

contact a family Ealing

for families with disabled children

incorporating

The Lady Hoare Trust newsletter

March 2010

Our family, our future

Families with disabled children have the same hopes and dreams as other families but often face bureaucracy and prejudice trying to achieve them.

That's the finding of a new Contact a Family report *Our family, our future* which features the stories of 30 UK families whose children are affected by a range of disabilities and rare conditions.

Srabani Sen, Chief Executive of Contact a Family, said: "Families with disabled children are just like other families; they want the best for their children. But frustratingly they face a barrage of bureaucracy and numerous battles to get the best for their children, which prevent them from enjoying family life."

All families show strength, determination and creativity in overcoming the challenges and pressures they face and there is a real sense of overwhelming love and pride for their children:

"Our greatest achievement was being able to bring our little girl home from hospital. We learnt all the procedures to care for Sienna. It's the most amazing feeling waking up in the morning with all the family home together." Natalie Pearson

But there are those at breaking point because of the constant battle to get support and help for their children and themselves, which is preventing them from enjoying family life.

Many are worried about the future and what will happen when they are no longer able to care for their child. There is great uncertainty about the support available to those who reach adulthood and this is adding to the pressures that families are under:

"It is absolutely terrifying thinking about the future. As long as we are here it is fine, but who will look after her when we're gone? Will she be put in some kind of home?" "It is absolutely terrifying thinking about the future. As long as we are here it is fine,

but who will look after her when we're gone? Will she be put in some kind of home?" Julie Ryan.

Others have to live with the heartbreaking knowledge that their children have life threatening conditions:

"Every day is a bonus and we must live day to day. Our future is today and each hour is very precious. We can't worry about next year, we just have to think about the here and now." Clare Lally

And most worry about how society accepts people with disabilities and wish for increased understanding and tolerance:

"Before Max was born, I was unaware of disability and the impact it has on a family. I hope those people whose lives Max touches will become more tolerant and understanding." Nicola Reid

Contact a Family would like to see families with disabled children given the same opportunities as others and is calling for:

- Government to invest in a campaign to raise awareness of the needs of families with disabled children
- Stronger focus on disability awareness taught in early years and schools
- People working in a public facing role to be given disability and equality training – so that they can recognise the unique talents that children bring – because of their disability.

The *Our family, our future* report is accompanied by an exhibition of photographs which will be touring the UK.

Parent Participation

Grant levels for parent participation have now been confirmed for 2010-11. These can be applied for by parent forums working in England to improve services in their local area under Aiming High for Disabled Children (AHDC).

A recent survey sent to parent forums shows that since the start of the AHDC programme more areas are now producing newsletters for families of disabled children, involving parents in consultations and have a structure to support parent forums.

You can read more about the types of activities that have been taking place across England on the TDC website—www.togetherfdc.org

Ealing Parents' Forum—for parents and carers of children with additional needs

We are a fairly new group of parents and carers. Each of us has a child aged 0-25 with some form of disability or special need. We aim to provide parents with a voice so that together we can work more effectively to improve the quality of our children's lives. We aim to represent parents and carers' view so that we can influence the development of services in Ealing.

To date we have represented parents' views on the Short Breaks Steering Group to plan how additional government funding can best be spent to extend short break provision in the borough. We would also like to set up focus groups on education, mainstream schooling, transition, housing etc. We have regular meetings and would be delighted to meet you there.

We can't do casework but we can hopefully point you in the right direction for help. If there is something that isn't working properly then please let us know as the chances are that you are not alone in experiencing a particular type of problem and we can flag this up with the appropriate people. If we work together and have a collective voice we have a much better chance of getting improvements in services.

It's free to join us, so please just come along to a meeting and chat to us.

You'd be welcome to get more involved at whatever level whether it's helping with teas and coffees at meetings, writing a letter to Ealing Council, attending a meeting or helping to set out chairs for a meeting. Contact us at ealingpf@yahoo.com or leave a message on our voicemail Mobile 07749 542467

Ealing Parents' Forum

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>

Free laptops for low income families

Thousands of families will be able to claim free computers and internet access under a Government drive to boost the achievements of children from lower income families.

The Home Access programme will allow 270,000 families with children in years 3 to 9 to apply for grants to buy computers and broadband connections from approved suppliers.

