

# Children and young people with type 1 diabetes: Managing at school

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## Article points

1. One-third of children do not have a school diabetes care plan.
2. There is no guidance on who tests a child's blood glucose on school premises.
3. Teachers and pupils require a basic awareness of diabetes as a major health issue.

## Key words

- Children and young people
- School diabetes management
- Education

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The Department of Health states that children and young people spend a quarter of their waking lives at school and believes that health and education go 'hand-in-hand' (DoH, 2004a). The school environment, attitudes of the staff and other pupils and what children learn in the classroom all have a major influence on the development of children's knowledge and understanding of their diabetes. As well as conventional insulin injections, many children are now managing their diabetes with pump therapy. The INSulin PUMp Therapy group (INPUT) and the UK Children With Diabetes Advocacy Group (UK CWD) conducted a survey examining the diabetes management of 73 school-aged children with diabetes. This article reports the findings of this survey and provides recommendations for practice for diabetes teams.

The *Disability Discrimination Act Part 4: Code of Practice for Schools* (Disability Rights Commission, 1995), amended by the *Special Educational Needs and Disability Act* (The Stationery Office, 2001) require schools in England and Wales to promote equality and eliminate discrimination relating to disability. In secondary schools, this was effective from December 2006, while in primary schools, this comes into effect in December 2007. Despite this, some children and young people with diabetes may be educationally disadvantaged because of their condition.

Type 1 diabetes is now occurring more frequently in younger children who are often still of a pre-school age (DIAMOND project group,

2006). Williams and Pickup (2004) reported a 6.3% annual increase in the prevalence of diabetes among children under 5 years of age, compared to an overall increase of 3.4% across all age groups.

Aspey (2001) suggested there could be many educational disadvantages for students with diabetes because of generally poorer health, fluctuating blood glucose levels and possible impairment of selective cognitive functions, missing school coursework due to clinic appointments and more frequent absences for illness due to lower immunity. Lack of awareness of diabetes by teachers and pupils can also lend itself to misunderstandings. Elamin et al (2005) found that children with diabetes have

poorer hearing than their peers who do not have diabetes. This suggests that the consequences of poor glycaemic control may affect cognitive ability and examination results, which in turn may affect the choices a young person has for employment and further education.

### Aim

To examine how children with diabetes are managing their condition in the school setting using pump therapy and multiple daily injections.

### Methods and procedure

Methods and procedures have been described previously (Wilson et al, 2007). Briefly:

- A questionnaire survey was designed to generate both quantitative and qualitative responses.
- Formal ethical approval for this study was not required as it did not involve an NHS group or entail altering the child's medication or diabetes management.
- Parents were invited to participate via a survey on the UK CWD website.
- Neither the online survey nor the postal questionnaires asked for names, thus ensuring anonymity.

### Sample

The sample in this study was subject to positive selection bias for pump therapy in terms of diabetes treatment and in terms of the INPUT and UK CWD databases from which the sample was sourced. The sample comprised 44 children using pump therapy and 29 using multiple dialy injections, residing in the UK and attending different hospitals. *Table 1* shows age at diagnosis.

### Data analysis

The quantitative data was analysed by percentage frequency of responses from the parents. The qualitative comments were analysed using thematic analysis of the content of comments provided.

### Pilot study

As little previous UK-based research exists

about children with diabetes in the school setting, the questionnaire design was informed by a qualitative pilot study indicating areas of diabetes management in schools that a sample of 20 parents of children with diabetes felt should be examined. The pilot sample comprised 10 parents from the INPUT database and 10 from the UK CWD database who were contacted by telephone or email. This allowed a measure of the validity of the research tool and research method to be assessed prior to use with the main questionnaire. The 20 parents involved identified several areas of concern, see *Box 1*. They were also asked to complete the main questionnaire (see *Box 2*).

### Results

All parents in the survey had discussed their child's diabetes with the school and, in almost all cases, the child's DSN had also informed the school about issues concerning the child's diabetes.

