

contact a family

for families with disabled children

In Touch October 2010

Contact a Family - Northern Ireland Bi Monthly newsletter

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Over 1,000 show support for Stop the DLA Takeaway

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Contact a Family and The Children's Trust want to say a huge thank you to everyone who has so far shown their support for our Stop the DLA Takeaway campaign.

We are calling for an end to the unfair benefits rules which mean a child's Disability Living Allowance (DLA) is taken away when they spend a long period in hospital. The rules are penalising families when they are at their most vulnerable.

We've had over 1,000 e-mails of support in just one week. The e-mails were also sent to the Department of Work and Pensions (DWP) consultation on welfare reform. The consultation has now closed and we hope that decision makers at the DWP have heard the Stop the DLA Takeaway message loud and clear.

Srabani Sen, Chief Executive of Contact a Family, said: "We've been overwhelmed at the huge response we have had from both parents and professionals.

"We want to say a huge thank you to everyone who has shown their support for our Stop the DLA Takeaway campaign. You have really helped us to get the attention of policy makers. We now hope that they give genuine consideration to scrap these rules which are causing misery to hundreds of families at such a difficult time."

To view the full report go to http://www.cafamily.org.uk/pdfs/Stop_the_DLA_Takeaway_2010.pdf
If you have any ideas for future campaigns big or small please contact nirelandoffice@cafamily.org.uk



Santander funding bid successful!

We are delighted to receive £3000 from Santander to run a series of Northern Ireland wide workshops for parents on managing finances and debt. More news will follow in our e zine and on the website about dates, times and content. To register your interest at this time contact Catherine Flannigan, Information Officer at tel 028 92 627 552 or email catherine.flannigan@cafamily.org.uk

Some Monkey Business going on!

Contact a Family organised and ran a very successful fun morning for parents and children in the Northern Health and Social Care Trust area on Tuesday 19th October. Mums and tots alike enjoyed a relaxing and fun filled few hours at Monkey Business in Ballymena. Virginia and Catherine chatted with mums as they enjoyed a cup of coffee and shared advice and information with each other while the tots had fun in the ball pool, slides or just had a nap!



New Podcasts from Contact a Family

Follow the links from to hear these two new podcasts at <http://www.cafamily.org.uk/news/index.html>

Juvenile Batten disease - a parent's story

The group of diseases known as Batten disease or the neuronal ceroid lipofuscinoses (NCLs) are rare, genetic, progressive neurodegenerative, metabolic diseases that occur in children and adults worldwide. This podcast is an honest account of a mother's experience of having a son with Juvenile.

Benefits: Disability Living Allowance - September 2010

Disability Living Allowance (DLA) is the main benefit for disabled people and is there to help meet any extra costs of being disabled. Listen to this podcast to hear the Contact a Family helpline advisers provide more information about this benefit.

Over the Wall - Activity camps coming up on 2011

Over The Wall will in the next month be announcing the dates for their spring and summer programme in 2011. They are an established charity providing week-long residential activity camps to children and young people aged 8 - 17 who are affected by serious and life-limiting illnesses. In 2011 they will operate camps for siblings and seriously ill children / young people:

Siblings - 80 (Easter) Dorset

Seriously ill children – 210 (Summer) Dorset & Midlands

Siblings – 60 (Summer) Scotland

Seriously ill Children - 50 (Summer) Scotland

Camp is an important social experience and life-changing for the children concerned. Improvements in well-being and self-esteem are widely reported which can lead to better self-care and also educational attainment and aspirations.

Any child who meets the criteria is eligible to apply. Please note that this experience comes at no cost to the family. The programme is open to all children living in the United Kingdom and they offer transport from central locations. The camps for seriously ill children operate with a ratio of 1 volunteer : 1 child with further on-site medical support working with 1 healthcare professional : 10 children.

These camps are very popular and you are encouraged to apply for children who may be eligible for this important social experience.

Over the Wall realise that every child is an individual with specific needs. If you are unsure whether a child meets the criteria or have any other queries, please do not hesitate to contact them on 0239 247 7110 or you can e-mail at info@otw.org.uk

New child and adolescent mental health unit opens

On the 9th September a new regional Child and Adolescent Mental Health Inpatient unit has been opened. Beechcroft, at Forster Green, Belfast, will provide 33 inpatient beds and a further five daycase beds for children and adolescents with mental health problems.

