

# A new approach to managing type 1 diabetes in school

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## Article points

1. School staff can play a key role in helping children to achieve glycaemic targets.
2. Raising awareness regarding the seriousness of diabetes and the need to respond by intensifying insulin management requires a collaborative multi-agency approach.
3. The Leeds Children's Diabetes Team developed guidance to achieve a tripartite agreement between parents, education staff and healthcare professionals.

## Key words

- Children
- Insulin regimens
- School

Author details are given at the end of the article.

Diabetes care in the UK is evolving; multiple daily injection regimens are increasingly being recommended for children of all ages (NICE, 2004). With education forming an essential part of a child's life, appropriate diabetes care in the school setting is crucial for the child's immediate safety, long-term wellbeing and optimum academic performance.

The incidence of type 1 diabetes is increasing, especially in children under 5 years of age (Gardner et al, 1997). Consequently, there are increasing numbers of children in schools and early years settings with complex health needs to be met.

Approximately 1 in 550 school age children have type 1 diabetes; 85 % of whom are not achieving the recommended HbA<sub>1c</sub> target of 7.5 % or less (The Healthcare Commission, 2006). As children typically spend a third of their day in school or day care, it must be recognised that staff at these institutions can play a key role in helping children to achieve target glycaemic control.

The role of the healthcare professional should involve providing the necessary education and training to school staff in order for them to support children with diabetes in school and enable them to manage their diabetes effectively. Key success factors involve

an ethos of inclusion; a strong collaborative relationship between school staff, the child and their family; and expertise from the healthcare professional (HM Government, 2004).

The DCCT outcomes have led to a drive towards more intensive treatment regimens in order to minimise the risk of long-term complications (DCCT Research Group, 1993). NICE recommends that multiple daily injection (MDI) regimens and continuous subcutaneous insulin infusion (CSII) should be offered as part of an intensive package of care for those over 11 years of age (NICE, 2004). These newer treatment regimens provide more flexibility and freedom and can improve glycaemic control, but require a greater level of education, support and involvement from those who care for the child (Hanas, 2004). The use of flexible insulin regimens is well established in Leeds

**Page points**

1. Since 2003, the full range of insulin management options, including MDIs of two or three injections per day or a basal–bolus regimen, have been offered at diagnosis to children of all ages with type 1 diabetes.
2. Parents and guardians regularly reported less variation in blood glucose results during weekends and holidays. A basal–bolus regimen was their preferred treatment option for their child.
3. Schools and Local Education Authorities (LEAs) have an obligation not to treat children with diabetes less favourably, without justification, than their peers without diabetes.

for children of all ages and therefore this has required the Leeds Children's Diabetes Team to address and solve barriers to treatment within schools (Robson and Gelder, 2006).

**The Leeds Children's Diabetes Services**

Since 2003, the full range of insulin management options, including MDI of two or three injections per day or a basal–bolus regimen, have been offered at diagnosis to children (up to the age of 16 years) with type 1 diabetes or their parents. Help is provided for parents and guardians to make informed decisions regarding selecting the best management plan for their child. Of those families who chose to use a basal–bolus regimen, a small proportion of the parents already worked within their child's school or were able to attend school at lunchtime to administer the lunchtime meal injection. Additionally, a proportion of the young people aged 9–16 years were able to administer their own injections with supervision, if required, by school staff. Children whose parents were unable to attend school and were unable to administer their own injections used a premixed insulin at breakfast on school days and reverted to a basal–bolus regimen during weekends and school holidays. Older children (those over 11 years of age) with established type 1 diabetes who were already self-managing independently were encouraged to inject at school when converted from a twice-daily to a basal–bolus regimen.

These approaches worked well in some cases, while in others they were accepted as a compromise. Parents and guardians regularly reported less variation in blood glucose results during weekends and holidays. A basal–bolus regimen was their preferred treatment option for their child. This prompted two questions:

- Are schools, rather than parents, dictating the treatment choice?
- Who is responsible for diabetes care in school?

School staff are under a common duty-of-care law to act in the same manner as a responsible parent to ensure children with diabetes are healthy and safe. This extends

to administering medicine as well as taking action in an emergency (DfES and DoH, 2005). Supervision of diet and exercise, plus the recognition and treatment of hypoglycaemia, are clearly covered under the duty-of-care law and have been carried out in schools for many years. How this refers to the issues of blood glucose monitoring and insulin administration is less clear.