Low income families in receipt of certain benefits could qualify for a grant to buy a computer and/or a minimum of 1 years' internet access. The programme is aimed at those that need it most and targets families that do not have access to a computer or the internet at home.

Depending on what is needed, the grant allows eligible applicants to buy one of the following packages:

1. Full package (a computer, one year's internet access, service and support)
2. A computer with service and support only
3. One year's internet access only

<http://www.homeaccess.org.uk/>

Young People's Corner

Choose Life, Choose Health

Ealing Council Young Ealing and Ealing NHS have jointly published a guide for young people 'Choose Life, Choose Health. A Guide to Healthy Living for Young People'. The booklet, which can be picked up from any Ealing Council premises and doctors' surgeries, stresses how important it is to have a healthy lifestyle. This guide points you in the right direction, tells you where to get information and gives clear, sensible ideas on what to do if you feel you need a bit of extra help.

The guide contains useful websites, agency advice and information about some key issues.

Information for young people around Ealing

Ealing Council have published a comprehensive list of links and references for young people. It's been issued in an attractive, small concertina-form colour-coded format. The Guide consists of 16 sections, covering fields such as: Personal safety and dealing with violence, young people with disabilities, young parents, youth and Connexions service, leisure and entertainment. You can pick up your copy from the Family Information Service, or phone 0208 825 5588, 25a Laurel Gardens, Hanwell W7 3JG.

Find out what is happening at your youth club

If you are between 13-25 years of age, why not drop in to our W13 Youth & Connexions Centre - W13 Social Club for Young people. You'll be meeting young people from the local community. The Centre provides learning opportunities and experiences and group activities. They try to create a diverse programme that recognises young people's achievements - one way they do this is through the Youth Achievements Award Schemes.

They are open on Tuesdays, Wednesdays (inclusive activities) and Fridays from 7-10pm. To find out more, contact Karen Jenkins on 0208 567 2821. The venue

Worried about a child or young person...?

Then call YoungMinds Parents Information Service on 0800 018 2138 for a free, confidential telephone service providing information and advice for any adult with concerns about the mental health of a child or young person.

Opening hours - Monday and Friday 10am-1pm; Tuesday and Thursday 1-4pm; Wednesday 1-4pm and 6-8pm
www.youngminds.org.uk

Ealing Youth and Connexion Service

Forward Steps Project

The Forward Steps Project aims to educate young people aged 13 - 19, about the consequences of street crime and anti social behaviour. The Forward Steps Project will enable young people to work in innovative ways to develop self-esteem and confidence to resist involvement. This project will reach out to young people and assist them in making positive choices that will prevent them from harm. Young people will be encouraged to take responsibility for their actions and make informed constructive decisions affecting their lives.

This project will tackle a wide variety of issues such as: anti-social behaviour, life skills, constructive use of leisure, anger management, victim awareness, graffiti, stop and search rights and procedures, street gangs, hate crime, careers, listening skills, cultural identity, respect, conflict resolution, moral dilemmas, peer pressure, gun and knife crime, drugs, offending behaviour. There will be a variety of mediums in which this work will be delivered such as: the use of video, art, music, drama that will keep young people interested and enthused.

This project is a referral-based project that works with young people who are outlined above. We will accept referrals from the following agencies: Police, YOS, and panels such as YISP, P&D, School inclusion, Social Services and ASBAG. There are limited spaces and the project will operate on a first come, first served basis.

These sessions will be held at the One Stop Shop in Ealing on a Friday afternoon from 1:30 - 3:30pm for 11 weeks. The next programme is due to start on Friday 23rd April 2010.

To find out more please phone 0208 825 9525

Disability information and advice near you

Ealing Centre for Independent Living (ECIL) run FREE local disability information and advice surgeries. To make an appointment please call 0208 840 8573.

The locations are as follows:

Acton Health Centre

35-61 Church Road, Acton W3 8QE

2pm-4.30pm – second and fourth Monday of the month

Albert Dane Day Centre

19-21 Western Road, Southall UB2 5HA

10.30-12.30 - Monday 8th March; Monday 5th April

Ealing Hospital – PALS Office

Uxbridge Rd, Southall UB1 3HW

10.30am-12.30pm – Tuesday 2nd and 16th March; 6th and 20th April

HADEA, Stirling Road Dance Centre

Stirling Rd, Acton W3 8DJ

11am-1.30pm – Wednesday 3rd and 31st March and 28th April

Islip Manor Youth and Community Centre

Arnold Road, Northolt UB5 5TB

12pm-2.30pm – Thursday 18th March and 15th April

Viking Community Centre

Radcliff Way, Northolt UB5 6HW

12pm-2.30pm – Thursday 4th March and 1st and 29th April.

