



Epilepsy Information for parents

What is epilepsy?

Epilepsy is a chronic condition, with recurrent seizures. Some still say 'fits, convulsions, shakes, jerks, grand mal and petit mal' for seizures. Seizures are abnormal grouped electrical firing from brain cells, causing either jerking of the body, altered awareness, consciousness or sensations/feelings. There are many types of seizures and many types of epilepsies. Half of children with epilepsy eventually 'grow out' of their epilepsy by adulthood, so is not always a condition for life.

How can I keep my child safe?

The risk that a seizure can lead to a serious complication is rare in children, but there are some general measures to reduce risk of serious injuries:

- 1) Avoid height or on roads activities (cycle on pavement instead, with helmets)
- 2) Supervised activities that involve water (such as a buddy system when swimming)
- 3) Take showers rather than baths, unless supervised

What should I do if my child has a febrile convulsion again?

Most seizures last under two minutes and will not need emergency rescue treatment

- Stay with your child and note the time it started.
- Lie your child on their side, this helps any moisture drain out of the mouth.
- Make sure your child does not hurt themselves during the convulsion.
- Do not attempt to put anything between your child's teeth, or in the mouth.
- Expect your child to look very pale or temporarily blue round the lips, during the convulsion.
- If your child has seizures longer than 5 minutes, he/she will probably need to be on a rescue medication, to stop the seizure. You will receive instructions regarding this if required

Do not bring your child to hospital while they are having a convulsion, call 999 for an ambulance.

What can I do to help?

Many parents find seizures very frightening initially, but it would help us to diagnose the type of epilepsy type if you could take note of the following:

- what the child was doing just prior to the episode
- which side did the seizure start- maybe both side or one side, symmetrical looking?
- what did the child look like during the episode: particularly, face & eyes movements and any colour change
- what happened after the event- any confusion or sleep, any injuries- especially tongue biting, wetting/soiling themselves.
- Videoing a seizure
- Keep a seizure diary, and record how often and the length and type of seizures, and activity before the seizure are all helpful for the your epilepsy specialist to manage your child's epilepsy.

If the episode is short and your child has fully recovered, contact the epilepsy team if you are unsure of the plan of action. Otherwise, make an appointment to see the G.P. If you are not able to get hold of a medical person and the episodes are frequent or prolonged, then you should bring your child to the Accident and Emergency department.

What treatment will my child need?

Most children with epilepsy require anti-epileptic drug (AED) treatment for several years, the dose is based on the child's weight. AED can suppress seizures and does not cure epilepsy. You will have received counselling regarding the drug options. See Medicines for Children.org.uk

When will my child be seen again?

Your child will be reviewed at least yearly by an epilepsy specialist. Please bring your medications with you, any seizure diary and bring the Red Book if your child is under 5 years old. For most patients/parents, we would encourage them to write down a list of questions to ask during the appointment, to help them remember all their queries. Please keep this letter and others I send to you in a folder as part of a 'Patient held record'. It will help health professionals when he/she is seen in clinics or A+E, here or elsewhere.

If you need further advice please ring the Starlight children's Unit.

Starlight Children's ward Tel: 0161 291 2248

Starlight Children's Observation & Assessment Unit Tel: 0161 291 5459
Wythenshawe Hospital
Southmoor Road
Wythenshawe
M23 9LT

Review March 2017
Editorial number 11147/15



Below are reputable epilepsy organisations, offering advice and support to parents and children regarding their child's epilepsy. If there are any further information, queries and support that you require, you can contact your epilepsy specialist nurse: Carolyn Taylor/Zoe Pearce (Manchester) 248 8501, Lisa/(Trafford) 934 8333, Bernadette Wilmot-Lee (Stockport) 419 2125. Failing that, you can contact my secretary Mrs. Sarah Taylor on 0161 291 2269. We will try our best to get back to you within two working days.

Epilepsy – Advice & Information

Epilepsy Action

British Epilepsy Association
New Anstey House
Gate Way Drive, Yeadon
Leeds, LS19 7XY
(Registered Charity No: 797997)

Internet: www.epilepsy.org.uk
E-mail: helpline@epilepst.org.uk
Freephone Helpline: 0808 800 5050

Epilepsy Society

Chesham Lane
Chalfont St. Peter
Buckinghamshire, SL9 0RJ
(Registered Charity No: 206186)

Telephone: 01494601300
Helpline: 01494 601400
(Mon-Fri 9:00am – 4:00pm)
Internet: www.epilepsysociety.org.uk

Young epilepsy

St Piers Lane
Lingfield
Surrey, RH7 6PW
(Registered Charity No: 311877)

Telephone: 01342832243
Fax: 01342834639
Email: info@youngepilepsy.org.uk
Internet: Youngepilepsy.org.uk

Expert Patients Programme

Internet: www.expertpatients.co.uk

MedicAlert Foundation

1 Bridge Wharf
156 Caledonian Road
London
N1 9UU
(Registered Charity No: 233705)

Telephone: 020 7833 3034
Fax: 020 7278 0647
E-mail: info@medicalert.co.uk
Freephone: 0800 581 420
Internet: www.medicalert.co.uk

Hoopers Medi-Tag

37 Northampton Street
Hockley
Birmingham
B18 6DU

Telephone: (0)121 200 1616
Fax: (0)121 212 3737
E-mail: info@medi-tag.co.uk

SOS Talisman

Talman Ltd
21 Grays Corner
Ley Street, Ilford
Essex IG2 7RQ

Telephone: 020 8554 5579
Fax: 020 8554 1090
E-mail: sostalisman@btinternet.com

SOS Bracelet / Necklace can also be found in most local Jewellery Shops.

Message in a Bottle (Medical information that can be kept in a bottle in fridge at home of which are looked for and recognised by emergency services). Information pamphlets and bottles can be

obtained free of charge from most GP Surgeries, Chemists and Pharmacies. (Launched by International Association of Lions Club).