Schools and Local Education Authorities (LEAs) have an obligation not to treat children with diabetes less favourably, without justification, than their peers without diabetes. To this end, schools may no longer have a blanket policy of 'this school does not administer medicines of any sort; parents must attend school to supervise such events'. Schools must also make reasonable adjustments to ensure that children with diabetes are not put at a substantial disadvantage; this might include providing training for staff or developing new guidance for staff (HM Government, 2001).

**Bringing about change**

The status quo of diabetes care in schools in Leeds was challenged in 2006 by the parent of a recently diagnosed 6-year-old boy. The child's mother worked full time and was willing to attend school to administer insulin injections in the short term, but was not satisfied with this as a sustainable long-term option. The child had tried mixed insulin on school days which had resulted in unacceptable swings to both hypoglycaemia and hyperglycaemia: this variation was not present at weekends when using a basal–bolus regimen. The mother approached one of the Children's Diabetes Nurse Specialists (CDNSs) to facilitate the implementation of a basal–bolus regimen on school days. Together, they initiated discussions with school staff about taking on the responsibility of administering necessary injections.

**Developing guidance**

In accordance with the Leeds Children's Diabetes Team philosophy (detailed in *Box 1*), the CDNS met with the parent and

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1. Discussions were held with the Trust Risk Management Team, parents, members of the Leeds Children's Diabetes Team and school staff. The result was the development of guidance in conjunction with updates in individual diabetes management plans and information available to the school.
2. Individual school staff members are named on the guidance after receiving training from, and demonstrating competence to, the Children's Diabetes Nurse Specialist.
3. The Risk Management Team advised that a fixed dose of insulin should be given to minimise errors in decision making and to enhance safety.
4. Training was implemented within the child's school with responsibility being gradually transferred from parent to school staff.

head teacher to facilitate the child's treatment within school. The head teacher wanted to include a liability statement that placed full responsibility with the Leeds Teaching Hospitals NHS Trust, but it was eventually decided that the responsibility should be shared between the trust and the school. Consequently, discussions were held with the Trust Risk Management Team, parents, members of the Leeds Children's Diabetes Team and school staff. The result was the development of guidance in conjunction with updates in individual diabetes management plans and information available to the school. This achieved a tripartite agreement between parents, education and health care.

The Trust Risk Management Team approved guidance includes a brief explanation of why more intensive management of diabetes has become necessary. There are different documents for each level of required supervision: administration of insulin by staff; supervision only; insulin pumps; and injections using pen devices. Injection technique and blood glucose testing procedures are detailed in written guidance, in accordance with the Medicines Act (HM Government, 1968). Individual school staff members are named on the guidance after receiving training

from, and demonstrating competence to, the CDNS. Competence assessment is defined in the document *Including Me: Managing complex health needs in schools and early years settings* (Carlin, 2005). The Risk Management Team recommended a summary of other responsibilities of these named staff on the same document.

Hypoglycaemia and hyperglycaemia recognition and treatment are detailed. The guidance is signed by parents, members of the Leeds Children's Diabetes Team and school staff (including the head teacher and the specifically trained staff). The Risk Management Team advised that a fixed dose of insulin should be given to minimise errors in decision making and to enhance safety. This dose is decided by the Leeds Diabetes Team and parents, based on the content of school meals or packed lunches. The dose for school dinners was decided in advance by looking at school menus. A safe fixed dose was then decided upon and communicated to the school. Any changes to this dose are made in writing, dated and signed by parents and school staff. Packed lunches may vary day to day; if a fixed dose is not used, parents put a note in the lunch box specifying the day's dose.

### Training

Training was implemented within the child's school with responsibility being transferred gradually from parent to school staff. This process has since been rolled out to over 20 other schools in Leeds. To be eligible, schools need to ensure they have sufficient numbers of support staff who are appropriately trained by a CDNS to manage diabetes medicines as part of their role (DfES and DoH, 2005). In the recent document *Making Every Young Person with Diabetes Matter* (2007), the DoH recommends that schools and early years settings should be encouraged to offer effective levels of support so that parents do not have to attend school to administer medicine. This remains a challenging process for some schools. In this case example, existing teaching and non-teaching staff volunteered

