



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Seasons Greetings

from the CPRS

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PREVIEW

Welcome to the 5th newsletter from the Cerebral Palsy Register for Scotland.

Over the last 6 months there has been many changes at the register. Cerebra is now funding the register to carry out specific research work (further details on page 4), and we have started to receive the medical information from your child's paediatricians.

We are looking forward to beginning to address the issues you have highlighted for us, and also to have the opportunity to possibly meet some of you face to face.

I'd like to take this opportunity to wish you all well, and a very prosperous 2006!

I hope you find the issue interesting

Abbi Green
Health Services
Researcher

Enquire

Enquire is the Scottish advice and information service for additional support for learning. It is managed by Children in Scotland and funded by the Scottish Executive.

The service is available to parents and carers of children and young people with additional support needs, to children and young people themselves, and to professionals working with them.

Enquire offers advice and information by way of a telephone helpline and through written responses to emails and enquiries via the website. It also offers training and talks, produces a range of free publications and has a legal subscription service.

Contact Details:

**Enquire
Children in Scotland
5 Shandwick Place
Edinburgh
EH2 4RG**

**Administration 0131 222 2425
Email: info@enquire.org.uk**

Helpline:

Helpline **0845 123 23 03** (charged at local rates)

Languageline interpreters are available to assist with enquiries if required.

Textphone 0131 22 22 439

Helpline Hours:

| | |
|------------------|------------------------------|
| Monday | 9am-5pm |
| Tuesday | 9am-5pm & 7pm-9pm |
| Wednesday | 8am-5pm |
| Thursday | 9am-5pm & 7pm-9pm |
| Friday | 9am-5pm |

Factsheets, guides, bulletins and other publications can be downloaded from the website: www.enquire.org.uk

Education (Additional Support for Learning) (Scotland) Act 2005



The new **Additional Support for Learning Act** came into force on the 14th of November 2005.

This Act aims to improve the way that children and young people are supported throughout their learning.

New Terms:

The Act introduces the terms “Additional Support” and “Additional Support Needs” to replace what was previously called Special Educational Needs.

Additional Support Needs are when a child is unable to benefit from the education provided without extra help, for whatever reason.

Additional Support is any support which is extra or different to the education provisions made generally to children of the same age.

The new Act gives parents new rights (see below), and also states that the education authority must identify children with additional support needs and address these needs. Also other agencies, such as Social Work and Health, must work with the educational authority to support them where necessary, to ensure that the needs of the child are met under the new Act.

There are many reasons why a child would require additional support; one of these could be that a child has cerebral palsy.

Parents Rights:

- The right to have their child assessed to see if they have any Additional Support Needs
- The right to access free mediation services
- The right to receive information and advice about their child’s Additional Support Needs
- The right to attend meetings with an advocate or supporter.

Coordinated Support Plan

The Act also introduces **Coordinated Support Plans** to eventually replace the ‘Records of Needs’. All children currently with a Record of Needs will be considered for a Coordinated Support Plan when their Record of Needs is reviewed.

Coordinated support plans are developed for children whose additional support needs are due to complex or multiple factors, and who require an input from a range of services.

A coordinated support plan must include details of the support required by the child, and outline who will provide this support. Also a contact name is provided to parents, along with the name of the person who will manage the plan.

Further Information?

If you require any further details about the Act, please contact **Enquire**.

(Contact details on page 2)

RESEARCH UPDATE...

Moving to Secondary School...

The move from Primary school to Secondary school can be a very difficult time for any child and their family, and possibly even more difficult for children with cerebral palsy.

Education is a big part of any child's life and it is important that children are supported in an appropriate way in order to achieve to the best of their ability.

Through your comments and meetings with people working with children with cerebral palsy we identified that the move from Primary school to Secondary school can be a very difficult time for the child and their family. We have been awarded funding from the charity Cerebra to carry out research into the experiences of children with cerebral palsy and their parents during this transition period.

The project is called; **"Evaluating the experience of children with cerebral palsy and their parents in the transition from primary school to secondary school."**

All families registered with the CPRS who have been through this transition period will be invited to give their views on this topic. We realise that this may have been a difficult experience for some of you but we need to find out the good and the bad in order to change things in the future for children and their families.

What we want to look into:

We want to find out what services and information children with cerebral palsy and their families need during this transition time.

Also we want to see if the new Additional Support for Learning Act, introduced in November 2005, has any impact on improving the experiences of children and their families.

(For more information about the Additional Support for Learning Act please see page 3.)

What we want to do:

We want help from those of you who have children at secondary school.

Firstly we'll have some questions we would like you to answer by phone, post, or e-mail, to find out what you think.

