

contact a family

for families with disabled children
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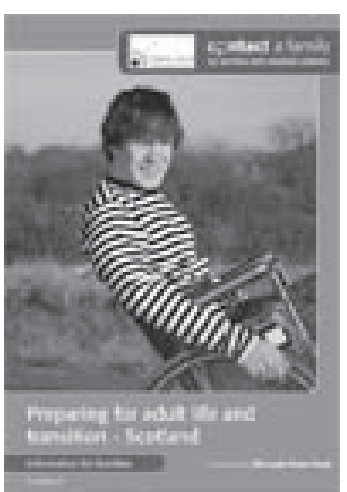
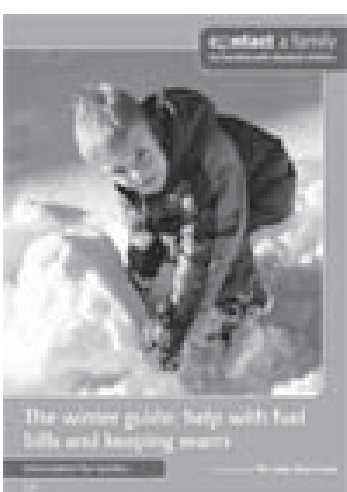
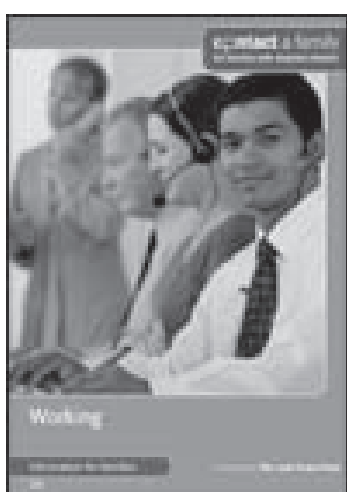
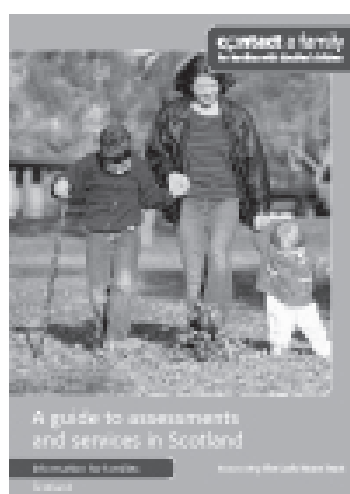
incorporating
The Lady Hoare Trust

in **contact**



The newsletter of Contact a Family Scotland

www.cafamily.org.uk/scotland



These are just a few of the factsheets available from Contact a Family. For a full list of all our publications go to www.cafamily.org.uk or call our free helpline 0808 808 3555.

Inside

New Volunteer Parent Representatives in Fife, Glasgow's new childrens' hospital, Contact a Family 30th Anniversary Competition and more...

Autumn 2008

Contact a Family Scotland

Craigmillar Social Enterprise & Arts Centre
11/9 Harewood Road
Edinburgh EH16 4NT
tel 0131 659 2930

email scotland.office@cafamily.org.uk

web www.cafamily.org.uk/scotland

Freephone Helpline

0808 808 3555

Textphone 0808 808 3556

Monday-Friday 10am-4pm, Monday 5.30-7.30pm
The Language Line interpretation service is available
for those whose first language is not English.

Ellenor Anwyl

Director

ellenor.anwyl@cafamily.org.uk

0131 659 2930

Lesley Gray

Enquiries and Group Development Officer

lesley.gray@cafamily.org.uk

0131 659 2930

Donna Tomlin

Development Assistant

donna.tomlin@cafamily.org.uk

0131 659 2930

Joanne McIntosh

Family Worker - Fife, Lothians and Borders

joanne.mcintosh@cafamily.org.uk

01506 828 899

Catherine Louttit

Family Worker - Highland & Moray

catherine.louttit@cafamily.org.uk

01463 831 506

Volunteer Parent Representatives

Our Volunteer Parent Representatives are all parents of disabled children who offer information and support to other parents in their area.