#### Box 1. The Leeds Children's Diabetes Team philosophy for children with diabetes in school.

- We recognise education is an essential part of a child's life.
- We recognise that collaborative working between the child, family, school and the diabetes team will promote the best health outcomes for the child.
- We recognise the importance of providing the best up-to-date treatment, delivered to the highest standard.
- We will strive to support schools where the child's immediate safety, long-term wellbeing and academic performance are paramount.
- We will act as the child's advocate whenever necessary.
- We acknowledge collaborative working will support the schools in their day-to-day management of diabetes with respect to insulin injections, monitoring of the condition, food, physical activity and the child's emotional wellbeing.
- We recognise the importance of anticipating pupil needs and creating an inclusive, solution-focused ethos.
- We will consider the child's age, development and individual needs in all decision making.
- Our ultimate goal is to ensure that children are facilitated to manage their diabetes according to their chosen management plan.

**Page points**

1. An information sheet has been developed for schools that highlights the knowledge and skills a staff member in school will need in order to supervise or inject a child, particularly one under 11 years old
2. National recommendation documents and resources supporting the use of more intensive insulin therapy in schools has enabled the Leeds Children's Diabetes Service to develop a philosophy and written curriculum in line with the DoH criteria for structured education.

for training. The school may apply to their LEA for funding for extra time, but it is up to the head teacher as to how this funding and time is allocated.

**Support**

The amount of support required by the child with diabetes in school has increased by this transition of care and thus the support, training and resources provided to schools must reflect this. The Leeds Children's Diabetes Team have critically analysed the impact of school diabetes management on different age groups. An information sheet has been developed for schools that highlights the knowledge and skills a staff member in school will need in order to supervise or inject a child, particularly one under 11 years old (see *Box 2*).

A timely meeting with key members of Leeds City Council Children's Services Unit enhanced the relationship with education staff affected by these new changes. The meeting was convened by Leeds City Council to discuss the government agenda laid out in *Every Child Matters: Change for Children* (HM Government, 2004) with a multi-agency audience from the health, education, leisure and voluntary sectors. This provided an opportunistic forum for the attending CDNS to announce the development of revised educational resources, request LEA backing and support further effective collaboration with all schools in Leeds.

It is clear that the child with diabetes, their parent or guardian, school staff, early years staff and the healthcare team all have individual responsibilities and must work together to improve diabetes care and support in school. The health and safety of all children and staff is of paramount importance to all schools. Having sharps and medicines in schools can provoke significant anxieties. In addition, school staff are often concerned about interpreting results and decision making and, understandably in a culture of blame, the issue of liability is raised. The Leeds Children's Diabetes Team have tried to address all of these legitimate concerns with schools, the Leeds Risk Management Team and parents. Despite progress being made, there is still a lot of work to be done in order to enable all children with diabetes to receive the support they need from the educational establishments they attend.

**The next steps**

In 2004, NICE described MDI as best treatment for children 11 years and over; a more recent DoH publication recommends that all children are facilitated to manage their diabetes according to their chosen management plan (DoH, 2007). Such national recommendation documents and resources supporting the use of more intensive insulin therapy in schools have enabled the Leeds Children's Diabetes Service to develop a philosophy and written curriculum in

**Box 2. Knowledge and skills required by a school staff member for supporting a child aged 11 years or younger. Adapted from the UK Children With Diabetes Advocacy Group (2007).**

- **Able to recognise low blood glucose.** Young children may not always recognise a low blood glucose level, particularly if they are involved in play or concentrating in class.
- **Able to treat a hypoglycaemic episode (where blood glucose <4 mmol/l).** Young people may not remember how to treat hypoglycaemia when hypoglycaemic. A child having a hypoglycaemic episode should not be sent to another location.
- **Approachable by young people and able to act as a child's advocate.** Young children may not feel confident enough or able to approach and question a person in authority.
- **Able to provide support and supervision with blood glucose testing.** Young children need reminding to wash their hands, may forget the correct procedure for testing, need assistance to clear away equipment and sharps safely as well as needing assistance to interpret the blood glucose result.
- **Able to assist in calculating the carbohydrate content of meals.** Untoward incidents will happen, such as sharing food with another child, loss of appetite or dropping an item of food on the floor, that may necessitate re-calculation.
- **Able to supervise or administer insulin via a pen or pump.**
- **Able to plan ahead.** Even if young children do know how to manage their physical activity lesson, they may forget or get distracted. See the child's healthcare plan for individualised action.