Wide range of therapies

There are a wide variety of therapies and treatments available in the unit. These will be delivered by highly-skilled staff working together to ensure that children and young people receive the highest quality assessment, treatment and care, in a modern and safe environment.

The Adolescent Unit provides a total of 18 inpatient beds, including two new intensive nursing beds. They are single rooms all with ensuite shower and toilet facilities.

The Child and Family centre has 15 inpatient beds and five day hospital places for children up to the age of 13. It also has overnight-stay accommodation for parents and a family flat.

Beechcroft also has dayrooms, dining rooms, quiet areas, together with therapy and education facilities and support accommodation for the staff, catering and administration. A recreation hall and outdoor recreational area is also provided for the patients.

Patient and Client Council launches new look website and social network

Chief Executive of the Patient and Client Council, Maeve Hully said

'We hope our website will give people across Northern Ireland the opportunity to access information, share their experiences and learn more about how they can get involved in health and social care.'

We want to reach all people living in Northern Ireland. The website was developed by working with patients and clients, to provide an interesting and easy way of letting people know about our work.'
Visit www.patientclientcouncil.hscni.net

To date, over 450 people have signed up to the Patient and Client Council Membership Scheme. The scheme is the first of its kind in Northern Ireland and offers people living here the opportunity to have their say on local health and social care issues. Visitors to the website can join the scheme online.

8% of the world is signed up on Facebook. Through the Patient and Client Council Facebook page, people can share their views and get involved in discussions about health and social care. You can find the Facebook page by searching 'Patient and Client Council' on the Facebook home page, www.facebook.com

By following the Patient and Client Council on Twitter, people will be able to keep up to date with current work and issues in health and social care www.twitter.com/patientclient

Contact a Family - Financial Publications

Contact a Family produce a wide range of publications that look specifically at finances and benefits. Below is the link to take you to these free downloadable resources, ensuring you are getting all you are entitled to. They include a N Ireland parent checklist, tax credits and social fund and community care grants

<http://www.cafamily.org.uk/publications.html?sp=30&scat=37>

Help with cutting costs

Top ten energy saving tips; save the planet and save money...

Sometimes it's easy to forget that there are some simple steps we can take to reduce energy consumption in our own homes. These kinds of measures can help to reduce the damage to our planet and importantly, save families hundreds of pounds...

- **Tip 1 – Insulation... wrap up**

You can lose up to 35% of the heat from your home through the walls and up to another 25% through the roof. Look into getting loft and cavity wall insulation it could save you up to £265 (Energy Savings Trust- EST). Most energy companies have discounts on these products and some schemes offer it for free, however check out eligibility criteria.(Warm Homes scheme- info below)

- **Tip 2 – Heating... turn it down**

Turn down your thermostat by just 1°C and cut your fuel bills by up to 10% saving about £55 a year (EST). You'll

notice the saving, but not the drop in temperature. Consider insuring your boiler for the coming winter months to avoid sudden huge repair bills. Keep furniture away from radiators so the heat can get out and consider using radiator panels behind your radiators. Turn radiators in unused rooms down or off. Use draft excluders and draft proofing tape. You could save £25 by just doing this (EST).

- **Tip 3 - Hot water... use less**

Zippering up your hot water cylinder with a lagging jacket could save you £35 (EST). Nip in the shower rather than filling a bath as a five minute shower uses about 30%

less water. Take a close look at your cylinder thermostat – there's no need for it to be set higher than 60°C/140°F.

- **Tip 4 – Lighting... switch!**

Energy saving light bulbs last up to 10 times longer than ordinary light bulbs. Just one will save you around £40- £65 in its lifetime (EST). By just switching off lights in empty rooms and corridors you can save up to 15% on your bill.

- **Tip 5 – Cooking... keep a lid on it**

– the saucepan that is! Use just enough water to cover vegetables, or use a steamer. Boil water for pans in a kettle (it's quicker and cheaper!). And chop it up... cooking smaller pieces of food is quicker and therefore cheaper. Where you can, use the microwave rather than the oven and try to cook in bigger batches, then freeze, it saves time and money!

- **Tip 6 – Washing... cooler**

Washing at 30°C uses about 40% less electricity than at a higher temperature because about 85% of the energy a washing machine uses goes into heating the water. Try to wash full loads for washing machines, tumble dryers and dishwashers although it's always cheaper to do your dishes by hand and dry your clothes outside when it's not raining!