### Clinical needs

Problems may arise at school with issues such as: blood glucose testing; injecting insulin; or giving a bolus of insulin with a pump as staff may not be trained in what to do, or may not feel that it is their job to assist the child with blood testing or injecting insulin. All 73 children in the sample take blood glucose tests during school hours. A third of these are carried out in the classroom and over a quarter are conducted 'anywhere' on school premises. All children under 5 years of age at school had their blood glucose tested by an adult, although for two of them, that adult was not a member of staff and had to come to the school to do it. For children aged 5–11 years, approximately one third were self-testing their blood glucose. This was also the case for teenagers (those aged 12–16 years).

Many parents felt unable to manage their child's diabetes once the child is at school. This highlights the difficulties for parents and DSNs in educating school staff to be aware of the child's needs.

### Pump therapy use at school

For those children using pump therapy to control

### Page points

1. A questionnaire survey, based on results from a pilot study, comprising both closed and open-ended questions was designed to generate both quantitative and qualitative responses.
2. The sample comprised 43 boys and 30 girls, residing across the UK, and attending different hospitals and schools.
3. The quantitative data was analysed by percentage frequency of responses from the parents.

**Table 1. Age at diagnosis. (n=73)**

Age	n
≤4 years	42
5–11 years	28
12–16 years	3

their diabetes in the sample, similar issues exist if the child requires help with mealtime boluses of insulin. Parents were asked if they agreed that treatment of their child's diabetes with insulin pump therapy had improved the quality of life of their child in the school setting: of the parents of children using pumps who responded, 27 agreed and 10 disagreed.

#### Social activities and school

The majority of young people with diabetes were able to take part in school trips and extra-curricular activities, although 29 had to be accompanied by a parent. This was the case for all age groups. On the issue of bullying, 19 parents stated that their child was bullied because of diabetes. Of those who disagreed, several mentioned that their child had been bullied in the past, but that this had now ceased.

#### Discussion

As diabetes is a 'hidden disability', children with the condition need to be known to the school to ensure their safety and medical needs are met during school hours. The Department for Education and Skills (DfES; 2005a) guidance, *Managing Medicines in Schools and Early Years Settings*, states that:

*'If a child's medical needs are inadequately supported this may have a significant impact on a child's experiences and the way they function in or out of school.'*

#### Box 1. Areas of concern regarding diabetes management in school, as identified by parents from the pilot study.

- Diabetes care plans for the child in school and awareness of the plan.
- The use of pump therapy in the school setting.
- Accessing a named member of staff for assistance.
- Making the school aware of the child's diabetes.
- Involvement of the child's DSN.
- Testing blood glucose at school.
- Injecting insulin at school.
- Administering insulin pump boluses at school.
- Provision for the child's diabetes at school.
- Participation in extra-curricular activities.
- Bullying because of diabetes.

As well as educational support, children with diabetes require diabetes-related support in school and, generally, the younger the child the more support needed. Twenty-two of the children in the sample did not have a school diabetes care plan and for those that did, 26 did not have a copy. The school diabetes care plan should detail what is required to manage the condition and how this care will be provided. It is often produced by the school in conjunction with help and advice from the child's DSN and parents. However, the large number of parents without a copy of the plan implies that parents are not equally involved with this decision.

Qualitative comments provided by parents of young people at secondary showed that, for those without a school care plan, less support was required from the school as the child grew older.

*'Now [she] is older she doesn't need the school nurse to inject her or test her blood as she can do this for herself.'*

*'Now she is a teenager she is very independent about her diabetes and doesn't want me or the school to make a fuss. She prefers to look after it herself.'*

This may explain why not all of the children in the sample had care plans. However, the age of the young person does not prevent hypoglycaemia, ketosis, or diabetes-related emergencies during school hours, therefore all children and young people with diabetes should have a care plan for school. It is also ironic that good control achieved in the home setting with the assistance of diabetes care teams may be undermined in the school setting, putting the child's short and long-term diabetes management at risk.