Then, if you agree, we would like to meet some of you, and if possible your son/daughter, for a discussion about your experiences.

Once we have a picture of what has happened in the past we will be looking for help and information from those of you with children approaching this transitional period.

At the moment we're still in the organisational stage, but we hope to start collecting your views in early spring 2006.

We hope you also think this is an area worth looking into, and we'll keep you updated with our progress.

If you would like to make any comments or suggestions about this project, please contact us at the usual address. (Back page)

The CPRS works closely with organisations working with children and young people with cerebral palsy and other disabilities. One of these organisations is the Special Needs Information Point (SNIP), who provides advice and support on services for children with special needs.

Sharon is an Information and Support Worker for SNIP, and is also a parent of twin girls with cerebral palsy. This is what she thought when we told her about the project:

You can contact SNIP at:

**SNIP, Freepost
SCO5846, Edinburgh,
EH9 0BR
0131 536 0583
snip@btinternet.com**

A parent's perspective...

My name is Sharon Dunlop and I am the mother of twin daughters who are 12. Both my children have Cerebral Palsy and one has just gone through the transition process. Although the transition went smoothly this is because I initiated it. I would never have thought that I would need to start the process when Danielle was in Primary 6 but learnt that unlike most children who go up to high school, a great deal of preparation needs to be done before a disabled child begins.

Often parents presume that one of the professionals involved would approach us at Primary 6 stage to talk over this process. And although there is some good practice out there, it often parent driven and the sad fact is that we are often not told until our child is due to begin secondary school.

My other child is due to start high school next August and unfortunately this process is not going as smoothly, in fact it has not even begun and as a parent I no longer have the energy to take this forward.

In many ways it is just **another** form to fill in but I think that this is a very important and much needed piece of research. To raise the awareness of the difficulty of the transition process but also to highlight to the professionals involved that as parents we don't know when the right time is and that we need their input and support.

HemiHelp is a support group providing information and support to children and young people with hemiplegia.

HemiHelp runs a website at www.hemihelp.org.uk which is a popular resource with parents, professionals and families. Part of the website contains a message board where parents can share their concerns and share information. Many of those concerns revolve around behavioural issues and how best to approach the management of a child with a brain injury.

Membership is free to both parents and professionals, although we encourage donations, and further details can either be found on the website or by contacting **Emilie Bates** at:

**HemiHelp, Unit 1 Wellington Works,
Wellington Road, London SW19 8EQ.
Telephone 0845 120 3713 or
email us on support@hemihelp.org.uk**



HemiHelp

For Children and Young People with Hemiplegia

The other ways that HemiHelp provides support include:

- A telephone Helpline on 0845 123 2372
- The publication of straightforward fact sheets and leaflets on various subjects of interest to members
- An informative and entertaining video for 8-14 year olds
- A resource booklet of useful names and addresses for parents and professionals
- An equipment list with details of where to purchase different types of equipment
- A regular newsletter for members
- Regional conferences for professionals and also for parents
- Sports and activity days for children

CPRS UPDATE

About the children on the register

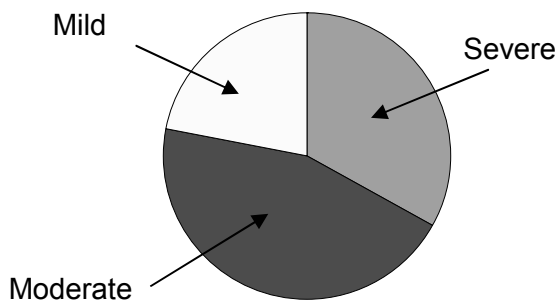
- ★ There are more boys than girls on the register, which reflects the findings that cerebral palsy is more common among boys.
- ★ The children on the register come from all over Scotland, with children from every health board area registered with us.
- ★ Most of the children on the register are of primary school age, although there is a good representation of children from a few months old up to 15 years.

Information you gave us

The green questionnaire (LAQ) we invite you to complete when your child is over 4 years old, tells us about how much of an impact cerebral palsy is having on your everyday life, and how much it affects certain areas of your life. This questionnaire has been really helpful to us to identify which areas of day to day life we need to look into.

All parents/carers of children over 4 years old are invited to complete the questionnaire, if you haven't received a copy, or if you've misplaced your copy, please let us know as we really want to hear about your experiences.

