

Health, education, policy and advocacy: Together we can improve the health and well-being of children in the school setting

The modern management of diabetes in children and young people involves the intensification of insulin therapy. In practice, this means that complex insulin regimens, calculating insulin:carbohydrate ratios, carbohydrate counting and correction doses, are here to stay. Our challenge is how we can ensure that this complex care can be delivered safely and effectively in all environments, including the times when children and young people are in schools. Against the backdrop of focused HbA_{1c} targets, set to help reduce the risk of developing chronic complications, we know that diabetes adversely affects a child's ability to learn because of fluctuating blood glucose levels that influence feelings of well-being and the ability to concentrate (Griffin and Christie, 2012). Recognition of the additional needs of a child with diabetes is essential and support needs to have an integrated approach from both health and education bodies. The Government, schools and responsible organisations must recognise not just the legal issues, but the moral and ethical obligation to provide a safe and healthy environment for children with type 1 diabetes.

The *National Paediatric Diabetes Service Improvement Delivery Plan 2013–2018* (NHS Diabetes, 2013) clearly identifies the need to provide safe and effective care in the school setting. The appropriate management for intensive insulin therapy, training of school staff and volunteers, and the need for an "Individual Health Care Plan" for each child or young person with diabetes needs to be embedded in the education system. In 2007, a group of national organisations produced a *Medical Conditions at School Guidance Document* (The Medical Conditions at School Website Project, 2007) that brought together current legislation and provided a framework for improving care in schools. Building on these guidelines over the past years, many successful collaborations between paediatric

diabetes units and Local Education Authorities (LEAs) have resulted in "School Intervention Programmes" that have successfully improved care and ensured that all legal obligations are met. Many authors describe the process undertaken to develop an integrated, collaborative approach between health and education not only as a way to optimise glycaemic control but also a way to maximise the well-being of the child and family (Hill et al, 2008; Mangle and Cuttell, 2008; Rani and Edge, 2013). A risk assessment allows the LEAs to provide indemnity to their voluntary school staff to give injections and carry out blood tests after training and competency sign-off by a Paediatric Diabetes Specialist Nurse (PDSN). Then parents, volunteers and PDSNs jointly agree a comprehensive "Individualised Care Plan" and utilise a hand-held communication record book. These programmes, like many others around the country, have succeeded in allowing the safe delivery of intensive insulin regimens in the school setting at the same time as reassuring parents that their child's diabetes is being optimally managed to improve their glycaemic control.

Currently, while the Government does recommend that there are policies in place for the management of pupils' medicines and their medical needs (Department for Education [DE] and Department of Health [DH], 2005), schools still have no legal duty to provide assistance. Many health support organisations believe that there should be clear legislation ensuring that children with long-term chronic conditions, including type 1 diabetes, are provided with proper care and appropriate support at school. Funding for extra support for these children in schools has always been a challenge, especially when the lines of responsibility between the schools and LEAs are unclear, despite the Special Education Needs: Code of Practice 2002 (DE, 2002) acknowledging a relationship between a child's medical status and



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educational needs.

Diabetes UK, in its advocacy role and as Chair of the Health Conditions in Schools Alliance, has lobbied successfully to ensure that the Government includes a duty of care for schools in the new *Children and Families Bill* (DE, 2013). The guidance will be statutory for governing bodies of maintained schools, pupil referral units, academies and free schools and, for the most part, it will include the duties that make a real difference for children in schools. The impact of the bill will provide a catalyst for all schools to ensure that they comply with the guidance and this has the potential to put greater demands on local paediatric diabetes units to provide more support, training and assistance to all schools. The Department of Education will issue draft guidance for consultation in January 2014, with publication in April 2014 in time for implementation in September 2014.

Diabetes UK continues to highlight care and policy for schools through the third and next phase of their children’s campaign set to launch in 2014, with a focus on ensuring all children receive the individualised care they deserve and, consequently, the same educational opportunities as other children. The focus of the campaign will be to raise awareness, and provide resources and interventions to improve care, whilst continuing to ensure that the statutory guidance (policy) is fit for purpose.

Parents also play a major role in advocacy. Parent-led groups, such as the UK Children with Diabetes Advocacy Group (UK Children with Diabetes Advocacy Group, 2008) and Families with Diabetes National Network, campaign tirelessly to bring families of children with diabetes together and tackle common issues; schools have always been a very topical subject. These parent-led groups have a vision to ensure the best possible educational and healthcare provisions for children and young people with diabetes throughout the UK, and work with different charities, organisations and the National Paediatric Diabetes Network to assist them in achieving these aspirations.

The National Paediatric Diabetes Network will have an important role in ensuring that schools are supported in their duty of care, and work is currently underway in partnership with Diabetes UK, the Children with Diabetes Advocacy Group, and the Families with Diabetes National Network to ensure that this happens in a coordinated way across the country. Further

work is ongoing to produce standard documents and resources for use across all the networks. The East of England Paediatric Diabetes Network recognised the importance of working together with a common protocol to enhance care in schools. A multiprofessional working group from the network, including PDSNs, paediatric consultants, teachers, health visitors, school nurses, LEA representatives and parents, worked together to document best practices in schools and produce an accessible protocol to be used in all educational settings. The document contains the building blocks of information communicated in a clear and accessible manner for teaching staff to start their learning journey about type 1 diabetes. This protocol was also presented as evidence in the debate to the All-Party Parliamentary Group on Diabetes at the House of Commons in June 2013, and contributed to the Department of Education consultation process on their guidance about managing long-term conditions in schools. The “East of England document” will now be used throughout the National Paediatric Diabetes Network along with the “Individual Health Care Plan for a Child or Young Person with Diabetes” designed by the North West Paediatric Diabetes Network.

It is only through working together across many domains that we will succeed in providing a safe environment for our children whilst maintaining optimum diabetes control and wellbeing of the child and all the family. ■

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