

New 'passport' suggested to improve epilepsy care for children

September 23 2013

A new report, published today by the Royal College of Paediatrics and Child Health, recommends that parents keep an 'epilepsy passport' to aid communication between professionals involved in their child's epilepsy care.

Over 85% of children with epilepsies admitted to intensive care or dying in the UK have associated developmental impairments. Nearly half (44%) of these children have at least three different health professionals involved in their on-going care, including paediatricians, health visitors, school nurses, [geneticists](#) and neurosurgeons, making communication about care between these professionals difficult.

The fact that many experience difficult to control seizures with frequent [hospital admissions](#), is resulting in an over-focus on day to day management of [acute episodes](#) at the expense of seeing the bigger picture which is key to keeping the condition under control.

The report, developed with the project's Clinical Lead Dr Peter Sidebotham, Consultant Paediatrician at Warwick Medical School, recommends that in order to address this parents should keep an 'epilepsy passport'. This passport would clearly identify the clinician coordinating their child's overall care as well as naming each professional treating them, the courses of medication they have prescribed and any emergency care plans in place.

Approximately one in 200 children (60,000) in the UK has a form of

epilepsy, making it the most common chronic childhood [neurological condition](#).

The report, published by the RCPCH as part of the *Clinical Outcome Review Programme: Child Health Reviews-UK*, studied data from a total of 162 children with epilepsies including 61 in-depth case reviews of mortality and morbidity.

The study highlighted that while the overall care of patients is good, there needs to be better coordination of care and communication between professionals and families. And in comparison to the last national review of epilepsy care, there have been substantial improvements in the involvement of paediatric neurologists and paediatricians with relevant expertise in the care of these children.

It also highlighted that:

- In addition to the involvement of different allied health professionals (74%), 46% of children also have specialists involved in their care
- 49% of children did not have documented access to an epilepsy specialist nurse, despite 67% of units reporting they had them
- Over half the children who died (56%), died as a consequence of their other health conditions, rather than their epilepsy. Nevertheless, there remains a small risk of death as a result of prolonged or unexpected seizures, and these conditions need to be taken seriously
- There were potentially modifiable factors identified in a number of the children's deaths reviewed, particularly in relation to the communication with parents. This further highlights the need for clear information and advice for parents on key warning signs

The study recommends that in order to improve epilepsy care, every

child should have:

- Details of their epilepsy, the professionals involved, and a comprehensive management plan clearly documented in an 'epilepsy passport'
- All information about the child's care documented in the child's notes including treatment and the reasons for that treatment - particularly important when clinicians have needed to deviate away from medical guidelines - to ensure each professional involved in the child's care understands why decisions have been made
- Good supportive and anticipatory planning for the children and their families
- Continued care by way of support and advice for families who have lost a child to epilepsy
- A peer review process established to monitor and improve clinical practice
- Any decisions around the management of a child's epilepsy treatment made by the clinician with overall responsibility for their care

Dr Peter Sidebotham, Warwick Medical School said:

"Epilepsies can be complex conditions, with 85% of those studies having additional developmental impairments; children often need to see a variety of healthcare professionals as part of their care. For many of these children, seizures are a frequent occurrence, with 36% experiencing seizures at least once a week, and nearly half (49%) having attended hospital because of prolonged seizures in the previous year.

So it's crucial that the child receives joined-up and well-planned care, including well documented medical history, regular briefings between those caring for the child and importantly, one lead clinician who has

oversight of the complete care package. Seeing this bigger picture has huge benefits for the quality of life of the child, peace of mind for parents and ultimately the day to day management of epilepsy."

In spite of the severity of these children's health needs, the CHR-UK review found many areas of good practice and confirmed the high quality of care provided by devoted parents and professionals working together. This could be enhanced further by a commitment by all professionals to clear and effective communication with parents and other members of the clinical team."

President of the Royal College of Paediatrics and Child Health, Dr Hilary Cass, said:

"We still don't know enough about what causes epilepsy and there is no cure. But we are getting increasingly better at treating and managing the condition.

This latest research found that in nearly a quarter of cases studied where children with epilepsies died, the reviewers identified things that could be done to reduce the likelihood of future deaths – including clear emergency care plans, more effective communication between professionals and parents, and the expertise and assurance that an epilepsy specialist nurse can provide. These are achievable interventions and if we can get them right, it will mean [children](#) with epilepsy can lead as normal lives as possible, their epilepsy will be managed well and we should ultimately see a reduction in [epilepsy](#)-related deaths."

Provided by University of Warwick

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