

Every Child Matters?

Or do they?

Children with type 1 diabetes are being let down by lack of support in school.



A report by the UK Children With Diabetes Advocacy Group, investigating the range of contemporary educational experiences of children with diabetes at school in the UK today.



A report by Jackie Jacombs and parents from UK Children With Diabetes Advocacy Group, investigating the range of educational experiences of children with diabetes in the UK. 2006/2007.

1. Introduction

- 1.1 What is diabetes
- 1.2 Hidden disabilities

2. Taking Diabetes To School

- 2.1 Starting school
- 2.2 Educational disadvantages of students with diabetes
- 2.3 Why it's important to fulfill the educational potential of a student with diabetes
- 2.4 Obtaining Funding
- 2.5 What teachers need to know
- 2.6 The legal position – Disability Discrimination Act
- 2.7 Department for Education and Skills Position – Medical Care Plan
- 2.8 Guidelines on diagnosis and management of Type 1 diabetes in children and young people
- 2.9 Choosing Health - Healthy schools

3. A Balancing Act

- 3.1 A Balancing Act
- 3.2 Why do children need more help now than they did in the past?
- 3.3 Information provided to schools is outdated and not always helpful
- 3.4 To be able to safely be able to look after themselves at school, a child needs numerous skills.
- 3.5 What happens when a child's blood glucose is not well controlled?
- 3.6 Choose health, choose life, choose to save money

5. Appendix Examples of school

- 5.1 Examples of negative experiences at school
- 5.2 Examples of positive experiences at school

Introduction

1.1 What is diabetes?

Type 1 diabetes is an autoimmune disease; it is not caused by overeating, poor lifestyle or self-induced, but by a combination of genetic and environmental triggers. The body destroys insulin producing beta cells in the pancreas. Insulin is required by the body to metabolise glucose. Without insulin the body literally starves to death. Before the discovery of insulin, people with diabetes died within a very short time, it was a distressing slow death. Type 1 diabetes is not preventable and there is nothing that a child, or their parents could have done to prevent type 1 diabetes from developing. 80 – 90% of children with diabetes have type 1 diabetes. Type 2 diabetes, a very different form of the condition, which requires totally different management. In type 2 diabetes there is usually a problem with insulin resistance and in genetically susceptible people, obesity can trigger the condition. Many things besides insulin affect the blood glucose levels, carbohydrate intake, exercise, illness, growth hormones and emotions. Stress can increase OR decrease blood glucose levels. This is one of the reasons why blood glucose levels can be unpredictable and hard to control.

A child can develop type 1 diabetes at anytime between birth and aged 18 years, but statistics are showing that more children are developing diabetes at a much younger age than previously. Diabetes is now occurring in much younger children, often preschool aged children (1). There is a 6.3% annual increase in the numbers of under 5's being diagnosed, compared to an overall increase of 3.4% in all age groups (2). The incidence of diabetes in the population shows a geographical variation, the incidence in Aberdeen being 24 children per 100,000 and in Oxford 17.8 per 100,000. Diabetes affects both males and females, with a very slight male preponderance, depending on age and season of diagnosis(3).

The National Institute for Health and Clinical Excellence (NICE 2004⁴) define type 1 diabetes thus; Type 1 diabetes happens when the cells in the pancreas that produce insulin are damaged by the body's immune system. Insulin is the main substance that co-ordinates how the body handle glucose (sugar) after it enters the blood from digested food. Without enough insulin, the amount of glucose in the blood becomes higher than normal.

There are two groups of problems that can happen as a result of type 1 diabetes. First, a sudden, severe lack of insulin can cause immediate problems, including one kind of coma. Second, having blood glucose levels that are too high for long periods can damage the blood vessels, heart, nerves, feet, kidneys and eyes.

Type 1 diabetes is managed by putting insulin into the body – this is sometimes called 'insulin replacement' because you are replacing the insulin that would normally be made in the body. There are different types of insulin, and insulin is usually given by injection or using what's known as an insulin pump.

¹ Hanas,R. 2006 Type 1 diabetes in children, adolescents and young adults

² Williams & Pickup 2004 Handbook of diabetes

³ Court & Lamb 1997 Childhood and adolescent diabetes

⁴ Type 1 diabetes in children and young people

1.2 Hidden Disabilities

Can you see who has diabetes? One twin does, the other does not. Which is which?



