

Sources of support and Information for parents of children with epilepsy in the Yorkshire region with other national resources available.

All internet sources accessed on 16 November 2009.

Hull help line on epilepsy 08715 222 060

Hull Contact for the British Association of epilepsy

Honorary Secretary: Mrs H Figg.

Telephone: 01482 791122

**Joint Epilepsy Council
Epilepsy Specialist Nurses Association**

Contact

Chris Morley,
Paediatric Epilepsy Nurse,
Children's Centre,
70 Walker Street,
Hull HU3 2HE

01482 617644

Christine.Morley@hercs.nhs.uk

Sunshine House in Kingston-upon-Hull

From the Roald Dahl Foundation supports specialist paediatric nurses throughout the UK caring for children with epilepsy, blood disorders or acquired brain injury and offers practical help. Sunshine house provides help for children with complex health needs, mainly acquired brain injury or epilepsy.

Contact

www.roalddahlfoundation.org

Email: admin@roalddahlfoundation.org

<http://www.roalddahlfoundation.org/CMS/Uploads/AnnualReviewAndFinances.pdf>

West Hull Primary Care Trust

Learning support and child development services

Clinics and support include; memory clinics, psychotherapy, child and adolescent mental health

Name of Contact: Allyson Kent
Phone: 01482 343 125
E-mail: Allyson.Kent@humber.nhs.uk

Hull City Council

Can carry out formal assessments of children with special educational needs (SEN).

Tel: (01482) 300 300

Email: Isspecialneeds@hullcc.gov.uk

Hull Learning Services

"Supporting Children" initiative

<http://www.granada-learning.com/press/supportingchildren.asp>

A series of 11 books for children with special educational needs (SEN) in mainstream school have been produced and are intended for teachers and teaching assistants. They include comprehensive guides for schools and additional resources including the following titles:

- Supporting Children with Epilepsy
- Supporting Children with Medical Conditions
- Supporting Children with Speech and Language Difficulties
- Supporting Children with Behaviour Difficulties
- Supporting Children with Motor Co-ordination

Hull City Council – learning support

64 Helmsley Grove
Hull
HU5 5ED
Tel: (01482) 300 300
Email: City.Psychologicalservice@hullcc.gov.uk

Epilepsy Action in Hull

Epilepsy Action has produced a manual in partnership with the Educational Service for Physical Disability (ESPD), the Special Educational Needs Support Service (SENS) in Hull and a specialist paediatric epilepsy nurse. This is aimed at teachers and support staff for children of school age and is

intended to increase their knowledge and understanding of epilepsy and to provide a guide to best practice for the support of students living with the condition. The manual also raises awareness of the possible educational implications of epilepsy and suggests strategies to overcome those difficulties.

http://www.epilepsy.org.uk/join/professional_pack.html

Moving on from child to adult disability services

Hull transitions team (multi-agency team)
Hull City Council
Cranswick House
182 Chanterlands Avenue
Hull
HU5 4DJ

Tel: 01482 467 540

Epilepsy friendly pharmacists in Hull

Newtons Pharmacy, 1028 Anlaby Road, Hull, HU4 7RA
Will give advice on, potential side-effects, consistency of supply and drug interactions

Local and regional resources

Yorkshire contact; Chris Challenger 01274 640 064

For North Yorkshire

Contact: Lynda Dyson, SEN assessment and review manager

lynda.dyson@northyorks.gov.uk

Tel: 01609 533214

Mid Yorkshire NHS Trust

<http://www.midyorks.nhs.uk/Our+services/Epilepsy.htm>

Mid Yorkshire Epilepsy support group

<http://www.myepilepsy.co.uk/>

Tel: 01977 794680

Email: info@myepilepsy.co.uk

Mersey Region Epilepsy Association - www.epilepsymersey.org.uk

Sheffield children's services

<http://www.sheffieldchildrens.nhs.uk/services/2-2-neurology.php>

The service is predominantly for children living in Sheffield and the surrounding Districts including South Yorkshire, North Derbyshire, North Nottinghamshire, North East and South East Lincolnshire. 0-16 can go up to 19 years old. Clinics are held at the Ryegate Children's Centre and at the Northern General Hospital in Sheffield. Additionally regular outreach clinics are held in Rotherham, Barnsley, Doncaster, Chesterfield, Worksop, Grimsby and Boston.

Books, publications and information

The National Institute for Clinical Excellence (NICE) an NHS organisation has issued guidelines for the care of adults, children and adolescents with epilepsy that are nation wide applicable. Recommendations for diagnosis, treatment and management. A patient's guide to these is available from:

Address;

National Institute for clinical excellence
Midcity Place
71 High Holborn
London
WC1V 6NA

Tel: 020 7067 5800

E mail; nice@nice.nhs.uk

www.nice.org.uk/CGO20publicinfo.

Health Libraries in Lincolnshire on-line

http://www.hello.nhs.uk/pchil_resources.asp#epi

National Organisations

Henry Spink Foundation. Research Information Centre. Charity to help children with disabilities including epilepsy.

<http://www.henryspink.org/home.htm>

Advice, treatment and therapies.

Epilepsy West Lothian - www.epilepsywestlothian.co.uk

NHS Choices – introductory on-line video on epilepsy

<http://www.nhs.uk/epilepsy>

Epilepsy Action - <http://www.epilepsy.org.uk/links/children.html>

Tel:- **0808 800 5050**

National Society for Epilepsy

www.epilepsynse.org.uk

Tel: 01494 601400

<http://www.epilepsysociety.org.uk/AboutEpilepsy/Epilepsyandyou/Childrenandeducation-1>

National centre for young people with epilepsy

<http://www.ncype.org.uk/epilepsy/information-links/family-support>

The National Centre for Young People with Epilepsy (NCYPE) is a national charity for children and young people aged 5 to 25 with epilepsy and other neurological conditions. For general enquiries about our residential special school, college and the assessment and rehabilitation service, please contact by telephone on: 01342 832 243 or by e-mail: info@ncype.org.uk .

