

Child Health Reviews - UK

Clinical Outcome Review Programme

Coordinating Epilepsy Care:

A UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies



Report for parents and carers of children with epilepsy

September 2013

Child Health Reviews-UK was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Health and Social care division of the Scottish government, The Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS) the States of Jersey, Guernsey, and the Isle of Man.

Epilepsy is a chronic neurological condition affecting approximately one in 200 children and young people in the UK. Some children and young people die as a result of their epilepsy but the risk is low. Some have prolonged seizures (lasting longer than five minutes) which can lead them to be admitted to hospital for intensive or high dependency care.

What is Child Health Reviews-UK?

Child Health Reviews-UK (CHR-UK) is a clinical outcome review programme funded by the Healthcare and Quality Improvement Partnership. This work was carried out by the Royal College of Paediatrics and Child Health to look at the medical care received by children and young people with epilepsy.

Who did we include?

We looked at children and young people from across the UK between their 1st and 18th birthdays who had a diagnosis of epilepsy. Specifically we focused on children and young people who died (of any cause) or received intensive or high dependency care in hospital following a prolonged seizure.

What did we do?

Between 1 June 2012 and 31 March 2013 we asked all consultant paediatricians in the UK to let us know when they saw a child or young person with epilepsy meeting our criteria.

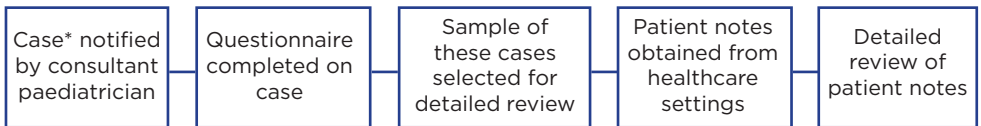
We collected questionnaire data for 161 children and young people and for 61 of these we carried out a more detailed review. These 61 cases were reviewed by pairs of assessors (a doctor and a nurse) who looked at the care received by a child or young person in different healthcare settings including general practice, community and hospital care.

To look at the overall quality of care of children and young people with epilepsy, we trained assessors to review patient notes from each of the healthcare settings against the recommendations and guidelines from NICE and SIGN. From this we were able to identify areas of good and unsatisfactory care so we could make improvements.



National recommendations for childhood epilepsy were first published by the National Institute for Health and Clinical Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) in 2004 and 2005. The NICE guidelines were recently updated in 2012. These recommendations, although not rules, were put into place to set standards and help health services achieve best practice in care for children and young people with epilepsy.

Process for collecting data



*Case - a child or young person with epilepsy who died or received intensive or high dependency care.

Why did we do this?

CHR-UK was carried out to make sure that everything possible is being done to make care, for children and young people with epilepsy, as good as it can be. With the aim to inform, provide learning and ultimately improve clinical practice and healthcare provided to children and young people in the UK.

Based on the review of children and young people's care, CHR-UK made nine recommendations to help improve healthcare for children, young people and their families.

What we found....

Recommendation 1:

Clinicians looking after children and young people with epilepsies should follow NICE and SIGN guidelines for all aspects of care and document the reasons for any deviations from these standard treatment guidelines.

Recommendation 2:

Clinical teams looking after children and young people with epilepsies should consider establishing a process of peer review as a means of monitoring and improving practice.

For most children and young people we found that clinicians were following NICE and SIGN guidelines when diagnosing and treating children and young people with epilepsy. It is important these guidelines are followed by all clinicians so they can give the best possible care.

However, in a small number of children and young people we found that these guidelines were not being followed. This may have been because clinicians found the processes or treatments suggested in the guidelines inappropriate for that child or young person, but this information was not recorded in their notes.

We think it's important that this information is recorded in the child or young person's notes, explaining why guidelines have not been followed so anyone treating the child or young person or reviewing their notes understands why things have been done differently. We recommend that clinical teams use a peer review process to make sure that all healthcare professionals are following guidelines and if they need to do something differently this will be recorded in the child or young person's notes.

Recommendation 3:

Clinical teams looking after children and young people with epilepsies should consider introducing an 'epilepsy passport' for all children as a means of improving communication and clarity around ongoing management.

Recommendation 4:

Whenever a child is admitted to hospital with a prolonged seizure, the consultant responsible for the admission should notify the clinician in charge of the child's overall care. The clinician with overall responsibility should then review the child's epilepsy management in the light of that admission.

Many of the children and young people had repeated hospital admissions for prolonged seizures throughout the course of their lives. This along with other health needs, multiple healthcare professionals being involved in their care, together with a lack of forward planning and appropriate care plans being in place has highlighted that, in some children and young people, healthcare professionals focus on treating a single event, rather than taking a step back and considering their overall epilepsy care. It is important that each child and young person has a clinician overseeing the coordination of their care and that they have regular reviews of their epilepsy so they receive appropriate treatment and parents and carers have care plans in place and know what to do in an emergency situation.

We recommend that clinical teams introduce an 'epilepsy passport' for all children and young people. This passport would hold information about each child or young person's epilepsy, such as up-to-date care and treatment plans as well as other important information needed for anyone looking after a child or young person with epilepsy. This would help with clear communication between different healthcare professionals as well as making sure parents, carers and young people are included in ongoing discussions and that these discussions are recorded in their notes.

