



Information about epilepsy

South East Thames Paediatric Epilepsy Group
www.setpeg.co.uk

Your child has been referred to a clinic where we think about possible causes for the episodes they have experienced. There are many different causes of unusual episodes but your doctor may be considering epilepsy. You may have been told that your child does have epilepsy.

Parents and carers often find it helpful to have plenty of information about epileptic seizures and epilepsy. You may find it helpful to know what having epilepsy might mean for your child, and for you and your family, and what can be done to help.

This booklet is to help you discuss some of the things you might want to know with your doctor or nurse, and to help you find other support and information.

We can discuss some things when we first meet your child, and some things later on, if they become important to you or your child. Of course, we will also talk with your child, and try to answer any questions or worries he or she has.

The next three pages of this booklet list some of the questions parents often ask us. We can't put all the answers in this booklet because every child is different. But we hope the booklet will help you think about the questions you may want to ask.

There are lots of different kinds of epilepsy, and many of these questions will not be relevant to your child. Some of them won't be relevant now, but might be more helpful in the future, if your child still has epilepsy.

You have probably thought of other things you wish to discuss. Sometimes it helps to make a list of your worries or questions so you don't forget anything at your appointment. Or you could bring this booklet with you.

There are lots of other ways you can get support and information about epilepsy. We have listed many of these later in this booklet.



Some of the things parents, children and young people with epilepsy want to know about...

Information about epileptic seizures (sometimes called epileptic fits or convulsions)

- What is a seizure and what is epilepsy?
- What causes epilepsy?
- What kind of epilepsy does my child have?
- Will my child grow out of his epilepsy?

What should I do if my child has a seizure?

What is likely to happen in the clinic? How do doctors diagnose epilepsy?

What is an EEG, what does it involve and how does it help?

How might my child feel about having epilepsy, and how do I feel?

Will having epilepsy make any difference to my child's life?

Will it make any difference to:

- my child's behaviour and the way he feels?
- my child's health and vaccinations?
- my child's growth and development?
- my child's learning?
- my child having friends?
- my child's sports and activities?



What support is available for my child and family?

What should I tell my child's school?

Is epilepsy dangerous?

- Are there risks associated with having epilepsy?
- What can be done to keep my child safe?
- Do we, as parents and carers, need any special training?



Some more things parents, children and young people with epilepsy want to know about...



Treatment for epilepsy

- What treatments are available?
- Does my child need to take anti-epileptic medicines (sometimes called anti-epileptic drugs or anticonvulsants)?
- What are the side effects of anti-epileptic medicines?
- What should I do if I am worried?
- How long might my child need to take medicine for?
- Can I stop my child's medicine?
- What about special diets or surgery?

Teenagers and Young Adults with epilepsy

- How can I lower the chances of having a seizure?
- What should I say to my friends?
- Will I be able to drive?
- Does having epilepsy make any difference to drinking alcohol, smoking tobacco, or taking illegal drugs?
- Do I need to avoid strobe lights and loud music?
- Will epilepsy affect my higher education or the jobs I can do?
- Will having epilepsy make any difference to personal and sexual relationships?
- Can I take the oral contraceptive pill?
- What happens if I would like to have a baby or if I am pregnant?

Organisations you may like to contact

As well as talking to your doctor or nurse, you might like to contact organisations set up to support people with epilepsy. They provide a lot of helpful information about these and other topics. Some organisations are helpful for all children with epilepsy, but others are only relevant for some children and their families. Please ask your doctor or nurse if you are not sure.

This booklet and all the links are also available on our website www.setpeg.co.uk

General information about epilepsy

Epilepsy Action

www.epilepsy.org.uk
0808 800 5050 (freephone)

Epilepsy Society

www.epilepsysociety.org.uk
01494 601400

Joint Epilepsy Council

www.jointepilepsycouncil.org.uk
01943 871852

National centre for young people with epilepsy

www.ncype.org.uk
01342 832243

MREA Neurosupport Centre

www.epilepsymersey.org.uk
0151 298 2666

International league against Epilepsy

www.ilae-epilepsy.org/

National Institute for health and Clinical Excellence

www.nice.org.uk

Information about anti-epileptic medicines

www.medicinesforchildren.org.uk/

Information about specific treatments for some kinds of epilepsy

Ketogenic Diet

www.matthewsfriends.org

Vagus Nerve Stimulation

www.vnstherapy.com

Books about epilepsy

The books below, and many others, are available from Epilepsy Action, MREA, and the Epilepsy Society. There are also a wide range of other information leaflets, DVDs, and a CD Rom (Discovering Epilepsy) designed for children.

For Parents/Carers

Your Child's Epilepsy

– A Parent's Guide

ISBN: 1872362613

Richard Appleton, Brian Chappell & Margaret Beirne

The Ketogenic Diet.

A Treatment for Epilepsy

ISBN: 1888799390

Freeman, Freeman and Kelly

For Children/Young people

The Illustrated Junior

Encyclopaedia of Epilepsy

ISBN: 0948270608

Edited by Richard Appleton

Living with Epilepsy

ISBN: 0750228407

Patsy Westcott

Everything a Child Needs to Know about Epilepsy

ISBN: 97809554803-3-1

Dr C Yemula and Prof. F Besag

More general health information

NHS Direct

0845 4647

www.nhsdirect.nhs.uk

Medic Alert

www.medicalert.org.uk

0800 581 420

General health Information

www.patient.co.uk

Transition to adult services/careers/driving information

Connexions (Careers/jobs)

www.connexions-direct.com

Health and Safety Executive (advice on health and safety at work)

www.hse.gov.uk/index.htm

0845 345 0055

Transition Information Network (transition to adult life)

www.transitioninfonetwork.org.uk

DVLA (driving)

www.dvla.gov.uk

0870 240 0009



Support & advice for children and adults with special needs and their families

Contact a family

www.cafamily.org.uk
0808 808 3555 (freephone)

MENCAP (Learning Disabilities)

www.mencap.org.uk
0808 808 111 (freephone)

Carers UK

www.carersuk.org
0808 808 7777

Special Needs Advice

www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds/index.htm

Easyhealth

(to aid the understanding of people with learning disability)
www.easyhealth.org.uk

Government strategies and laws and Childrens Rights

Valuing People

(for people with learning disability and their families)
www.valuingpeoplenow.dh.gov.uk

Council for Disabled Children

(works to influence national policy which impacts on children with a disability)
www.ncb.org.uk/cdc/home.aspx
020 7843 1900

Equality and Human Rights Commission and Equality Act 2010

www.equalityhumanrights.com/
0845 604 6610

There are many other organisations which offer support to children and families affected by specific conditions which can be associated with epilepsy. Please ask your doctor or nurse about these.





NHS



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