



We are a group of young people and parents / carers with lived experience of epilepsy, who sit on the UK Paediatric Epilepsy Programme Board. As part of Purple Day 2025, we would like to share with you what matters to us around epilepsy care across all four nations in the UK. We have shared these topics with the Board and advocated for children, young people and families in our Expert by Experience role.

To find out more contact: and_us@rcpch.ac.uk

SUDEP

- ✓ Guidance for health care professionals on how to discuss SUDEP with children, young people and families
- ✓ Supported the next steps for the SUDEP Action safety checklist
- ✓ Raised the need for all children and young people to be risk assessed for SUDEP
- ✓ Asked for leaflets and flyers to be created to display in hospitals and to be given out to children, young people & families that educates and supports them

Location and access to healthcare

- ✓ We called for access to a specialist epilepsy nurse regardless of location
- ✓ There should be rescue medication training for all schools
- ✓ We would like to see a flow diagram to show what epilepsy services are available in each location
- ✓ We should ensure the same standard of care across all four nations

Transition to adult services

- ✓ All teams should have access to youth workers to support transition plans
- ✓ There should be joint handover meetings with paediatric and adult services
- ✓ UK wide transition support for children and young people needs to be prioritised
- ✓ Transition extends beyond the medical and includes work, university and leaving home....

Unifying communication between health and education

- ✓ Education gap assessment we believe there should be an Epilepsy Education Health Care Plan Strategy
- ✓ We would like to see epilepsy training and awareness for all schools
- ✓ Improved communication between health and education and data sharing systems will support children, young people and families
- ✓ There needs to be a review of the legislation for schools across all four nations in relation to epilepsy support to ensure consistency
- ✓ Epilepsy resources should be provided for all schools including leaflets and websites to support mental health and wellbeing.