Aberdeenshire Carol McBride

Tel: 01651 891 468

e-mail: carol.mcbride@cafamily.org.uk

Borders Frances Teckkam

Tel: 01450 379 081

e-mail: frances.teckkam@cafamily.org.uk

Dumfries & Galloway Jacqui Law

Tel: 01387 263 563

e-mail: jacqui.law@cafamily.org.uk

Dunfermline Fiona Fisher

Tel: 0131 659 2930

Inverclyde Nicola Reid

Tel: 01475 635 022

Leven Bernadette Bastiman

Tel: 0131 659 2930

North Lanarkshire Elaine Glyn

Tel: 01236 840 049

Orkney Trudy Marwick

Tel: 01856 761 835

e-mail: trudy.marwick@cafamily

South Lanarkshire Elaine McKelvie

Tel: 01355 237 569

e-mail: elaine.mckelvie@cafamily.org.uk

Welcome to the autumn 2008 edition
of *In Contact*.

Contact a Family News

Although we have had a very wet summer hopefully you have all had a good break and are looking forward to a sunny autumn. Jacqui Law, our Dumfries and Galloway Volunteer Parent Representative is certainly looking forward in taking up the challenge of studying again (see page 5). We also now have on board two fantastic new Volunteer Parent Representatives for Fife - Bernadette Bastiman in Leven and Fiona Fisher in Dunfermline - see page 5 for details. Finally, for an update on For Scotland's Disabled Children Campaign (FSDC) turn to page 3.

The views and suggestions in this newsletter are those of individual contributors and are not necessarily supported by Contact a Family. Contact a Family cannot accept responsibility for any goods or services mentioned in or enclosed with this newsletter.

Contact a Family News

For Scotland's Disabled Children Campaign (FSDC) Update

FSDC now has over 25 disability organisations signed up – a list is available to anyone who requests it from the Edinburgh office.

The FSDC Liaison Project, which is being funded by the Scottish Government, is moving forward with the post of Liaison Officer being advertised in September and interviews scheduled for October.

The main thrust of the project is to strengthen the capacity of FSDC to ensure that there is effective liaison between children, young people, and parents, the partner organisations within FSDC, the Scottish

Government, Local Authorities and COSLA (the Convention of Scottish Local Authorities).

The project will liaise closely with the sister campaign "Every Disabled Child Matters" (EDCM) and work in active partnership with the Children's Disability Issues team within Safer Children, Stronger Families Division, ensuring Scottish Government is kept informed about FSDC activity, and that families concerns and issues are fed back from workshops, as well as in wider processes such as ensuring children's disability issues are reflected and acted upon within the Scottish Government's objectives.

The Education (Additional Support for Learning) (Scotland) Act 2004

For Scotland's Disabled Children Additional Support for Learning subgroup are currently consulting parents on the ASL act with a view to making recommendations to the Scottish Government on changes that are required. This consultation will take the form of an online questionnaire (details will be available soon) and focus groups where we are inviting parents to venues across Scotland to consult with us. These focus groups will be held in October and November in Edinburgh, Glasgow, Borders, Ayrshire, Perth, Aberdeen, Inverness and Dumfries.

If you are interested in attending the Borders event in Hawick please contact Joanne McIntosh, Contact a Family Scotland Tel - 01506 828899. For all other events please contact - Faye Gatenby, Capability Scotland, Tel: 0131 337 9876.



Benefits change

Urgent call for families with disabled children to get advice on their benefits and tax credits entitlements.

Contact a Family has identified that some families with disabled children could miss out on vital income due to imminent changes in benefit rules. From 27 October 2008 Incapacity Benefit and Income Support for people with health problems will be replaced by Employment Support Allowance (ESA). Families with a disabled teenager born before 27th October 1992 have a choice – they can either claim the existing benefits now or wait and claim ESA at a later date. Some will be worse off on the new ESA depending on individual circumstances.

Sarah Rush, Head of Advice at Contact a Family, said: "We know that families with disabled children face enormous financial challenges with more than half living in poverty. It is therefore vitally important

that families get advice now, to find out how these benefits changes will affect them. "The Contact a Family freephone helpline – 0808 808 3555 - is staffed by benefits experts and trained parent advisers who can help to maximise a family's income."

Contact a Family working with HM Revenue and Customs (HMRC), has also identified there are 28,000 families in the UK who are missing out on much needed extra income through additional tax credits. Families who have not informed HMRC that they receive Disability Living Allowance could be missing out on this additional income, which is paid in addition to existing tax credits they may already receive.