'Independent Living' Surgery at Bayham Road

A chance to bring your disability and carer related concerns to **Councillor Mark Reen**, The Ealing Council Cabinet Member with responsibility for Adult Services and Health.

The next surgery is on Saturday, **27th March 2010**

11.30am-1.30pm, ECIL, 1 Bayham Road, Ealing W13 0TQ.

For an appointment contact ECIL on 0208 840 8537, email: info@ecil.org. Website: www.ecil.org

Ealing PlusBus

A pilot door to door transport service to help you get out and about.

Do you find it difficult to get out and about due to a lack of reliable and easy to use transport?

If so, then the Ealing PlusBus is designed for you!

The service is accessible, comfortable and reliable.

The Ealing PlusBus is available between 10am and 2pm, Monday to Friday.

Simply phone 0208 842 0220 to book your trip. Small group bookings are encouraged. There is a charge of £1 per trip, children below the age of 5 travel free.

Fitness Wednesdays & Fridays

South Acton Community Fitness Centre is open every Wednesday 5pm-7pm and Friday 3pm-5pm **FREE!** 118 Hardy Court, Bollo Bridge Road, W3 8DD.

It's not necessary to book but useful if you would like a personal trainer during your initial visit. To book a place contact Jim Wong on 0208 280 2233 or email Jim@ealingcvs.org.uk

NHS Health Trainers in Ealing

Health trainers provide advice and support on leading a healthier lifestyle. They provide advice, motivation and practical support to people who want to adopt healthier lifestyles. They know the local area and can help you find relevant services, community groups and projects. A NHS trainer can:

- * Direct you to services
- * Give practical support and advice to help you develop healthy lifestyle
- * Support healthier choices while taking into account personal circumstances
- * Act as a link between professionals and communities

To find out more about the Ealing NHS Health Trainer Programme please call 020 3313 9247 or email:

eal-pct.ealinghealthtrainers@nhs.net

SAFE - Supportive Action for Families in Ealing

We know that family life is not always easy. When difficulties and problems come up and you need someone to understand your situation and offer you help and support, please contact Ealing's SAFE service.

We will listen to you and work with you to get the help you need. We can give you information and advice and help you to access the appropriate services and support to help you with your problem or situation before it becomes bigger and more difficult to solve.

The SAFE service is a partnership between Ealing Council, West London Mental Health Trust, Ealing Primary Care Trust and Ealing Youth Counselling and Information Service.

The team is made up of health visitors, therapists, counsellors, pupil/school workers, family workers and other experts. We also have links with other support groups and services in Ealing to ensure you are given support within your community and the area where you live.

We also run a variety of groups for children, parents and families, and can offer you counselling, health services and other therapy.

The SAFE service is split into two teams because older children and their families sometimes face very different issues to younger children. The SAFE 0-12 team works with children under 12 and their families and the SAFE 12-19 team, known as the Adolescent Service, works with young people aged 12 and up and their families.

For families of children aged under 12, please call SAFE 0-12:

Acton, Central Ealing and Hanwell - Tel: 020 8825 7819

Northolt, Greenford and Perivale - Tel: 020 8842 0220

Southall - Tel: 020 8825 9800

For families with children aged 12 and up, please call SAFE 12 - 19:

Tel: 020 8825 5080

or email: safeadolescentservice@ealing.gov.uk

Do you need advice and guidance on form filling? Is your child's DLA due soon?

We run monthly Disability Living Allowance Workshops. The next one is on Thursday, 29th April 2010 at St Andrews Church Centre, Mount Park Road, Ealing, W5 2RS at 10.00am.

Please book in advance by calling 020 8810 8151

or email ealing.office@cafamily.org.uk

Ealing Contact a Family Advice Sessions

Drop-in monthly advice and information sessions are run at St Andrew's Church Centre. The next session will be on Monday, 19th April, 10am-12pm.

