use our internet forum or you can contact them through the details on the website.

If you would like any further information about the CRU, their website or contact Claire Lloyd on 01392 262901.

#### **d. Changing Places, changing lives**

Thousands of disabled people, including 40,000 people with profound and multiple learning disabilities, need Changing Places toilets.

Without these facilities, families have to change the person they care for on a cramped and dirty toilet floor. The alternative is to limit outings to a few short hours - or to not go out at all.

Since the campaign was launched last year Mencap is delighted to announce the first Changing Places toilet in an airport , in George Best, Belfast City Airport. There are an additional two changing places toilets in NI located at the Divis & Black Mountain and in Lisburn Civic Centre....for more on the campaign go to [www.changing-places.org](http://www.changing-places.org)

#### **e. Employers for Childcare- new service launched**

As part of their ethos “to make it easier for parents with dependent children to get into work and stay in work” Employers for Childcare have extended their services to offer parents a Childcare Benefits Advisory Service. This new service offers advice and information through its Childcare Benefits advisors on childcare, employment, entitlements and workplace legislation. They aim to help parents with dependent children by informing them of their rights and entitlements and performing benefits calculations using benefits advice software from the Department of Social Development. They can also provide an outreach service.

For more information about this service and the work of Employers for Childcare call free on 08000286538 or e-mail [info@employersforchildcare.org](mailto:info@employersforchildcare.org)

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## **4. Events and training.....**

### **a. Mencap’s Segal House 40<sup>th</sup> Anniversary Event!**

From May 2009 -May 2010 Mencap’s Segal House is celebrating its 40th Year. To mark this important milestone a fun event for pupils, staff and families past and present will take place on Sunday 9th May at La Mon Hotel & Country Club from 3-6pm. For further details about the event please contact Una McAliskey Tel: 028 9069 0186 or email:

[una.mcaliskey@mencap.org.uk](mailto:una.mcaliskey@mencap.org.uk) by the 26<sup>th</sup> April 2010.

## **b. Peat Autism training workshops on Toileting, Sleeping and Eating**

These workshops are targeted towards parents, tutors and professional working with children with autism. All PEAT training uses the principles of applied Behaviour Analysis (ABA). Costs are PEAT Parent= £15, Parent =£25, Student =£ 20, Professional =£60

For more information and to register your interest for any of the training courses and/or secure a place please contact the PEAT Office directly on 02890324882 or e mail [info@peatni.org](mailto:info@peatni.org)

Date Monday 7<sup>th</sup> June 2010, Venue, Ramada Davincis Hotel, L/derry, Time 10am to 3 pm

Tuesday, 8<sup>th</sup> June 2010, Venue, The Lodge Hotel, Coleraine, Time 10-3

Thursday 10<sup>th</sup> June 2010, Venue, Leighinmohr House Hotel, Ballymena, Time 10-3

Friday 11<sup>th</sup> June 2010, Venue Lagan Valley island Centre, Lisburn, Time 10-3

Monday 14<sup>th</sup> June 2010, Venue Silverbirch Hotel, Omagh, Time 10-3

Tuesday 15<sup>th</sup> June 2010, Venue Killyhevlin Hotel, Enniskillen, Time 10-3

Thursday 17<sup>th</sup> June 2010, Armagh City Hotel, Armagh, Time 10-3

## **c. Wills and Trusts, planning for future events...**

If someone in your family or someone you care for has a learning disability. You can take steps now to ensure their finances are well looked after when you are no longer around...

Mencap have organised some free information sessions where you can find out more about setting up Wills and Trusts for the benefit of someone with a learning disability.

**Thursday, 6<sup>th</sup> May, 11am -1pm at Newtownbreda Presbyterian Church, 374- 378 Ormeau Rd, Belfast BT7 3HX**

**Thursday, 6<sup>th</sup> May, 6.30pm - 8.30pm , Dunsilly Hotel, 20 Dunsilly Road, Antrim,BT41 2JH**

**Friday, 7<sup>th</sup> May, 10.30 am -12.30pm, Armagh City Hotel, 2 Friary Rd, Armagh, BT60 2HE**

There will be a local solicitor speaking, who has experience of drafting wills for the benefit of people with a learning disability. These seminars are always very popular, so please book your places as soon as possible.

To book a place please call **Gina Collins on 020 7696 6925**. All places and venue details will be confirmed in writing.

**AND Sadly a final note .....**

## **Loss of valuable Family Support Service**

Contact a Family, N Ireland loses a very valuable service due to lack of funding. At the end of March 2010 the Family Support Service, Eastern Area, having provided vital support to families of children and young people with a wide range of disabilities ended.

Families who live in the Belfast, South Eastern and Southern Trust areas are devastated and outraged at the loss of this "lifeline", and their very valued Family Support Officer, Karen Patterson who has worked tirelessly with local families for 3 ½ yrs.

This post was funded by the Big Lottery and the Health Board, and despite very determined efforts to secure ongoing funding from statutory and other sources, no funding has been forthcoming at this time.

All telephone enquiries can be directed to the Lisburn Office, tel 02892627552 or by e mail on [nireland.office@cafamily.org.uk](mailto:nireland.office@cafamily.org.uk) and the Family Support Service for families living in the Northern Trust area remains operational.

The staff at the NI office hope that you will join with them in thanking Karen for all her committed work during the last 3 ½ years and wishing her all the best for the future.

April 2010 e zine