1.2 Hidden Disabilities

When someone is disabled, people expect them to be in a wheelchair, or have a guide dog, or hearing aids. People just don't understand that a child can be disabled without looking disabled. Here lies part of the problem. How can this happy, healthy looking child, possibly have some life threatening chronic condition? Of course, many parents who have children with diabetes, do not consider their child to be disabled, but it is partly because diabetes is not seen as a disability by many, that schools and LEAs (Local Education Authorities) do not always recognise the importance of providing good support and care. Or, when a school does realise that the needs are time consuming and sometimes complex, they are not getting the necessary support from the LEA or PCT to obtain funding for the extra care needed for those children in the nursery, infant and early junior school years.

Taking Diabetes to School

2.1 Starting School

Starting school is a emotional and exciting experience! Your child's first day at school is a big event, but for children with type 1 diabetes the first day at school is a particularly worrying time for both children, parents and teachers. When a young child starts nursery or school for the first time, most parents are naturally very anxious about whether their child will be looked after well and if they will settle in.

How much more worrying is it, if parents find that their child with diabetes is not being properly supervised or cared for, despite talking over the problems months before the child starts school or nursery. Some schools are finding it increasingly difficult to manage the care of young children who have type 1 diabetes, without having any extra support in the classroom. Some schools make it clear when parents first visit the school, before the child starts, that they are not at all happy to take on the responsibility.

Some schools have flatly refused to help with blood glucose testing, or supervision of eating snacks and meals. Blood testing is a vital part of diabetes management especially with the modern insulin regimens. Very few schools will agree to administer a lunchtime injection if needed, even though many schools will find a volunteer to agree to administer an Epi Pen for children with severe allergies. This is a single dose epinephrine auto injector device and is used to treat anaphylactic shock in someone who has a severe allergic reaction. It has become a common method used in schools. Devices used to give insulin are also pen devices, though not single dose. Most schools will not give an emergency Glucagon injection to a child that has had a severe hypo and is having a seizure or has become unconscious, despite the NICE (National Institute for Clinical Excellence) guidance which recommends training should be given. Why is this? Some children live in rural areas where it could take a long time for an ambulance to reach the school. Giving Glucagon could save a life.

Many children will have to eat snacks at times that do not fit in the school routine or have to eat snacks before PE or games. When a child has a life threatening condition, which needs careful and sometimes complex management, one would assume that schools would automatically be able to have extra help in the classroom.

After all, a teacher may well have 30 other young children in the class to look after and many educational targets to achieve. However, this extra support is often unavailable.

Many very young children and some older children have little or no hypo awareness blood tests may be needed several times a day and the teacher has to be on the lookout for signs of hypoglycaemia. If snacks are needed someone must ensure that they are eaten. They may not be optional for some injection regimens, which also may require that lunch is eaten at a specified time.

Not eating lunch or snacks on time can cause severe hypoglycaemia which, as well as being life threatening can badly effect a child's confidence.

2.2 Educational disadvantages of students with diabetes

A study on the educational disadvantages of students with diabetes (5) suggested there could be many educational disadvantages for the diabetic student because of generally poorer health, fluctuating blood sugars and possible impairment of selective cognitive functions. The lack of awareness of this medical condition can also lend itself to misunderstandings between lecturer and student.

In addition, it has been shown children with diabetes have poorer hearing than their non-diabetic peers (6), that poor glycaemic control affects cognitive ability and examination results, which in turn could affect the choices that young person has for employment and further education.

2.3 Why it's important to fulfill the educational potential of a child with diabetes

Having diabetes is a substantial current and future health risk, but having a poor education and low IQ can make this worse. A lower childhood IQ is linked to a higher early mortality risk (7), low cognitive ability in children linked to excess mortality in adult men, whereas having education and improved early adult socioeconomic conditions halved the risk of early death for men(8). Educational attainment is a very important factor in reducing

⁵ Aspey,C. 2001 The educational disadvantages of students with insulin dependent diabetes: Problem based enquiry.

⁶ Elamin,A, Fadlallah,M.& Tuevmo,T. (2005). 'Hearing loss in children with diabetes.' *Indian Pediatrics* 42 (1) 15-21.

⁷ Hart et al 2003 Childhood IQ, social class, deprivation, and their relationships with mortality and morbidity risk in later life' *Psychosomatic Medicine*. 65 (5)

⁸ Kuh,D et al 2004 Childhood cognitive ability and deaths up until middle age: a post war birth cohort study. *International Journal of Epidemiology*. 33 (2)

health inequalities⁽⁹⁾. Also, children with diabetes will grow into adults with diabetes, and there are many extra financial costs associated with having diabetes, eg buying properly fitting and well finished shoes, additional cost of car, life and holiday insurance.