If you feel you might be affected by either of these issues or simply want to check that you are getting all the money you are entitled to, telephone the Contact a Family helpline – 0808 808 3555.

Contact a Family News

Contact a Family 30th Anniversary - Competition Time!

**Families with disabled children - win a laptop.
Tell your story and raise public awareness.**

Contact a Family is calling on parents to tell their story of raising a disabled child in a national competition which aims to highlight the many issues they face.

On the theme of 'Me and my disabled child', Contact a Family is looking for families to make a short video about the joys and challenges of caring for a disabled child. For those families who don't have a video camera, or have other creative impulses, you could share your experience in a written story, make an audio recording or take a photograph. The competition has been launched in the run up to Contact a Family's 30th anniversary and entries are invited from any family member or friend involved in caring for a disabled child since the charity was set up in 1979.

Mark Robertson, Contact a Family's Head of Information and New Media, said: "The best clips, pictures and stories will be featured on Contact a Family's website and other online channels such as Youtube, My Space and in our parent magazine, Connected. And throughout our 30th anniversary year we'll be using submitted stories whether they're in words, images or video footage, to raise public awareness of the everyday challenges families face raising a disabled child."

Entries can be in the form of:-

- a diary account
- show a day in the life
- focus on a particular time raising your child, such as around diagnosis
- highlight a particular challenge – using public transport, coping with behavioural problems, peoples' attitudes, attending endless assessments and meetings.

All entries will be considered in a category alongside others using the same medium, with a chance to win a digital camera – and for the overall winner, a laptop. Prizes for the competition have been kindly donated by Hobbs the Printers.

Entries must be submitted by 30 November 2008. Video entries should be no longer than three minutes and written stories no longer than 2,000 words. Videos, podcasts, word documents and digital photos can be submitted by email to new.media@cafamily.org.uk with Competition in the subject header. They can be submitted either as an attachment or a link.

All printed stories, photographs, tapes, DVDs can be posted to: Competition, Contact a Family, Freepost Lon8801, London EC1B 1EE.

Yoga classes in Fife for children with additional support needs

Classes are run in Balloch Park, Dunfermline at 9am on Saturdays - to find out more, contact Susan McGrath on 01383 412 741

Volunteer Parent Representatives - News

New Volunteer Parent Representatives for Fife

Fiona Fisher - Dunfermline



My name is Fiona Fisher and I live in West Fife with my husband Alan and our three children; two girls and one boy aged 15, 7 and 14.

I was born in Glasgow, did a degree in Biochemistry with Genetics and worked for a spell with the NHS in London and also the Scottish Blood Transfusion Service as a haematology technician. I met and married Alan and we lived in Lossiemouth as he was serving with the RAF at the time. With our son being born with profound and multiple learning, physical and sensory disabilities I decided to give up working to be his full-time unpaid carer. We moved from Lossiemouth to Fife 10 years ago to get our son into the fabulous special needs school he still attends today.

I met Jacqui Law, Contact a Family Scotland's Volunteer Parent Representative for Dumfries and Galloway, at an event hosted by Contact a Family concerning changes to the ASN Education Act and I am utterly delighted to become part of such an esteemed organisation today. I have a huge passion for supporting people with learning disabilities and their family carers and I am really looking forward to meeting my fellow reps in Fife, Scotland and the UK and talking to the families I hope to support.

Bernadette Bastiman - Leven



Hello. My name is Bernadette Bastiman. I am a single parent with two children. Jade is 9 years old. Blayne is 10 years.

Blayne was diagnosed autistic when he was 15 months and after various tests diagnosed with cerebral palsy. He eventually walked unaided when he was 5 years old.

Before I had my own children, I was a Au-pair/ Nanny. I worked abroad and was in charge of children at different ages and abilities. My first family was in America where I looked after premature twin boys, one of whom had severe cerebral palsy.

Through my background and personal experience, I am well aware of what a struggle it can be at times and how difficult it can be to find and access information and help, so I'm looking forward to my new job and helping as many of you that are in a similar position as a parent and carer.