They offer training and support for professionals, parents and young people through our [Childhood Epilepsy Information Service](#). Our Childhood Epilepsy Helpline is open Mon-Fri 9am-1pm on 01342 831342

NCYPE also have a handbook for parents which includes; a simple guide to epilepsy and its diagnosis and treatment, tips for dealing with school, holidays and travel, living with epilepsy and the emotional issues, epilepsy and teenagers a guide to useful websites, forums, books and DVDs and a sample seizure and health record charts.

They also provide epilepsy awareness in schools sessions including raising awareness of epilepsy, how it is treated, how to help people with epilepsy and dispelling epilepsy myths. This is worth bringing to the attention of your child's school

Other Epilepsy Organisations

British Epilepsy Association

Tel: 0808 800 5050 for a Parent's Guide to epilepsy

Epilepsy Research Foundation www.erf.org.uk

Epilepsy Bereaved www.sudep.org

Enlighten www.enlighten.org.uk

Epilepsy Scotland www.epilepsyscotland.org.uk

Brainwave (*Epilepsy Ireland*) www.epilepsy.ie

Epilepsy Foundation www.epilepsyfoundation.org

Epilepsy.org.uk <http://www.epilepsy.org.uk/links/children.html>

University College London Developmental Epilepsy Clinic

http://www.gosh.nhs.uk/gosh_families/information_sheets/developmental_epilepsy_clinic/developmental_epilepsy_clinic_families.html

For more information call 020 7837 7618 extension 2958

More books and publications

Epilepsy Parent's information

<http://www.epiweb.org/education.html>

information on seizure types, financial help, advice on medications, advances in treatment, special needs schools, post 16 schools.

Sudden Unexpected Death in Epilepsy: A global conversation. (2005).
Editors; Denise Chapman, Brendon Moss, Rosemary Panelli, Russell Pollard.
ISBN 0-9758011-0-4. Published by, Epilepsy Bereaved. Wantage, Oxon.
UK.

www.sudep.org

Primary Care Guidelines for the Management of Females with Epilepsy.
(2004). Editors: Susan Duncan, Anne Fairey, Sally Gomersall, Mike Kerr,
Anita March, Jim Morrow, Ley Sander, Steve Simons. Royal Society of
Medicine Press Ltd., ISBN 1-85315-588-8
www.rsmppress.co.uk

Seizures explained. Epilepsy Action. www.epilepsy.org.uk

Brainstorms: epilepsy in our words. Personal accounts of living with seizures
Steven C. Schachter. Raven Press. New York. Try Amazon.co.uk for a
copy.

Schachter, S. C. (1995). The brainstorms companion: epilepsy in our view.
New York, Raven Press.

CHIP + Birnie Child Development Centre
Raigmore Hospital
Inverness
IV2 3UJ

Tel: 01463 711189

e-mail info@chipplus.org.uk

Publications available from CHIP are listed below

EPL1

Epilepsy

Alice Hanscomb and Liz Hughes

Covers all aspects and types of epilepsy.

EPL2

Epilepsy

BILD

One of the titles in the British Institute of Learning Disabilities series of books aimed to discuss issues with people with a learning disability.

EPL2.1

Epilepsy and the Young Adult

EYA

Answers questions about living with epilepsy.

EPL3

Epilepsy and your child

Richard E Appleton, Brian Chappell and Margaret Beirne

A very clear book in question and answer format, covering all aspects of your child's epilepsy.

EPL4

Epilepsy: The Detective's Story

Peter Rogan & David Hollam

Fictional story for children to explain epilepsy

EPL5

Epilepsy Reference Book

J Oxley & J Smith

An indispensable information source on epilepsy for patients, their families, GPs, health workers and carers

EPL6

Family Doctor Guide to Epilepsy

Dr Matthew Walker & Prof Simon D Shorvon

Discusses symptoms, tests, diagnosis, treatments, self-help & lifestyle

EPL7

SIGN Guidelines on Epilepsy

SIGN

National guidelines for professionals on diagnosis and management

EPL7.1

Supporting Children with Epilepsy

Hull Learning Services

Comprehensive guide for schools (see above)

EPL8

Weathering the Storms: Living with Epilepsy

Julie Dennison

The author tells her story of living with epilepsy.

EPL9

What Does It Mean to Have Epilepsy?

L Spilsbury

This book explores what it means to have epilepsy what causes it & what can family & friends do to help?

Research into epilepsy and how you can help

If you would like to contribute to research into epilepsy, Epilepsy Action Research Network (EARN) is keen to involve people with epilepsy and their carers in research that is being planned and your views are greatly valued. Please contact;

Margaret Rawnsley

mrawnsley@epilepsy.org.uk

Also **INVOLVE** who promote public involvement in NHS, public health and social care research value your input;

<http://www.invo.org.uk/index.asp>

The full report related to this briefing paper, 'An overview of epilepsy with a focus on the affects and implications of the condition for children', authored by Valerie Featherstone (Consultant researcher) is available from the Research and Education Department, Cerebra, The Lyric Building, King Street, Carmarthen, SA31 1BD.

Telephone: 01267 244200

email: info@cerebra.org.uk

website: www.cerebra.org.uk