- **Tip 7 – Appliances... go 'A' rated**

Domestic appliances account for about 47% of households energy bills. Look out for the energy efficiency rating if you buy new ones. "A" rated appliances are the most efficient and cheapest to run. Switching to an energy efficient fridge freezer for example, could save you £36 a year (British Gas- BG).

- **Tip 8 – Don't standby... switch off**

Appliances can use a shocking amount of their original energy consumption when on standby or left on charge, so get into the habit of turning them off. An average household can save £30 a year by just doing this! (BG).

- **Tip 9 – Curtains... draw them closed**

Shutting the curtains, especially lined ones, will stop heat escaping through your windows and doors after dark, but don't pull them over radiators or you'll lose heat.

- **Tip 10 – Get involved... it's a family affair**

Get the whole family involved in thinking about ways to save energy; they'll become very energy conscious and may well think of something we haven't!

If you'd like any information, advice or support this Winter around energy issues you can call Contact a Family's free phone helpline on **0808 808 3555** or visit our website at **www.cafamily.org.uk**

Warm Homes Scheme

If you need help paying for heating and insulation improvements in your privately owned or rented home, you, your partner or civil partner may be able to get help from the government's Warm Homes Scheme. The Warm Homes Scheme provides a package of energy-efficiency and heating measures. Energy-efficiency advice, tailored to each household, is provided in accordance with the Energy Savings Trust's Code of Practice.

Who is eligible?

The Warm Homes Scheme has two elements: Warm Homes and Warm Homes Plus. All applicants will be considered for Warm Homes in the first instance and direct applications to Warm Homes Plus will not normally be accepted. The applicant must be the owner occupier of a dwelling or in the case of private rented sector the applicant must be named on the Tenancy Agreement.

Warm Homes

Warm Homes will be the point of entry for all applicants to the Warm Homes Scheme. Warm Homes is open to eligible householders and will provide insulation measures up to a maximum set value. The current statutory maximum is £850. This figure is reviewed every year.

Entry into Warm Homes will require applicants to be in receipt of a qualifying benefit. The full list of qualifying benefits and available measures are set out below:

Warm Homes - Eligibility Criteria	Measures Available
Householder of any age in receipt of one or more of the following benefits:	Cavity Wall Insulation
<ul style="list-style-type: none">Income SupportIncome Related Employment Support AllowanceIncome Based Job Seekers AllowancePension CreditChild Tax Credit (with NHS exemption certificate)Working Tax CreditDisability Living AllowanceAttendance AllowanceHousing BenefitRate Rebate	Loft Insulation
	Hot Water Cylinder Jackets
	Benefit Entitlement Check
	Energy Advice

Warm Homes Plus

The assessment process within Warm Homes will identify households where additional measures, such as heating or complex insulation, are required.

Heating measures will focus on those with no central heating system, a solid fuel, Economy 7 or bottled gas system (LPG). These households will be passported through into Warm Homes Plus. Direct applications to Warm Homes Plus will not normally be accepted.

The current statutory maximum for Warm Homes Plus is £4,300. This figure is reviewed every year.

Gas will be the fuel of choice in areas where it is available. In other areas, oil will be available.

A summary of the eligibility criteria and measures available under Warm Homes Plus are set out below.

Warm Homes Plus	Measures Available
Householder of any age who are in receipt of one or more of the following benefits:	Installation of a fully controllable, energy efficient oil or gas central heating system where no system currently exists;
<ul style="list-style-type: none">• Housing Benefit• Rate Rebate• Income Support• Income Related Employment Support Allowance• Income Based Job Seekers Allowance• Pension Credit• Working Tax Credit	Conversion of an existing bottled gas (LPG), solid fuel or Economy 7 heating system to a more energy efficient oil or natural gas central heating system;
AND	Insulation requirements which exceed the statutory grant maximum available under Warm Homes
who are passported through from Warm Homes as their home requires one of the measures available under Warm Homes Plus.	For properties of solid wall construction, further measures may be considered to minimise heat loss or reduce fuel bills. These may include use of solid wall insulation or use of a renewable technology.

How to apply

You can find out if you qualify for a Warm Homes grant over the phone by contacting the Warm Homes Scheme Manager on freephone 0800 988 0559.