All parents had discussed their child's diabetes with the school and in almost every case, the child's DSN had also informed the school about issues concerning the child's diabetes. In the majority of instances, the school also had written information to back this up. In 50 cases, the school had provided a named member

**Box 2. Questionnaire results.**

*Closed questions*

	yes	no	NA
● Has having a pump affected your child's education/schooling situation?	27	10	29
● Does your child have a school diabetes care plan?	47	22	
● Do you have a copy of the care plan?	43	26	
● Does your child have access to a named member of staff for assistance?	50	20	
● Did you speak to the school about your child's diabetes following diagnosis?	70	0	
● Did your child's Diabetes Specialist Nurse speak to the school staff?	64	6	
● Does the school have written information about your child's diabetes?	60	10	
● Does your child need blood glucose tests during school?	73	0	
● Do school staff check your child's blood glucose reading?	20	53	
● Does your child need insulin injections during school?	29		
● Do school staff oversee your child's insulin injections?	6	23	
● If your child needs help with testing or injecting, is it available?	49		
● If using an insulin pump, does your child need help/overseeing bolusing?	11	11	
● Is your child able to participate in all school trips/outings/clubs?	59	14	
● Is your child bullied/picked on at school because of diabetes?	19	54	
● Are you satisfied with school provision to support your child's diabetes?	1	11	

*Open-ended questions*

- How has having a pump affected your child's education and schooling situation?  
*'Life freer, joins in with peers. He can be "normal" for the majority of the time, happier, confident, alert, energetic, no need to snack now. Feels "less diabetic". Self manages at school and feels more like peers and become more independent and confident/doesn't have to hide away to inject. Doesn't have to be separated from friends at lunch time.'*

*'School prefer it, easier to teach, better school performance. Staff less stressed now he does his own boluses.'*

- Who does your child's blood glucose tests during school hours?

Who tests	Age			Total
	Under 5 years	5–11 years	Over 12 years	
Child	0	25	25	50 (68.4%)
Teacher	2	5	0	7 (9.6%)
Teaching/classroom assistant	3	4	0	7 (9.6%)
Office staff	1	2	0	3 (4.1%)
Carer/mother	2	1	0	3 (4.1%)
School nurse	0	2	0	2 (2.7%)
Head teacher	0	1	0	1 (1.4%)

- Where are your child's blood glucose tests done in school?

Setting	n
Classroom	22
Anywhere	19
Medical room	15
School office	7
Locker room	1
Computer room	1
Toilets/cloakroom	3
Head's office	1
Side room	1
Own room	1
Library/reading room	2

- Where are your child's insulin injections done in school?

Setting	n
Medical room	15
School office	7
Locker room	3
Toilets/cloakroom	3
Head's office	1

- Who does your child's insulin injections during school hours?

Who injects	Under 5 years	5–11 years	Over 12 years	Total
Child	0	9	11	20 (68.9%)
Parent	1	5	0	6 (20.6%)
Teacher/classroom assistant	1	5	0	6 (20.6%)

- Do you have any comments about the school's provision to support your child's diabetes?

*'School provision? This is a joke.'*

*'The school don't seem to understand how serious diabetes can be.'*

**Page points**

1. All 73 children in the sample have blood glucose tests during school hours.
2. It is understandable that schools will have concerns about taking children with diabetes on trips but ideally, a risk assessment carried out long before the planned trip should identify any problems ahead.
3. Some parents mentioned that there was confusion at school between type 1 and 2 diabetes.

of staff for the child to go to if required. Some parents added that they had written out detailed information about how diabetes affected their child. The responses suggest that schools are receiving adequate information about children with diabetes; however, in the authors' opinion information is not enough: it must be translated into action.

Parents' responses showed inconsistencies in help available in schools for children with diabetes to carry out blood testing and insulin administration. One child was sent home for half a day each week as nobody was able to administer insulin on that half day. In view of the DfES (2005a) campaign *Every Lesson Counts* this is unacceptable. The *Every Lesson Counts* campaign aims to raise awareness of the importance of regular school attendance. It is clear that in cases such as the above example, parents understand the importance of regular school attendance, but schools must also share this concern for children and young people with diabetes.

All 73 children in the sample have blood glucose tests during school hours. A third of these are carried out in the classroom and over a quarter are conducted 'anywhere' on school premises. This raises the question of whether this is the child's choice, or merely convenient to whoever is overseeing the testing. For children needing insulin injections, insulin pump boluses, and blood glucose tests during school hours, the awareness of problems and availability of staff to assist the child appears inconsistent in different schools. There also appears to be no clear guidance for schools when children do require assistance with administering insulin or testing blood glucose away from the home setting.

