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
Hull City Council
Can carry out formal assessments of children with special educational needs (SEN).
Tel: (01482) 300 300
Email: lsspecialneeds@hullcc.gov.uk

Hull Learning Services
"Supporting Children" initiative
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 (SENSS) 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
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

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](http://www.epilepsyscotland.org.uk)
Brainwave *(Epilepsy Ireland)*  [www.epilepsy.ie](http://www.epilepsy.ie)
Epilepsy Foundation  [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

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](http://www.epiweb.org/education.html)

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

[www.sudep.org](http://www.sudep.org)

[www.rsmpress.co.uk](http://www.rsmpress.co.uk)

Seizures explained.  Epilepsy Action.  [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Brainstorms: epilepsy in our words.  Personal accounts of living with seizures  

New York, Raven Press.
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