Thinking about the future? - keep learning by Jacqui Law

I've been thinking about the future. Sounds deep and meaningful, doesn't it? It's not surprising. Lately I have attended workshops about planning for my daughter's future. The more I thought about it the more I realised that we have to think about the future, we have no choice.

But still something nagged away at me. I had to think about the changes for me too. Then my local Carers Centre announced that someone from the Open University was coming along to talk about their "Openings" courses. These are short courses, available in a wide range of subjects. It was great; here was something I could do which would fit in with my life and my family. And the cost? Well at around £100 they are cheaper than many other courses, but for the average carer that's still expensive. Then someone told me about the Individual Learning Account. If you personally earn less than £18,000 per year then you may be eligible for £200 to £500 per year towards the cost of training. I phoned the number for ILA Scotland (0808 100 1090) and spoke with an advisor. I have now received my application pack, and have just completed my application for the Open University. And what am I going to study? Making sense of the Arts... now that really does sound deep and meaningful!

You can use the Individual Learning Account for a whole range of courses, not only the Open University. To find out more you can call them on 0808 100 1090 or visit their website at www.ilascotland.org.uk Information on the Open University is available at www.open.ac.uk

Information, groups and resources

Parents Together:

An event for parents affected by disability

A free information and workshop event on Thursday 16th October 2008 at Capability Scotland, Edinburgh.

Parents who have a disability or parents who have a disabled child are welcome to come along to attend workshops on Addition Support for Learning; Respite and Short Breaks; Parenting Strategies and Post-School Transition Options. Also available on the day will be relaxation sessions and beauty therapists.

This event, hosted by Capability Scotland in conjunction with One Parent Families Scotland, Firsthand and Enable, will also give parents the opportunity to meet other parents. Lunch and refreshments are included and childcare can also be provided if booked in advance.

To book a place please contact : Justine Davidson, One Parent Families Scotland Tel: 0131 556 3899, Email: justinedavidson@opfs.org.uk or Nicola Duffy, Capability Scotland, Tel:0131 347 1098, Email: nicola.duffy@capabilityscotland.org.uk

Parents Inclusion Network (PIN) - Information Day on Adult Services

Thursday 25 September, 10am-4pm,
Kirkcudbright Town Hall.

Heads of various departments in Social Services will be there to explain how their service works and to answer your questions.

- You will hear from adults who receive support to live independently, and hear from agencies which provide this support.
- Many agencies, which develop the services and actually deliver the support our children need, will have a display stand with information and will be able to answer your questions.

The day is free and lunch is provided. Please telephone 01387 252683 by Thursday 11th September for further information.

RADAR - the National Key Scheme (NKS)

This scheme offers independent access to disabled people to approximately 7000 locked public toilets around the country. The NKS is suggested for use only if the provider concerned has to keep the toilets locked to stop vandalism and misuse.

RADAR (a national organisation run by disabled people) makes no profit supplying keys but needs to make a small charge to cover the costs of supply.

For further information on how to obtain a key check the website: www.radar.org.uk or
Tel: 020 7250 3222. Minicom: 020 7250 4119
Email: radar@radar.org.uk

Carers go free to the cinema!

Good news for carers accompanying someone with a disability to the cinema. With the cinema exhibitors' association's card you can verify who you are and the holder is entitled to one free ticket.

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

- be in receipt of Disability Living Allowance
- be in receipt of Attendance Allowance
- be a registered blind person

The card is valid for three years from the date of issue. Application forms are available from cinemas across the UK supporting this card. Alternatively, you can download an application form to fill in from www.ceacard.co.uk. Tel: 0845 123 1292. If you have any difficulty please contact The Card Network, Network House, St. Ives Way, Sandycroft, CH5 2QS

There is a processing fee of £5.50 per card. This should be returned with the completed application form to the above address.

Information, groups and resources

National Deaf Children's Society - Family Weekend

NDCS Scotland is holding a family weekend in 19th-21st September 2008. This weekend is especially for families with deaf children who have been newly identified within the last 12-18 months.

The weekend is an opportunity for families from across Scotland, to spend a relaxing and informative few days in the company of other families who all have at least one thing in common - they have a child who has recently been diagnosed with a hearing loss. The weekend will be led by experienced NDCS staff and guest speakers will join us for specialist sessions.