The DfES (2005a) states that:

*'Older children may be on multiple injections and others may be controlled on an insulin pump. Most children can manage their own injections, but if doses are required at school supervision may be required, and also a suitable, private place to carry it out.'*

These recommendations do not suggest at what

age 'older' starts and as the age at which children are able to and willing to perform their own injections varies, support may be required by some 'older children'. It is also safe practice for children injecting or testing their blood glucose to be overseen by a responsible adult, preferably a member of the school support team. The majority of insulin injections in schools are done by children themselves, which may give them a sense of independence and self-efficacy in their diabetes care. The need for assistance can be overcome if the child has a higher basal rate for the lunch period to cover food. However, this can be dangerous as the child may not eat, or may delay eating in the presence of a larger amount of insulin than is required to keep blood glucose levels within the normal range.

Some school subjects require field trips as part of the course. Although these may be optional, anecdotal evidence suggests some children with diabetes are still being denied access to such trips, giving them less experience and learning opportunities than their peers without the condition. It is understandable that schools will have concerns about taking children with diabetes on trips, but, ideally, a risk assessment carried out long before the planned trip should identify any problems and could be discussed with the child's DSN and parents. Unless the child's school can provide valid justification for excluding the child, they are acting unlawfully in discriminating against that child (Disability Rights Commission, 1995).

Some parents mentioned that there was confusion at school between type 1 and 2 diabetes. This highlights the need for schools to educate children about health topics and perhaps invite a DSN to talk to children about the growing epidemic of diabetes. This would serve the purpose of educating the school staff and pupils.

The findings of this study have been condensed into recommendation for practice (see Box 3).

**Study limitations**

The main potential problems with the study were the two different mediums used to administer the questionnaire: email and postal.

It is possible that this may have introduced a confounding factor between the two groups in terms of response. However, response rates for the questionnaires were very similar from each group: 73.1 % for the email surveys and 63.6 % for the postal surveys, suggesting that the mode of administration was not a confounding factor.

### Conclusion

A number of issues have been raised in this study concerning the difficulties faced by parents, children and young people with diabetes in school. For the children themselves, being integrated into educational and social aspects of their learning experience is vital. This emphasises the importance for children and adolescents with diabetes to be able to achieve their full educational potential, to compete against other students on a 'level playing field', and be able to use their cognitive ability to its full potential regarding access and further education opportunities. This relies on the school's awareness of diabetes and the maintenance of good diabetes management in young people with the assistance of school staff. If children and young people with diabetes are discriminated

against, psychosocial problems may develop, which can alienate the child (Jacombs, 2007). It is therefore imperative that schools recognise the needs of children and young people with diabetes and take the opportunity to work in an alliance with the child, their parents and the DSN to provide the best possible diabetes care while the child is away from their home environment. ■

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### Box 3. Recommendations for practice.

- As DSNs offer valuable assistance in deciding the child's school diabetes care plan they should be involved in educating school staff about the child's diabetes management requirements.
- For those children without a school diabetes care plan, the authority of the DSN may enforce the need and importance of a care plan when schools are not working with parents.
- Implementation of diabetes education by DSNs for school staff to encourage correct attitudes towards children with diabetes.
- Collaborative working between the child/parents/school should emphasise the importance of regular blood glucose monitoring, including – why and when they are needed, and what the results mean in terms of the child's individual diabetes management.
- DSN involvement with schools in assessing risk of child's participation in school activities should target preventing discrimination.
- Schools should utilise the knowledge and skills of DSNs to inform and educate pupils and teachers about diabetes as a major health issue. An increase in knowledge in this area may reduce bullying and discrimination if the facts are understood.

The INPUT organisation, the UK CWD advocacy group, Diabetes UK, concerned consultants and paediatric DSNs have now set up a group to look into the area of school care for children with diabetes. If you are interested in joining them, or have experience and suggestions of 'what works', please contact: John Davis, National Co-ordinator for INPUT on 01590 677911 or at [john.davis@input.me.uk](mailto:john.davis@input.me.uk) or Jackie Jacombs at [jackie.jacombs@childrenwithdiabetes.com](mailto:jackie.jacombs@childrenwithdiabetes.com)