

Roadmap of Resources

There is a lot of information to read when you/your child first gets diagnosed with epilepsy (and throughout childhood). In order to help with this, we have tried to break down the main bits of information and have provided some resources which you may find useful. We have grouped these by subject to make it easier for you to navigate through this roadmap.

For **general information** about epilepsy, here are websites that you may find helpful:

- <u>http://www.youngepilepsy.org.uk</u>
- <u>https://www.epilepsy.org.uk</u>
- <u>https://www.epilepsysociety.org.uk</u>

For more **specific information**, see below:





Area/Topic	Possible resource
Clinical	
Attention Deficit Hyperactivity Disorder	https://thechannel.org.uk/wellbeing/epilepsy-and-adhd#:~:text=Studies%20suggest%20that%2030- 40,adults%20in%20the%20general%20public.
Autism	https://epilepsyresearch.org.uk/our-research/research-blog/the-link-between-epilepsy-and-
Spectrum Disorder	autism/?gclid=CjwKCAjwt52mBhB5EiwA05YKo0wqfEbF7WMpa-
	fnShho0pe1fNfOYBuOBFzUwH5W2J1vluow4PSA2BoC1F8QAvD_BwE
Disabilities	https://contact.org.uk/
Learning	Link between epilepsy and LD: https://www.epilepsysociety.org.uk/learning-
Difficulties	disabilities#.WyuKT02Wy73
E 9	Explaining epilepsy: <u>https://www.epilepsy.org.uk/living/for-carers</u>
Epilepsy	
Epilepsy treatment	https://www.youngepilepsy.org.uk/about-epilepsy/epilepsy-treatment/
	Medication: <u>https://www.youngepilepsy.org.uk/about-epilepsy/treatment-for-epilepsy/antipileptic-medication.html</u>
	All medication: https://www.medicinesforchildren.org.uk/medicines?medicine-search=epilepsy
	Diet: <u>https://www.youngepilepsy.org.uk/about-epilepsy/treatment-for-epilepsy/dietary-</u> treatments.html
First Aid Quick Guide	https://www.epilepsysociety.org.uk/seizure-first-aid#.WyuKzn8na72
For the young person	https://www.youngepilepsy.org.uk/for-young-people/
Safety at home	https://www.youngepilepsy.org.uk/sites/default/files/dmdocuments/Safety_precautions_125.pdf
Seizures	General information: https://www.youngepilepsy.org.uk/about-epilepsy/epilepsy-seizures/
	Management: <u>https://www.youngepilepsy.org.uk/about-epilepsy/seizures/managing-seizures.html</u>
	Night time seizures: https://www.youngepilepsy.org.uk/sites/default/files/dmdocuments/Night-
	<u>Time-Safety-equipment.pdf</u> Seizure diary: https://www.epilepsy.org.uk/living/seizure-diary
Sleep	https://epilepsysociety.org.uk/about-epilepsy/epileptic-seizures/seizure-triggers/sleep-epilepsy

Sudden	https://sudep.org/
unexpected death in	
epilepsy	
(SUDEP)	
Surgery	https://www.youngepilepsy.org.uk/dmdocuments/Neurosurgery-1303-2%20(1).pdf

	General support for the child and family
I have epilepsy	https://www.youngepilepsy.org.uk/support-you/i-have-epilepsy
	General mental health resources
Youth in mind	http://youthinmind.info/py/yiminfo/
MindEd	https://mindedforfamilies.org.uk/young-people/
	Transitioning to adulthood
General information	https://epilepsyspace.org.uk/medical-issues/transition/
Higher education	https://www.epilepsy.org.uk/living/education-and-epilepsy/going-to-college-or-
	university
Contraception	https://epilepsysociety.org.uk/living-epilepsy/women/contraception-and-epilepsy
Alcohol	https://www.epilepsy.org.uk/info/daily-life/alcohol
Driving	https://www.epilepsy.org.uk/info/driving

Keep up-to-date with the **latest research** here:

https://www.youngepilepsy.org.uk/for-professionals/research/

https://epilepsysociety.org.uk/what-we-do/research

https://epilepsyresearch.org.uk



Epilepsy Action Helpline – 0808 800 5050 (free to call from UK landlines and mobiles). 8.30am to 5.30pm, Monday to Friday. Helpline advice in 150 languages

Epilepsy Action text service – 0753 741 0044 (aim to reply within 24 hours) Young Epilepsy – 01342 831342. 9am – 1pm, Monday – Friday. Epilepsy Society – 01494 601 400. Monday & Tuesday 9am-4pm, Wednesday 9am-7.30pm

In the case of an emergency:

- Dial 999 or go to your nearest Accident and Emergency department
- Call your **GP**

For emergencies r
For children/young people
Confidential counselling service for
children and young people:
Call Childline – 0800 1111 or visit their
website https://www.childline.org.uk/

or emergencies related to mental health

For adults Service that provides emotional support for anyone: Call Samaritans – 116 123 or email them jo@samaritans.org