Topics covered will include, sharing experiences, understanding audiology, communication in the family, information on benefits and support and "A deaf child in the family - *Deaf Role Models experiences*".

Registered childminders will be on hand during the day and children can take part in a range of activities.

For further information contact Amanda Carlton, The National Deaf Children's Society on Tel: 0141 248 4457 or email amanda.carlton@ndcs.org.uk. For details of other NDCS events happening in your area log on to www.ndcs.org.uk

Interested in learning to Sign?

The West of Scotland Deaf Children's Society is starting a basic sign language class in September/October. For more information please contact Tel: 0141 243 2958

Special Needs Care Seat for sale Glasgow

Reccarro Car seat £350 (original cost £850). Used for less than a year. Prefer if buyer can pick-up. Contact Caroline Kelbrick carlysk_1@yahoo.co.uk or Tel: 07974 702071.

Monthly Open Door Sessions at Donaldson's School for the Deaf

Donaldson's will be hosting Open Door sessions run by experienced NDCS Family Officer, Marie Cafferky, and will provide an essential lifeline for families covering topics such as finance; help with benefits; medical support and education. The sessions will also provide parents and carers access to a number of other professionals and local support organisations.

Sessions start from 2nd October 2008, 10am - 1pm

For further information please contact Marie Cafferky, Family Officer, NDCS Tel: 07800 972002 or email: marie.cafferky@ndcs.org.uk

Finding the Balance - Health Guide for Carers

Carers Scotland's have produced an updated health resource guide for carers 'Finding the Balance: Promoting Positive Health'. This provides information on ways carers can support their own health and wellbeing. Topics include eating and sleeping well, caring for your back, good emotional health, practical help and financial support. To order your free copy download an order form from the Carers Scotland www.carersscotland.org.



UK Road Atlas for Blue Badge Drivers

This atlas provides information to make your journey smoother, such as which petrol stations are accessible, where you can park when you reach your destination, and how accessible the accommodation is. PIE are offering a free copy of the UK Road Atlas for Blue Badge Drivers (worth £12.99). To order your free copy send a cheque for £3.99 (p&p only) payable to PIE Enterprises, and quote the reference FREEATLAS with your contact details to PIE Enterprises Ltd, Caledonia House, 223 Pentonville Road, London, N1 9NG.

Information, groups and resources

Working Together on Glasgow's New Children's Hospital

Planning is now well underway for Glasgow's new children's hospital. Part of NHS Greater Glasgow and Clyde's commitment was to find out how children, young people and families wanted to be involved. The Community Engagement Team met with families, support groups, charities and voluntary organisations, attended public meetings, sent out survey forms and met with young people (over pizza and ice cream!) to find out what they wanted from the new hospital and its services, how they could help the NHS to design the building and how they would like to be kept informed. They identified many different ways for you to add your ideas, views and hopes to the planning process and below are some of the ways you could help.



Join the Family Panel

A Family Panel works alongside the Community Engagement Team to ensure that the views and opinions of families are raised within the planning process. The Family Panel meets about 4 times a year but, for those who find it hard to come to meetings, you can also contribute by e-mail, letters and phone calls.

Let Us Know What You Think

Regular surveys and group discussions are arranged to determine your views on the buildings, facilities and services for the new hospital. On-line surveys and mail outs are also used to help involve children, families and young people who find it difficult to attend meetings. Currently, feedback on the following areas are needed:

- Proposals to establish a Pre-admission Service and a 23-hour Surgical Admission Unit have been developed, would you like to comment on them — send in your details and a survey form will be sent out to you.
- What is it like travelling on public transport with children? The Community Engagement Team particularly want to hear from you if you travel to Yorkhill from outside Glasgow.
- The architects will need your help when looking at areas like the wards, family facilities, the main entrance and A&E.

...contact the team if you would like to help.

In addition to regular briefings to community groups and public events, a newsletter will be published to keep families up to date.

Supporting Families

To help families participate, meetings are held in the evenings and weekends and alternatives such as on-line surveys. Help is also available for travel, personal assistance and childcare.