Withdrawal of Funding for Disability Action's Access Service

The Planning Service will cease funding Disability Action's Access services by the end of September. Disability Action is actively campaigning for the retention of the service. As part of this campaign they are asking you to support them.

Discussions with the Minister Poots have seen the reinstatement of 25% of the original funding but what was a comprehensive service has now been decimated.

Disability Action will no longer be in a position to examine planning applications to ensure that in future public buildings continue to be accessible, nor to provide advice and advocate for disabled people experiencing discrimination and exclusion.

Disability Action is actively campaigning for the retention of the service, as part of this campaign they are asking you to support them.

Go to <http://www.surveymonkey.com/s/accesssurvey> to complete the online petition.

If you require any further information please contact us on the details below:

Sinead Owens, Communications and Campaigns Officer, Disability Action,
Portside Business Park, 189 Airport Road West, Belfast, BT3 9ED.

Telephone: 028 9029 7880 Textphone: 028 9029 7882 Fax: 028 9029 7881

Email: ceo@disabilityaction.org: www.disabilityaction.org/access

Reducing the waste of medicines

In 2009/10, around £400million was spent on prescription medicines in NI. DHSSPS figures show that 70% of the population is taking medicines and around **50% of these are not being used at all by patients and many do not take their medicines as intended.**

Given the difficult economic times that we face, it is vital that we make best use of all resources. In late November, the **DHSSPS will be running a publicity campaign aimed at reducing the waste of medicines.** This will be an

important initiative for the public and communities to get behind given the enormous waste that exists in the current system.

Connect off to flying start!

CONNECT, a new information and support network for parents of children with additional education and support needs, first meeting in Dromore, was a resounding success on Wednesday 29th September.

Judith Clarke co-founder said “We were delighted so many parents took the time to come, it was a great success in terms of contacts made. I believe that, even at this early stage, parents who attended will have been helped, whether through introduction to someone who can advise and support them or through just knowing that there is now an organisation in this area that is ready, willing and has the contacts and information to help them – Connect. We are looking forward to our next gathering and welcome requests from any parent as to which organisation they would like to hear from.’

Sharon Sneddon, a parent who attended commented “Thanks for a great night Connect. It was great to finally talk to others that understand and have similar experiences. Both speakers were great and it was a very informative evening. Looking forward to the next meeting already! “

Niamh Shiells co-founder says “it’s humbling to meet parents who dedicate so much time in trying to get the right support for their children as well as dealing with day to day challenges. Many of these parents have to battle tooth and nail with education and health services to get what they are entitled to and what their children need. Connect is here to help! If you are a parent with concerns, then please get in touch and if you think you can help us in our aims then please contact us too.”

Contact Judith Clarke on 07764200870 or Niamh Shiells on 07985064908 for further information or you can visit Connect on Face book.

Horizon Sure Start, Carrickfergus

NEW! Support group for parents of children with special needs.

Next meeting the 27th October and 10th November.

Running every fortnight in the Sands Court premises at Sunnylands Primary School, Sunnylands Avenue, Carrickfergus.

Meeting time 1pm- 2.30pm

Contact Susan Stevenson for more information on tel 93 359 734

nidirect – government services

A wealth of information on a wide range of topics. Keep up to date with the Spending Review news and impacts on services . Below is the link for caring for a disabled child. Information includes DLA and Direct Payments.

<http://www.nidirect.gov.uk/index/information-and-services/caring-for-someone/caring-for-a-disabled-child.htm>

Autism Buddy Resources

AutismBuddy aims to provide a user-friendly website that provides high quality printables and resources for teachers and parents for use with children with Special Educational Needs.

We provide easy to download resources in many categories including booklets, puzzles and games, flashcards, worksheets, visual timetabling, activities, visual aids, emotions, teaching aids, matching and sorting, classroom display, clip-art, E-books and social skills. <http://www.autismbuddy.com/cms.php?id=1>

Consultations

Follow the link to see the latest consultations that may effect you and your family, have your say!

<http://www.cafamily.org.uk/inyourarea/nireland/consultation.html>

'In Touch' is issued every two months (end of August, October, December, February, April & June) 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 REALLY NEED YOUR FEEDBACK! about 'In Touch' and all our services and publications. Please take a few minutes to forward you comments to the e mail address below. Without feedback our funders don't see the value of various pieces of work we do!

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 bookmark this page and then you can access it quickly!

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@cafamil.org.uk