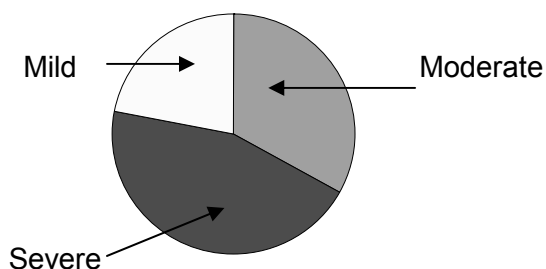
Impact of cerebral palsy on you and your child's everyday life:



For most children and their families on the register the impact of cerebral palsy on their everyday life is moderate or severe.

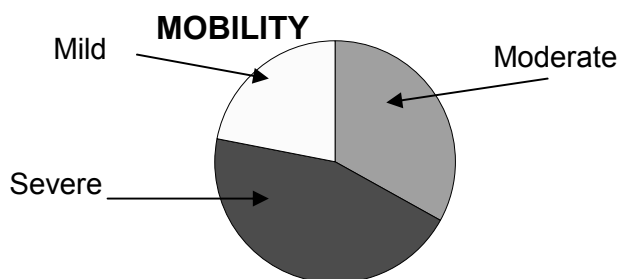
The areas which are reported by you to be the areas most severely affected by cerebral palsy are physical independence, and mobility. Around half of the children on the register report a severe impact in these areas.

PHYSICAL INDEPENDANCE



Physical Independence includes things such as :

- ❖ Assistance required with personal care
- ❖ Number of times needing lifting
- ❖ Assistance required in the night

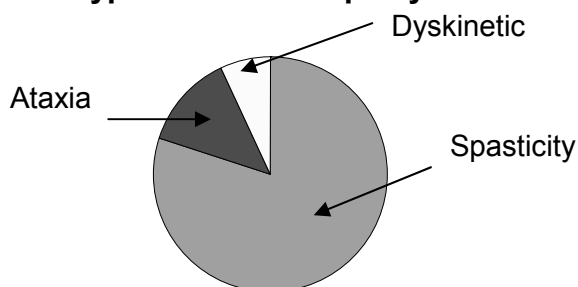


Mobility includes things such as:

- ❖ Number of rooms entered unassisted in the home
- ❖ Help required to go in & out of the house

Medical Information

Types of cerebral palsy



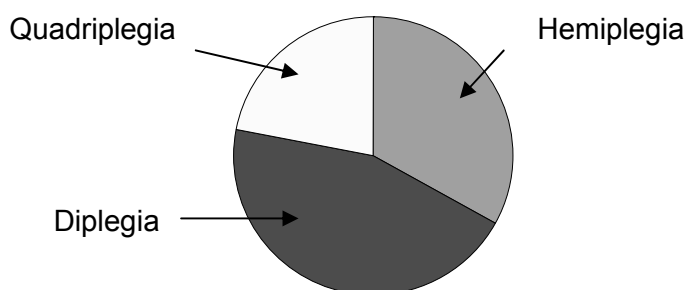
Over the last few months the CPRS has obtained the information from your child's paediatrician that you agreed to us receiving about your child's cerebral palsy.

So far we have found out that most children on the register are diagnosed with 'Spasticity' (80%), followed by Ataxia (13%) and then Dyskinesia (7%).

Spasticity: Of the children diagnosed with the Spastic form of cerebral palsy, most of these children had the diplegic type,- where mainly both legs are affected.

Dyskinesia: Children with Dyskinesia where mainly recorded as having the dystonic type.

Types of Spasticity



★ We hope to bring you more findings from this data in our next newsletter. ★

For more information about the green questionnaire (LAQ) please see the website, and newsletter 2, which is available online or through contacting the CPRS office.

About pie charts:

The whole circle represents all the children on the register for whom we have the information. For each different group a part of the circle is shaded in to show how many of the children are in this group. The bigger the section, the more children there are in that group.



SCOTTISH DISABILITY
SPORT

Scottish Disability Sport CP Football Squad Training & Competition

Over the summer, SDS and the SFA have been working to put in place a comprehensive programme of training and competition opportunities for footballers with Cerebral Palsy in Scotland.

Talks with Stirling University have resulted in this facility being established as a National Centre for Disability Football with access to facilities and sport science support. In addition, an SFA physiotherapist will be in attendance at all training sessions to treat injuries and to operate a physical conditioning clinic.

The SFA's National Development Officer for Disability Football is also busy organising a series of international friendly matches, on a home and away basis, in preparation for the involvement of a Scottish squad in an international competition next summer.

For Further Information please contact: Gavin Macleod

Scottish Disability Sport
Caledonia House
South Gyle
Edinburgh
EH12 9DQ

TEL: 0131 3171150
FAX: 0131 3171075
email:
gavinmacleodsds2@aol.com
www.scottishdisabilitysport.com

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