If you would like to learn more about the opportunities to get involved in the New Children's Hospital then please contact Kate Munro, Community Engagement Manager, Dalian House, 350 St Vincent Street, Glasgow G3 8YY. Tel: 0141 201 4755 or E-mail: kate.munro@ggc.scot.nhs.uk

To keep up to date with the developments visit the website at www.nhsggc.org.uk/newchildrenshospital

Information, groups and resources



Karen Sinclair, Francis Edwards and Katie Rigg

First dedicated Children's Palliative Care Consultant Nurses for Scotland

Scotland's first dedicated Nurse Consultant posts for children's and young people's palliative care were formally announced at the ACT (Association for Children's Palliative Care) and SCYPPCN (Scottish Children's and Young People's Palliative Care Network) Conference in Edinburgh (3 June 2008).

Speaking at the Conference three of the four new Nurse Consultant post holders unveiled their new vision for children's and young people's palliative care, and said they wanted to ensure that children and their families are at the heart of policy and practice developments across Scotland.

These four new Nurse Consultant posts have been funded for two years by the Scottish Government Health Directorates and will play a major role in helping to raise awareness of the need for dedicated children's palliative care services in Scotland. One of the first challenges will be helping to 'make the case' for this sector by more accurately mapping the extent and need for these services across Scotland.

It is anticipated that they will all start in post by late August 2008. The posts will work across four main NHS regions, and will have both regional and national responsibilities. The Nurse Consultant appointments have been made to:

Katie Rigg (to jointly cover the North of Scotland – based in Tayside)

Jane Scotland (to cover the East of Scotland – based in Lothian)

Francis Edwards (to jointly cover the North of Scotland – based in Grampian)

Karen Sinclair (to cover the West of Scotland – based in Greater Glasgow and Clyde)

Once in post the four consultants will take the lead on supporting nurses and other health providers to realise their full potential and placing children, young people and their families at the centre of care planning.

Improving Transitions

There are three important transitions in the life of most young people, especially those with additional support needs: the transition from nursery to primary 1, from primary 7 to S1 and from school to post-school. Fay Waddell has been employed by the Education department of Scottish Borders Council to find out about current practice, and to suggest ways of improving the transition process.

Having talked to professionals from many agencies and to young people, Fay would now like to hear from

parents and carers about their experience of transitions and to find out what aspects of transition parents and carers think are good, and what changes or improvements they would like to see.

If you and your son, or daughter have been involved in any form of transition within the past two years Fay would like to hear from you.

E-mail: fwaddell@scotborders.gov.uk Tel: 01890 750618 or by post to Mrs Fay Waddell, Additional Support Needs, Council Headquarters, Newton St. Boswells, TD6 0SA.

Make the Move CD-Rom - now available from Signpost

A new CD-Rom aimed at young people with learning disabilities is now available via the Signpost library. It will help young people understand what happens, and what choices they have, when leaving school and going into work, training, college or a day service. It helps them know themselves better and choose what and where to go next. For further information please contact Signpost Tel: 01506 431 123 or e-mail enquiries@signpost-online.co.uk.

Contact a Family Workshops


Money Matters Workshop

Hamilton, South Lanarkshire, 18th November 2008


Parents of disabled children are often entitled to help from the benefits system as well as other assistance. However it can be difficult to find exactly what you are entitled to. This workshop in Lanarkshire will cover benefits, Tax Credits and other sources of financial support for families of disabled children including Disability Living Allowance and the different rates it is paid at; who can claim Carer's Allowance; the Tax Credits system, including overpayments of Tax Credits and how to deal with them and also claiming for young people once they are aged 16.


For further information and a booking form Tel: 0131 659 2930 or email:scotland.office@cafamily.org.uk. Alternatively you can use the form below and post to the Contact a Family Scotland office.

Keep an eye on the Contact a Family Scotland webpage for details of other forthcoming workshops and events for parents. Visit <http://www.cafamily.org.uk/scotland>

If you would like more information about the *Money Matters* workshop in Hamilton please tick this box and add your details below. We will then send you a booking form. 

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 I would like to be added to your mailing list and receive the Contact a Family Scotland newsletter (free of charge).

 Please remove me from your mailing list

Name:

Organisation (if applicable)

Address

..... Postcode

Tel:

Email:

I am

a parent / carer

a parents' group contact

a professional

Please detach and return this form to:

Contact a Family Scotland, Craigmillar Social Enterprise
& Arts Centre, 11 Harewood Road, Edinburgh EH16 4NT