To book your 15minute slot please call 020 8810 8151

Southall Contact a Family Advice Sessions

Southall CaF hold a walk-in surgery on Wednesday mornings, during term time. To be seen by an adviser, you need to be registered with Contact a Family Southall. They are at St George's Community Centre, 8-12 Lancaster Road, Southall UB1 1NW (opposite Mc Donald's on Southall Broadway). Please phone them on 0208 571 6381

Good-bye to Ursula

After almost 3 1/2 years at Contact a Family Ealing, I am leaving my desk at St Andrew's Church Centre. It's been a real pleasure and honour to be working with the families. I have learnt so much while being here, for example doing newsletters, like this one.

I will miss you all. I'll be around though as I am a local girl from Ealing. All the best to you all,

Ursula

P.E.S.T.S.

P.E.S.T.S (Parents of Ealing Self Help Training Scheme) is a term time support group for families with children aged 0–5 years with disabilities and special needs. Sessions are run for parents and children, who meet every Tuesday and Friday at Heller House Annexe, 124 Norwood Road, Southall, Middx. UB2 4DX.

The meetings run from 10.30am till 12.30pm.

If you'd like to come along, please phone P.E.S.T.S on 0208 571 9954

EASE Domestic Violence Buddy Service

Empowering Action & Social Esteem (EASE) offer a safe and confidential Buddy Service which provides emotional support and signposting for men and women aged 16+ who are suffering domestic abuse. They also run courses.

They accept self referrals and referrals from other agencies and organisations

Law for All – Community Solicitors

They have drop-in services in Ealing areas and can give legal advice and help with problems concerning debts, benefits, housing, family and employment. Advice is free. Just drop in.

Ealing – Meeting House, 17 Woodville Road, Ealing W5 2SE; Tuesday and Thursday 9.30am-12.30pm then 1.30pm-5.30pm

Hanwell – The Salvation Army, Leeland Road, London W13 9HH; Monday, Thursday & Friday 9.30am-12.30pm then 1.30pm-5.30pm. Tuesday 9.30am-12.30pm

Northolt – Viking Community Centre, Radcliffe Way, Northolt, Middx. UB5 6HW; Monday, Tuesday and Thursday 2-5.30pm. Friday 9.30am-12.30pm.

Caring with Confidence

Caring with Confidence is a new FREE training programme, designed by carers, for carers. It aims to build on your skills, share coping strategies and help you balance your caring role with finding time for yourself.

The Course is made up of seven sessions. The first one, Finding Your Way, will give you a flavour of what is to come and more information about the topics covered by the other six. You can then decide if you would like to come to all of them, or just choose a couple. These are the subjects the sessions will cover:

Caring and Me (your health)

Caring and Coping (your emotions)

Caring and Resources (money matters)

Caring Day to Day (practical issues)

Caring and Life (balancing caring and a life for yourself)

Caring and Communicating (dealing with service providers and other professionals)

ContinYou Parent Partnership Service

Invite you for a Coffee and a Chat at Carers Centre, South Ealing Road W5 4QA.

Primary School Parents—11th March—10am-12pm

High School Parents: Year 9 Transition Planning Information (with Ealing Mencap Transition Project) - 11th March—1pm-3pm.

If you'd like to come, please call ContinYou on 0208 280 2251, or email cepps@continyou.org.uk

The NHS Constitution

The NHS Constitution establishes the principles and values of the NHS in England. It sets out rights to which patients, public and staff are entitled, and pledges which the NHS is committed to achieve, together with responsibilities which the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. All NHS bodies and private and third sector providers supplying NHS services will be required by law to take account of this Constitution in their decisions and actions.

The NHS Constitution was published on 21 January 2009 and applies to NHS services in England. To order a copy, go to www.orderline.dh.gov.uk or telephone 0300 123 1002



WEB Links



Ealing Help is a website containing information on all the services available in the LB Ealing and surrounding areas for children with disabilities. It covers all aspects of disability, including Discussion Area.

www.ealinghelp.org.uk

Extreme Ability Programme—is designed for people with disabilities and additional/supported needs. **January-June 2010 Activities Programme: Multi-Sports**—Saturdays 10.00-11.30am, West London Academy, Northolt. **Indoor Climbing**—Saturdays 10.00-11.30am, West London Academy, Northolt. **Table Tennis**—Wednesdays 3.30-5.30pm West London Academy, and Sundays 3.00-4.30pm, Southall Sports Centre. **Dance**—selected school holidays at Gurnell Leisure Centre. **Swimming**—Saturdays 1.00-3.00pm, Gurnell Leisure Centre, and Thursdays 12pm-1pm, Acton Baths. **Kayaking**—various days/times, Brentford Boating Arch at Kew Bridge, and Acton Baths.