2.4 Obtaining Funding.

When parents approach the LEA to apply for extra support, they are often told that the schools should meet these needs and the cost of employing someone to help with the management of the diabetes. However, some schools, then state that there is no money available for funding this extra care and will not or cannot not pay. Parents get caught in the cross fire between the schools and the LEAs, making the situation very unpleasant; this strains the relationship between the parents and school. Meanwhile the child does not receive the appropriate care and support that they require to remain safe at school and to learn properly. This is the reality for many young children with diabetes and of course this applies to children who are diagnosed when they are already pupils at the school. Older children too do not escape the realities of taking diabetes to school, which will be discussed later.

2.5 What Teachers Need to Know

Type 1 diabetes is due to an absolute loss of insulin production and therefore administration of insulin is necessary for survival. All children with type 1 diabetes are treated with insulin. Parents need to make an appointment with the school or pre-school/nursery, well in advance of the child starting. The school will need to know about hypoglycaemia, the importance of the timing of snacks and meals, the effect of exercise on blood glucose levels, blood glucose monitoring and any insulin injections, which may be needed during the school day. Some children may use an insulin pump and will need help or supervision with this. Usually the child's parents and Diabetes Specialist Nurse (DSN) will come to the school to provide the education and training needed. The parent needs to be there, as every child is treated differently according to their needs. A school may find that they need to make arrangements for extra help in the classroom to ensure all the necessary things are done. Application to the local authorities needs to be done early in the year. However, this doesn't mean that any extra support will be easy to obtain, LEAs frequently say it's not their problem. These days, most school nurses do not work at just one school; they are often responsible for up to six schools and are not based at one particular school. The school nurse is rarely able to take part in any day-to-day management of a child with diabetes. Though they should be aware of the children with diabetes in their schools. It is the day-to-day management that takes up the time.

2.6 The legal position – Disability Discrimination Act

The Disability Discrimination Act 1995, amended by the Special Educational Needs and Disability Act 2001 states disabled pupils may not be *substantially*

⁹ Lawlor, D.A et al 2006 Association of childhood socio-economic position with cause- specific mortality in a prospective linkage study of 1,839,384 individuals' *American Journal of Epidemiology*. 164 (9)

disadvantaged “in relation to education and associated services...” but it does not require the school to “provide auxiliary aids or services” which may include extra staff.

Enforcement of the Act in schools is via a SENDIST tribunal, and will not necessarily put a child with diabetes in the same position as a non-diabetic peer. There are a list of remedies available if you win your tribunal, but the reality of life with a young family and caring for a child with diabetes, is that it is not very practical to be able to take time and stress to apply for and follow through a tribunal hearing, especially if the remedy will not rectify the problem.

2.7 Department for Education and Skills Position – Managing medicines in schools and early years settings - Medical Care Plan

Managing Medicines in School and Early Years Setting 2005. Some of the wording in this document is contradictory!

Para 16 “There is no legal duty that requires school or setting staff to administer medicines” (Is insulin a medicine? It isn’t really; it’s a replacement hormone). Then there is a section on administering medicines (42-44)

Section 87 “All staff should be aware of the likelihood of an emergency arising and what action to take if one occurs”.

A severe hypo is an emergency.

(section 89 and 90) advises “schools should ensure that they have sufficient members of support staff who are employed and appropriately trained to manage medicines as part of their duties.

Any member of staff who agrees to accept responsibility for administering prescribed medicines to a child should have appropriate training and guidance. They should also be aware of possible side effects of the medicines and what to do if they occur. The type of training necessary will depend on the individual case.”

The guidance also details the Health Care Plan children should have at school.⁽¹⁰⁾

2.8 Department of Health Position – NICE Guidelines on diagnosis and management of Type 1 diabetes in children and young people

“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.” (11P41)

This has been highlighted as it is very important to some children and their parents. Some schools comply with this, and are examples of good practice.

¹⁰ Department of Health/Department for education and skills 2005 Managing Medicines in schools and early years settings.

¹¹ NICE 2004 Guidelines on diagnosis and management of Type 1 diabetes in children and young people

Some do not, and this can be very worrying for the family. It is an important issue that needs addressing where relevant.

2.9 Choosing Health (2004) – Healthy schools – health and education going hand-in-hand (p55) Children spend an average of a quarter of their waking lives in school. The school environment, attitudes of the staff and other pupils, as well as what children learn, in the classroom, have a major influence on the development of their knowledge and understanding of health.

