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Are we failing to provide adequate rescue medication to children at risk of prolonged convulsive seizures in schools?

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ABSTRACT

Objective This paper explores the issues that arise from the discussion of administering rescue medication to children who experience prolonged convulsive seizures in mainstream schools in the UK.

Situation analysis Current guidelines recommend immediate treatment of children with such seizures (defined as seizures lasting more than 5 min) to prevent progression to status epilepticus and neurological morbidity. As children are unconscious during prolonged convulsive seizures, whether or not they receive their treatment in time depends on the presence of a teacher or other member of staff trained and able to administer rescue medication. However, it is thought that the situation varies between schools and depends mainly on the goodwill and resources available locally.

Recommendations A more systematic response is needed to ensure that children receive rescue medication regardless of where their seizure occurs. Possible ways forward include: greater use of training resources for schools available from epilepsy voluntary sector organisations; consistent, practical information to schools; transparent guidance outlining a clear care pathway from the hospital to the school; and implementation and adherence to each child's individual healthcare plan.

Implications Children requiring emergency treatment for prolonged convulsive seizures during school hours test the goals of integrated, person-centred care as well as joined-up working to which the National Health Service (NHS) aspires. As changes to the NHS come into play and local services become reconfigured, every effort should be made to take account of the particular needs of this vulnerable group of children within broader efforts to improve the quality of paediatric epilepsy services overall.

INTRODUCTION

Significant shortfalls in service delivery for children with epilepsy have recently been reported in the UK.^{1,2} A particularly vulnerable group are children who experience prolonged convulsive seizures, defined as seizures lasting 5 min or more.³ National Institute for Health and Clinical Excellence (NICE) guidelines⁴ recommend immediate treatment of children with such seizures to prevent progression to status epilepticus and neurological morbidity.^{5,6} Most seizures occur outside of the hospital setting. Children are often unconscious during prolonged convulsive seizures; thus, whether or not they receive their treatment in time depends on the presence of a caregiver trained and able to administer rescue medication. This paper explores the issues that arise from the discussion of administering

What is already known on this topic

- ▶ It is recommended that children who have prolonged convulsive seizures receive rescue medication as quickly as possible to avoid progression to status epilepticus.
- ▶ Most seizures occur outside of the hospital setting.
- ▶ Whether or not a child receives rescue medication in time depends on the presence of a trained caregiver.

What this study adds

- ▶ Whether or not a child receives rescue medication at school depends on the resources and training available at each individual school.
- ▶ Many schools will either rely on parents or call an ambulance whenever a prolonged seizure occurs, with clinical consequences for the child.
- ▶ Clear guidance linking educational and healthcare sectors is needed for all children to receive rescue medication for prolonged seizures regardless of where they occur.

rescue medication in mainstream schools in the UK in the hope of raising awareness of unmet needs in this area.

PROLONGED CONVULSIVE SEIZURES IN CHILDREN

Seizures that last more than 5 min are unlikely to stop on their own;⁷ thus, guidelines recommend that rescue medication (buccal midazolam or, if preferred or if buccal midazolam is unavailable, rectal diazepam) be administered for any convulsive seizure lasting 5 min or more in a community setting.⁴ Delays in treatment increase the risk of status epilepticus,⁸ which may result in possible cognitive deficits^{5,9} and even death.¹⁰

The NICE guidelines for the diagnosis and management of the epilepsies in primary and secondary care recommend that all relevant caregivers, who include parents, teachers and other school staff, receive dedicated training to be able to administer rescue medication as promptly as possible to children according to a prespecified protocol.⁴ Guidance on medicines management in mainstream schools also



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Box 1 Summary of recommendations in existing national guidance on the management of medicines in schools^{11–13}

- ▶ Parents submit a request to the school for their child to receive prescribed medication as needed. They provide all the necessary medical information from the treating physician.
- ▶ An individualised healthcare plan is agreed among the parents, school head, local health service and school doctor or nurse (if available).
- ▶ This is supported by a school policy on the administration of medicines and/or epilepsy.
- ▶ Teachers (or other staff members) are asked to volunteer to take responsibility for administering the medication in question.
- ▶ They receive specific training to do so either from the school nurse or local health service.

exists within the educational sector; however, it is not specific to the situation of children with prolonged convulsive seizures, and thus recommendations are subject to interpretation (box 1).^{11–13}

ARE SCHOOLS OBLIGED TO ADMINISTER RESCUE MEDICATION TO CHILDREN?

In the UK, children with epilepsy are considered disabled for the purposes of the Equality Act of 2010 and are thus protected from discrimination in terms of admission and participation in school activities.¹⁴ Under the Education and Inspections Act of 2006, schools must make all arrangements necessary to meet the needs of any child requiring medical assistance during school hours.¹⁵ However, it is not a legal requirement for school staff to administer medicines to children (this role is entirely voluntary). Most teachers' unions actively discourage their members from accepting responsibility for doing so claiming that this falls outside of their duty of care and that they may be liable if anything goes wrong.^{16 17}

What happens in practice? Little published evidence exists on the experience of children who require rescue medication at school but the situation is thought to vary between schools. Insights from epilepsy specialists suggest that schools often react with panic and fear when faced with a child having a prolonged convulsive seizure. Fear of liability is a major barrier to overcome (PERFECT, data on file, 2012).