For more details contact Christie Moloney, Co-ordinator, Active Ealing, tel 0208 825 6675, email: moloneych@ealing.gov.uk or Peter Shears on 0208 326 7047 or email: pshears@brentfordfcst.com

The Family Information Service is part of the Ealing Council website. It provides information and advice for children, young people and families. It lists childcare options, including special needs care and support.

www.ealing.gov.uk/childcares

ContinYou Ealing Parent Partnership provides practical, relevant advice and information and one to one support for parents facing such educational issues as assessment for a Statement of Special Educational Needs, exclusion, moving schools.

www.continyou.org.uk/cepps

Young Ealing is a one stop advice and information point for young people and their parents on: things to do, such as events, clubs and sports activities; important issues, such as legal rights, health and crime prevention; how to access education, training, apprenticeships and employment; how to access financial assistance and housing; ways to get involved in the community through volunteering.

www.youngealing.co.uk

Advice Agencies. There are several organisations in Ealing, specialising in information and advice on specific issues, such as debt, employment, housing, homelessness, immigration, mental health etc. You can find the list of such agencies and organisations on the Ealing Council website:

http://www.ealing.gov.uk/services/community/advice_agencies/

Directgov is a one-stop advice website of the public services. There is a comprehensive section on disabled people. You can find there information on existing services, types of benefits etc. There also is a link to benefits adviser that will help you assess your entitlement.

<http://www.direct.gov.uk/en/DisabledPeople/index.htm>

Concerned about your safety?

Ealing Safer Neighbourhoods Teams in your area are there to help:

Acton Central—0208 721 2921
Cleveland—0208 721 2920
Dormers Wells—0208 649 3572
Ealing Broadway—0208 649 3573
Ealing Common—0208 721 2948
East Acton—0208 721 2708
Elthorne—0208 721 2951
Greenford Broadway—0208 8721 2916
Hanger Hill—0208 721 2947
Hobbayne—0208 721 2919
Lady Margaret—0208 721 2918
North Greenford—0208 721 2950
Northfield—0208 721 2950
Northolt Mandeville—0208 721 2945
Northolt West End—0208 721 2770
Perivale—0208 721 2917
South Acton—0208 649 3574
Southall Broadway—0208 721 2771
Southall Green—0208 721 2047
Southfield—0208 721 2946
Walpole—0208 721 2949

Do you care for a child with additional needs?

Join *Another Way* today for support, encouragement and understanding

- * Telephone support network
- * Regular email newsletter
- * Shared experiences

"It helps to know that you are not alone".

Your opportunity to say what you *really* feel.

Talk openly on the phone with a trained befriender who is in a similar situation to you and can offer insights from their personal experiences.

Your regular email newsletter.

Receive practical insights, personal stories and encouragement through your inbox.

Contact them on
www.careforthefamily.org.uk/anotherway
Tel: (029) 2081 0800

A newly launched ADHD Parent Group

Parents of children with ADHD (Attention Deficit Hyperactivity Disorder) will be meeting on Monday, 15th March, 10am-12pm, at the Jubilee Hall, Green Man Gardens, W13 0SE (behind Ealing Magistrates Court). This Group is parent-led and facilitated by Contact a Family Ealing. If you'd like to attend, please phone Contact a Family Ealing office on: 0208 810 8151

Ealing Contact a Family

St Andrew's Church Centre
Mount Park Road
Ealing
W5 2RS

Tel: 020 8810 8151

Email: ealing.office@cafamily.org.uk

9.00am - 5.00pm

Website www.cafamily.org.uk

National Freephone Helpline

0808 808 3555

Monday - Friday 10.00am - 4.00pm



Community
Legal Service



Contact a Family incorporating The Lady Hoare Trust
Registered Charity No. 284912

Company Limited by Guarantee No. 1633333

Registered Office: 209/211 City Road, London EC1V 1JN

Tel: 020 7608 8700