A Balancing Act

3.1 A Balancing Act

Type 1 diabetes can present two faces. On one hand we want our children to fit in and be able to do the same things as their peers. We tell them that diabetes should not stop them doing anything that they want. However, to be able to do the same things as their peers they need to take extra care and require support to do so. The youngest of the children will need a lot more support than children who are 9 or 10 years old. Though of course, the needs are very individual and older children still need support, and teachers always need to be aware that hypos can occur at any time without children recognising them. Older children sometimes need reminding about drinks or food to treat hypos.

Currently there is no consistency with help available in schools

Some schools do manage to give excellent support and are happy or able to provide support and help and work as a team with parents. Some examples are given at the end of this document. Many schools try to get out of having to provide any extra help in the classroom and are sometimes expecting children as young as four and five years old, who cannot yet even read and write, to take responsibility for totally managing their condition at school.

A school's duty is to provide education in a safe non-restrictive environment for children with diabetes. How can a school successfully educate our children, if it cannot provide a setting that is conducive to learning?

3.2 Why do children with diabetes need more help now than they did in the past?

In the last 20 years there has been a significant increase in the numbers of very young children diagnosed with type 1 diabetes. At present the cause of the increase is unknown. **This steep rise in the number of under fives diagnosed with diabetes, means that there are now many young children starting infant school or nursery departments who have quite complex needs to be met.** At the present time, 80% of children with diabetes are failing to maintain adequate glycaemic control and are not

achieving the recommended HbA1c target under 7.5%. Achieving good control can be a difficult and complex business, but here I am concentrating on the roles that schools can play in helping to achieve the goal of good control and most important a good quality of life right now. If not properly controlled, diabetes leads to a significantly reduced lifespan and a high risk of complications involving the kidneys, eyes, heart and the circulatory system. The effects of poor control can be clearly measured in young people in their early 20's. Diabetes is the single largest cause of blindness in UK. **Complications cost the NHS a huge amount of money in the long term. In the short term, poor provision of care in schools can lead to frequent hypoglycaemia or hyperglycaemia, which effects a child's ability to learn properly, unhappy children who are not fulfilling their potential and stressed parents and teachers.**

Children need more support with diabetes management now than in the past.

The current problems with schools, has much to do with the fact that the type of care and the insulin regimens currently used by many clinics, are quite different to the single, or twice-daily injection regimens commonly used in the last 20 years. With the advent of newer insulin preparations, insulin pumps and the small blood glucose monitors, it is possible to improve blood glucose control and achieve the goals and allow for blood sugar levels to be as close to the normal range as possible. This is the main goal of all insulin therapy. These newer, flexible insulin regimens require more education and a higher level of carer/parent/patient involvement. **This often means that the children and teachers need more help in the classroom.**

Although the newer regimens mean fewer short-term problems and much better long-term health prospects, it also means a more blood glucose tests and more insulin injections. Children using multiple daily injections or using insulin pump therapy are most likely to need an injection at lunchtime or insulin given via the pump and possibly at snack time and at times when the blood sugar level is elevated. Some children will require supervision for this. Some younger children will need the insulin administered by someone who is trained.

Schools worry about coming into contact with blood, doing finger prick tests, interpreting them and giving injections or even supervising them. They worry about whether they have made the right decisions. Some schools are telling parents that the school cannot do any of these things and cannot take liability. Teacher or staff who volunteer would be given training by the parents and the DSN. Usually the parents remain in close contact so the school can telephone at anytime with any problems.

Liability

Teachers or school staff may worry about the liability should something goes wrong, but the issue of liability is set out. If a teacher, head teacher or other member of staff carries out the treatment, using the agreed procedures and care plans and have received regular training, then they will be covered by the local authority insurance and cannot be held liable for accidents.

Employers, either the LEA or the governing body has a legal duty to provide a health and safety policy in writing with procedures for the management and administration of medication. If these are followed, then the teacher or school

support worker will not be liable if something goes wrong and a member of the school staff has acted in good faith.

