Why the guideline is needed

1:220
1 in every 220 children has epilepsy in the UK.
Source: Joint Epilepsy Council UK & Ireland 2011

5000
Approximately 5000 children under 18 have epilepsy in Scotland.

Key issues

Investigations
Clarity around diagnostic tests to:
• diagnose epilepsy
• reduce inappropriate testing
• improve quality of life by having the right treatment choices

Management
Increased awareness of non-pharmacological treatment in the management of epilepsy.
Greater knowledge about the use of new antiepileptic medicines.

Transition
Enabling young adults to feel confident by addressing the issues that are important to them for a seamless transition from paediatric to adult care.

What matters to young people with epilepsy?
Taking part in decisions about their health.

"It’s very important to be involved in conversations about epilepsy.”
Members of the Epilepsy Scotland Youth Group

"Make sure people get support at the right time, managing epilepsy and coping with impact it has on daily living.”
Chris Fall, Young Person’s Representative on the SIGN Guideline Group

"We now know about SIGN and what they do and how they help.”
Parent at SPEN family day

Developing the guideline

18 – 20 months to develop the guideline.

43
Issues identified as important to patients from a patient focused literature search.

29
Multidisciplinary guideline group members.

503
Research papers reviewed.

35
Expert peer reviewers.

What we are doing

Publication
Summer/Autumn 2019
SIGN guideline for multidisciplinary audience making key recommendations about evidence-based practice.

Autumn/Winter 2019
A co-produced version of the guideline for young people.
Recommendations to be presented at the Scottish Parliament Cross Party Group on Epilepsy.

Partners

12
Partners from across:
• health, community and social care
• academic groups
• charities
• the public

Predicted impact of the guideline

For young people with epilepsy

"It will help people with epilepsy and their families make informed choices about the options available to them.”
Anissa Tonberg, Charities Representative, Policy Officer, Epilepsy Scotland

"People will receive the best care at the right time which will result in a positive experience of services.”
Chris Fall, Young Person’s Representative on the SIGN Guideline Group

"Help services to treat people as equal partners in their own care.”
Anna Scott, Young Person’s Representative on the SIGN Guideline Group

For parents and carers

"The earlier the correct information, treatment and services are provided the better the outcome.”
Emma Williams, mother and carer of a child with epilepsy and SIGN Guideline Group Parent Representative

"This guideline will help clinicians, young people with epilepsy and their families to better understand ALL epilepsy risks, and the positive steps they can take to reduce them. Not only can this improve quality of life but could prove life saving for some.”
Christine Jeans, SIGN Guideline Group Bereaved Parent Representative

For healthcare professionals

"Psychological aspects of this guideline are so person centred.”
"This has given me direction as to where research needs to be done.”
Jay Shetty, Consultant Paediatric Neurologist and Chair of SIGN Guideline Group

"This will help inform service provision for the mental health and developmental needs of potentially vulnerable children, young people and their families.”
Aileen McCafferty, Clinical Psychologist, Paediatric Neuropsychology, Centre for Child Health, Dundee and member of SIGN Guideline Group

"I would hope the guideline provides patients and carers with some clarity in the treatment pathway of epilepsy and contributes to continuity of care across the country. I think the guideline will clarify the referral criteria for epilepsy surgery and enable clinicians to identify potential surgical candidates sooner.”
Janice Fyall, Epilepsy Surgery Nurse Specialist and member of SIGN Guideline Group

"This will empower families.”
Celia Brand, Paediatric Epilepsy Nurse and member of SIGN Guideline Group

Key:

SPEN – Scottish Paediatric Epilepsy Network
SUDEP – Sudden Unexpected Death in Epilepsy

www.sign.ac.uk