Some schools call an ambulance for every prolonged convulsive seizure that occurs at school, potentially causing treatment delays and subsequent complications for the child.^{18 19} Others may expect parents to be permanently on call in case their child experiences a seizure during school hours, forcing many parents to abandon full-time employment for the safety of their child. Both situations may threaten the social integration of the child and lead to stigmatisation.

Certain requirements must be met for the needs of these children to be addressed during school hours, the most important being training, clear information and communication, resources and accountability.

TRAINING, INFORMATION, RESOURCES AND ACCOUNTABILITY

Several studies point to inadequate training on epilepsy in schools. A survey of schools carried out by Epilepsy Action in 2012 found that over a quarter had not received any epilepsy

training in the past 3 years.²⁰ One in six teachers said that pupils with epilepsy at their school either did not have an individual healthcare plan or that they did not know if they had one.

Better information and communication to schools is the key.¹ Charitable organisations, in particular Young Epilepsy, the Joint Epilepsy Council and Epilepsy Action, have played an essential role in providing helpful resources on rescue medication to parents and schools in the form of guidance, templates and training courses.^{21–23} But implementing training requires firm commitment from staff volunteering to be trained as well as the school. For example, the Joint Epilepsy Council recommends two full days of training within school settings to ensure competency.²²

Resources outside of the educational system are also critical. NICE recommends that every child with a diagnosis of epilepsy should have a dedicated paediatric epilepsy specialist nurse (ESN) who acts as the liaison to the child's school and provides support and training in the child's home and school.⁴ Unfortunately, poor resourcing of paediatric ESNs is a long-standing issue, despite their proven role in reducing the number of admissions to hospital for children.²⁴ In all, 47% of the paediatric epilepsy centres audited in the Royal College of Paediatrics and Child Health Epilepsy12 (2012) survey had no ESNs.¹ Without a dedicated ESN, parents are left as the sole link between the health service and the educational system, yet they may lack the necessary skills and information to fulfil such a role.

The issue of accountability is also important. NICE guidelines recommend that only children who have had a previous episode of prolonged convulsive seizures should be prescribed rescue medication. The implication of this 'responsible prescribing' is that schools are only asked to invest in training to administer rescue medication when they have a pupil who is known to be at risk.

THE WAY FORWARD

Children requiring emergency treatment for prolonged convulsive seizures during school hours test the goals of integrated, person-centred care as well as joined-up working to which the National Health Service (NHS) aspires. Whether a child receives rescue medication at school currently depends mostly on the goodwill and resources available at each school. Consequently, some children are effectively denied their basic legal right to mainstream education, a clearly unacceptable situation.

This situation is not unique to the UK²⁵ and some possible ways forward are suggested in box 2. They include: greater use of training resources for schools available from epilepsy voluntary sector organisations; consistent, practical information to schools; transparent guidance outlining a clear care pathway from the hospital to the school; and implementation and adherence to each child's individual healthcare plan.

Of course, the recommendations outlined above are not only relevant to children with epilepsy. Lack of support from schools is thought to be the main reason why diabetes specialists refrain from prescribing certain forms of insulin to children in the UK.²⁶ And across Europe, organisations representing the interests of children with asthma, diabetes, epilepsy and anaphylaxis have joined forces to campaign for greater recognition of the medical needs of children with these conditions in schools (eg, <http://www.medicalconditionsatschool.org.uk>).

It is important to recognise that inadequacies in the current system are due to lack of resources and unclear guidance as opposed to lack of good will or professionalism on the part of schools and healthcare professionals. There are many promising

Box 2 Areas for improvement in the management of children with prolonged seizures in schools

- ▶ Treating specialists should work with voluntary sector organisations to provide *clear and practical information* to schools on prolonged convulsive seizures and rescue medication.
- ▶ Every child with a history of prolonged convulsive seizures should have an *individual healthcare plan* put in place at his or her school.
- ▶ A *clear link* should be established, ideally via an epilepsy specialist nurse, between the treating physician and the school for each child who requires rescue medication.
- ▶ All caregivers responsible for a child at risk of prolonged convulsive seizures should receive *specific training* on their rescue medication.
- ▶ *Comprehensive guidance that spans across the health and educational sector* is needed to ensure that children at risk of prolonged convulsive seizures are treated as quickly as possible regardless of where the seizure occurs.
- ▶ *More empirical data* are needed to gain a better understanding of the experience of children who experience prolonged convulsive seizures at school, including the perspective of teachers. The role played by emergency services also needs to be clarified.

Adapted from Wait *et al.*²⁵

examples of primary care trusts working together with local educational authorities to find workable and sustainable solutions. As changes to the NHS come into play and local services become reconfigured, every effort should be made to maintain such collaborations. And more needs to be done generally to plan good epilepsy services at the local level, a point made evident in the 2013 Epilepsy Action survey and raised subsequently in the House of Commons.²

Limited resources will be an ongoing issue. Yet somehow, we need to ensure that the needs of children at risk of prolonged convulsive seizures are met in a similar manner regardless of where they go to school. As was expressed by a group of parents of children with diabetes: ‘Every child matters—or do they?’²⁷ For the sake of all children who require medical assistance at school, this is not a question we wish to be asking ourselves in years to come.

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participated in developing the study methodology and interpretation of findings. A first draft of this manuscript was written by SW and was reviewed by all other coauthors. HC is the guarantor of the paper.

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