**Additional requirements to support children using insulin pump therapy**

- **Able to provide assistance with numeracy skills.** This relates particularly to the position of decimal points and the necessary action to take according to results. Even if the child does have these skills normally, they may be impaired at times of hypoglycaemia.
- **Able to recognise equipment failure and insulin pump alarms and know who to contact.**

**Page points**

1. Future developments of risk management-approved guidance for schools are anticipated in the following areas: flexible doses of insulin, ketone testing and glucagon administration.
2. Parents are concerned about potential delays in treatment while waiting for the emergency services.
3. Such significant changes to existing practice within schools require a far more collaborative multi-agency relationship between healthcare professionals, education staff and the child's family.

line with the DoH criteria for structured education (2005). The aim of the Leeds diabetes team is now to audit and work with the Type 1 Education Network to achieve quality assurance.

Future developments of risk management-approved guidance for schools are anticipated in the following areas.

**Flexible doses of insulin**

Flexible doses of insulin at mealtimes are often given by parents and children at home and may be given by parents attending school at lunchtime or by a self-managing young person. This dose is based on many factors, including meal carbohydrate content, physical activity levels and preprandial blood glucose level. In schools with staff supervision, this would mean a move away from the agreed fixed dose and an increased risk of misinterpretation or accidental overdose. Flexible dosing in schools may be achievable in the future with a decision-making algorithm, but owing to the large number of variables is likely to be difficult to achieve.

**Ketone testing**

Schools are currently able to test blood glucose levels, but contact parents and carers regarding ketone testing. To do this within school would raise the demands on the trained staff and would need to be supported by robust additional resources to assist decision making. Ultimately, ketone testing in school may help to keep in school children who may otherwise be sent home due to a high blood glucose level. In times of illness, it may enable faster recognition and treatment of a child who is developing diabetic ketoacidosis.

**Glucagon administration**

Glucagon in school remains a contentious issue. Currently, all parents and carers are encouraged to use glucagon if necessary at home. However, in school, staff are told to contact the emergency services. The Leeds Children's Diabetes Team have been considering existing practice in this area in response to recent developments regarding

insulin administration and an increasing number of requests from parents. Parents are concerned about potential delays in treatment while waiting for the emergency services; particularly the potential risk of lasting cognitive impairment after severe hypoglycaemia. This view is supported by NICE guidance (2004) that states: 'Parents, school nurses and other carers should have glucagon available to use if there's an emergency, especially if severe hypoglycaemia is quite likely. They should also be given the opportunity to learn how to give glucagon.'

This is an important area to address and is an opportunity to place the child firmly at the centre of decision making.

**Conclusion**

Recent major advances in diabetes promise a healthier future for children with diabetes. Professional views have changed in light of the NSF for diabetes and National Diabetes Audit and it is the opinion of the authors that diabetes care for children in the UK needs to improve. We have started to make improvements to diabetes care in schools to enable young people to be able to use their preferred treatment. These positive changes are supported by parents and, in the majority of cases, by school staff.

Such significant changes to existing practice within schools require a far more collaborative multi-agency relationship between healthcare professionals, education staff and the child's family. Raising awareness regarding the seriousness of diabetes through school visits and the need to respond to this by intensifying insulin management facilitated by specific skills training is fundamental to this process. The Leeds Children's Diabetes Team aims to provide this as an annual study day for local education staff with the support of the LEA. To sustain these significant changes in practice, working with school nurses will be essential. To date, this has been achieved on an individual basis, but formal annual training for larger numbers is planned.

The Disability Equality Duty has been added to the Disability Discrimination Act

(Department for Work and Pensions, 2005; Disability Rights Commission, 2006), which places a statutory duty for schools to promote equality of opportunity for disabled children and young people to eliminate discrimination. Diabetes is a named condition within the Act.

Improved diabetes management for children is a major focus for Diabetes UK this year. The UK Children With Diabetes Advocacy Group report (2007) highlights examples of schools giving excellent support, but also an equal number of schools that expect much more of children with diabetes than is appropriate for their age. It criticises how many children are unsupported within school and that many aspects of diabetes management are unacknowledged within the school setting.

An unacceptable variation in practice currently exists nationally and more needs to be done to address this. In the current absence of a national approach, the Leeds Children's Diabetes Team is responding to the needs of our local children and families. Positive comments from parents have been reported in verbal and written communications. We will continue to challenge existing practice, and move forward with all schools and early years settings within our locality, to ensure that children with diabetes are educated in a safe environment that respects future health and enables individuals to realise their full academic potential. ■

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