Recommendation 5:

When prescribing buccal midazolam for rescue medication in prolonged seizures, prescribing clinicians must clearly state the formulation being used and the dose to be given in both mg and ml. The consultant in overall charge of the child's epilepsy care should ensure that the parents and all other carers have an up to date emergency treatment plan that clearly outlines the dose to be given and the circumstances in which to give the rescue medication.

There is more than one type of buccal midazolam used to treat prolonged seizures. These have different strengths and need to be given in different dosages. This can sometimes lead to mistakes in giving too much or not enough medication, particularly when children are changed from one type of buccal midazolam to another. Therefore it's important that prescribing clinicians explain to parents and carers the type and dosage of buccal midazolam they have for their child along with information on how to administer it. If you have any questions about buccal midazolam or other rescue medications please contact your GP, doctor or nurse.

Recommendation 6:

Ambulance Trusts should consider updating their protocols for seizure management in children and young people, to recommend the use of buccal midazolam as the first line treatment for prolonged seizures. This should be backed up with appropriate training of all ambulance crews in the use of buccal midazolam, and provision of buccal midazolam to all ambulance crews.

Overall we found evidence of good care from ambulance crews, but some concerns were raised around delays in giving emergency treatment or incorrect treatment for seizures. Recently, the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) published new

guidelines on treating seizures, highlighting buccal midazolam as the best emergency treatment for seizures. We support these guidelines and think they could be strengthened further to make sure all ambulance crews are trained and equipped to be able to use buccal midazolam in children and young people who are having prolonged seizures.



Joint Royal Colleges Ambulance Liaison Committee provides clinical advice to ambulance services in the UK.

Recommendation 7:

Emergency departments should ensure that children and young people presenting with prolonged seizures are treated according to current NICE and APLS guidance through appropriate departmental guidelines, training of staff and audit.

We found high standards of care in emergency, intensive and high dependency care departments treating children with prolonged seizures. However, in some cases we found healthcare professionals did not recognise the signs of status epilepticus (seizures lasting longer than 30 minutes) and did not respond as necessary. It is important that all healthcare professionals are trained and supported in following NICE and APLS prolonged convulsion (seizure) guidance and have appropriate emergency medications available and know how to use these. We recommend that all healthcare professionals have hospital based training in how to recognise and treat status epilepticus, making sure there is clear communication between different hospital teams so individual episodes can be managed.



Advanced Paediatric Life Support gives guidance on life-threatening emergencies in children.



Status epilepticus is a seizure that lasts longer than 30 minutes or a cluster of shorter seizures lasting for 30 minutes or more. This is a medical emergency.

Recommendation 8:

Child Death Overview Panels in England and the all-Wales Child Death Review Programme should ensure that the case of each child with epilepsy who dies is subject to a child death review, including, where appropriate, a multi-agency rapid response to investigate the death and provide support to the family. NHS Scotland, HSC Northern Ireland, Public Health Jersey, Public Health Guernsey and Department of Health Isle of Man should consider how such reviews could be built into any plans for development of child death review.

Many of the children and young people who died had known life-limiting illnesses and received good care and had appropriate plans in place for their death. When a child dies in England and Wales a child death review is carried out so that clinical findings and circumstances around the child's death are looked at to find out why the child died and make sure the cause of death is accurate. We think this process should be rolled out across the whole of the UK so lessons can be learnt from previous child deaths and reduce the risk of child deaths in the future.



A child death review is carried out by child death overview panels in England and the all-Wales review in Wales. These review deaths of all children from birth to 18 years old to understand why children die and use these findings to take action to prevent other deaths and to improve the health and safety of children.

Recommendation 9:

The consultant responsible for the care of any child with epilepsy who dies should ensure that all subsequent actions after death, including registration of the death, referrals to the coroner or procurator fiscal, and follow up of the family together with child death review are documented in the child's notes and shared with other members of the clinical team.

It is important that when a child or young person with epilepsy or other neuro-developmental impairments dies, clinicians recognise that they do not stop being part of the family and make sure the family receives appropriate support, advice and information. We found there were often a lack of documented information in the child or young person's notes on the cause and the circumstances of the child or young person's death and how the family had been supported. It is important that families are offered the necessary support following a child or young person's death and this information is recorded in children and young people's notes.

What happens next?

We think it is important for parents, carers and young people to be aware of the risks associated with epilepsy and the care they should be receiving so they can gain a better understanding and ask the necessary questions. The recommendations we have developed for improvements in care reinforces the need for clear communication of all relevant information to parents, carers and young people and the need for this to be documented in children and young people's notes. The full report with these recommendations is available to all paediatricians and clinical teams in the UK for them to learn from these recommendations and make changes in their daily practice to improve care for children and young people.

SIGNPOST/resources

If you have any questions about you or your child's care, please speak to your GP, doctor or nurse.

If you would like to read the full report this can be found here:
[www.rcpch.ac.uk/child-health-reviews-uk/programme-findings/
programme-findings](http://www.rcpch.ac.uk/child-health-reviews-uk/programme-findings/programme-findings)

The organisations below provide information and support for patients and parents and carers of those with epilepsy:

- Epilepsy Action: www.epilepsy.org.uk
- Epilepsy Society: www.epilepsysociety.org.uk
- Scottish Epilepsy Initiative: www.scottishepilepsy.org
- SUDEP Action: www.sudep.org
- Young Epilepsy: <http://youngepilepsy.org.uk>

Please note the RCPCH is not responsible for the content provided by these or other external organisations.



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