Useful websites

Young Epilepsy
www.youngepilepsy.org.uk

Epilepsy Action
www.epilepsy.org.uk

RCPCH &Us – Epilepsy12 Youth Advocates
www.rcpch.ac.uk/epilepsy12-youth-advocates

RCPCH Epilepsy12 National Audit Programme
www.rcpch.ac.uk/epilepsy12

Local Support

Use this space to keep a note about details of services local to you

Celebrating 10 years
RCPCH &Us
The voice of children, young people and families

Epilepsy Insight

Parent/carer leaflet

It can feel very overwhelming when you first get a diagnosis of Epilepsy for your child. There will be a lot of information to take in. This leaflet is designed based on feedback from parents and carers and aims to give you some helpful links to information about Epilepsy and some tips on how to prepare for your child's clinical appointments.

Your child has been diagnosed with

_____

Your support team is:

_____ Consultant

_____ Specialist Epilepsy Nurse

You can contact your team on

_____

Making the most of your appointments....

You and your child may have lots of questions you would like to ask at your appointment, but it can be easy to forget things in the moment, especially if there is a long gap between your appointments.

You can use the space below to keep a note of any thoughts, observations and questions you might have about your child's epilepsy as they come up, so you have them to hand when your appointment comes around.

Date	Thoughts, observations questions....

Top tips

- Photograph your clinic letter so you have all your important info and contacts to hand on your phone
- Look out for useful apps to record seizures and medications
- Film and keep records of your child's seizures – speak to your doctor about this
- Call ahead to ask questions you may not want to ask in front of your child

"I keep the videos of seizures in a locked folder on my phone, so my child doesn't accidently watch them and get upset" (Parent)

"I put my camera on selfie mode when filming so I can be alongside my child while they are having their seizure but still film and keep an eye on the timer – it feels more comfortable for me than just standing back and filming them" (Parent)

Supporting your child to have a voice in their care ...

Children and young people's views, questions, worries and ideas can get missed in clinical appointments where lots of medical language may be used. It is crucial that children and young people are the centre of their appointments and feel like they are able to get their views across – either directly or with your support.

Ways that you can help:

Ask your team for 'child or young people friendly' information about Epilepsy. Make sure your child understands key information about their Epilepsy and care plan. Ask your child if there are any specific things they would like to talk about in their appointment. Do they want you to ask for them or would they like to ask themselves?

Download and use the *RCPCH &Us Epilepsy Impact and Influence* cards and resources. These card sets have topics for discussion, feelings cards and a 'how I like to communicate' sheet. They are designed to support communication for children who may be less comfortable or able to communicate verbally. This could be because they are non-verbal in their communication style or don't feel comfortable to speak up yet in appointments. Go to www.rcpch.us and look for the epilepsy resources.

As your child reaches the stage of wanting or needing more independence, encourage them to have some time to speak to their doctor or nurse alone. This is an important stage in growing up and also allows them to ask any questions they might be shy or embarrassed to ask in front of parents and carers.

Use this space to make notes of questions your child would like to ask

Date	Thoughts or questions from *(child's name)*