New regimens

These newer regimens are more complex and require decisions to be made based on current blood glucose values, consideration of the food intake and whether or not exercise is planned. There are other factors, which also influence the blood glucose levels, such as illness and hormone levels, as a result there is always a slight variation in the insulin needs each day. Most parents, along with their diabetes team and school will have written up a care plan. It is not practical to be able to include every situation that will arise, so the parents usually remain in close contact with the school. However some schools still struggle to cope with dealing with very young children with diabetes. There are disagreements with the school about the care that children need and what the school can offer. Even when a child is not requiring insulin injections to be taken at school, the care is sometimes woefully short of that needed. Sometimes the child's DSN has not helped the situation by leading the schools to think that diabetes care is too simple and requires no more than looking at a child to see if they are ok and saying that most children can recognise a hypo and will be able to treat it themselves. There are of course many very dedicated DSN's who are able to help the teachers to understand what is needed. Many of the youngest children with diabetes require extra help above and beyond that which a school would have normally have been expected to do in the past with the older insulin regimens. Many parents are finding accessing this extra help impossible. It appears to some parents, that some local authorities seem to deliberately refuse children an assessment and provision of help, to which the children are legally entitled, knowing that only few parents will take them to a tribunal. This applies to children with other disabilities besides diabetes! The parents and the school are often placed in an extremely uncomfortable position as the struggle goes on with the LEA. Parents, who are worn down from dealing with their child's condition and the lack of support from the schools, sometimes give up. Some parents have removed their child from school altogether because of the safety issues and these weren't always very young children.

Few chronic conditions require as much vigilance as diabetes

3.3 Information provided to schools is outdated and not always helpful

Schools are still being given outdated information and consequently, schools are expecting too much from very young children. Currently, Diabetes UK's advice to schools only seems relevant to children using the older insulin regimens and not for very young children using modern insulin regimens or insulin pumps, who are unable to do any of the diabetes care themselves. Little information is given in the leaflet Children with Diabetes at School about going to see the school months before the child even starts school, to make sure that there are provisions in place to give the necessary support. There is no mention of being trained to give life saving glucagon in the event of a severe hypo or unconsciousness or of the school administering insulin or helping with blood tests if a child is too young carry out these things on their own. There is no mention of older children who may also have poor hypo

awareness. Information about school trips is not helpful, as days out of school are likely to be very different to a day spent at the desk. Days out of school are more likely to be very active and the attention needed will be more than the usual attention required for in a day in the classroom. Insulin needs will almost certainly be different. There is no advice about what to do if a school refuses to help with injections and blood tests when a child cannot do these alone.

In the guidance “Managing Medicines in School and Early Years Setting” (section 89 and 90) it advises that “schools should ensure that they have sufficient members of support staff who are employed and appropriately trained to manage medicines as part of their duties” Although no member of staff can be forced to administer insulin or glucagon, in some schools where good care prevails, teachers or classroom aides do volunteer to carry these duties out. One solution is to employ a member of staff whose job description includes responsibility for managing medicines and administration of insulin or glucagon if needed. The LEA or diabetes specialist team can arrange training.

Effective diabetes management is crucial

- **For the immediate safety of children with diabetes**
- **For long term health of children with diabetes**
- **To ensure that children with diabetes are able to learn and fully participate in school activities and to minimise the possibilities that diabetes related emergencies will disrupt education.**

3.4 To be able to safely be able to look after themselves at school, a child needs numerous skills. Few very young children will have all of these skills. Young children need a classroom aide.

Recognition. They need to have recognition of how their own body feels; they need to be able to know when they are feeling low or high. This can depend on the activity level i.e. sometimes it's harder to notice if you have low blood sugar when you are running about playing outside or taking part in P.E, swimming, or when blood glucose level is falling gradually.

Advocacy. Are the children willing and able to tell others, especially teachers when something is necessary (e.g., testing, feeling low, feeling sick, snack time etc.) Does the child recognize a problem, or are they too shy to speak up?

Blood glucose testing – Is the child able to wash their hands properly and dry them thoroughly, can they put a test strip into a meter and code it if necessary, can they use the lancet device, obtain the necessary drop of blood and put it in the right place. Too little blood may result in an error. A contaminated blood sample may result in an erroneous reading. Can the child clean up, place the equipment away and put all the blood related items safely

in a sharps bin? Do they know to do if their blood glucose level is too high or low?

Numeracy, Can a child read numbers and interpret them correctly?

Does the child have basic diabetes knowledge - knowing what a low number means (e.g. needs fast acting sugar) and what a high number means (e.g., needs more insulin) Understanding the necessity to test for ketones and when. Especially important for pump users! Does the child know how much fast acting carbohydrate is needed?

Simple maths - Is the child capable of calculating and doing subtraction to determine what to eat? (e.g., 4 crackers = 30 carbs, but one fell on the floor)!! Doesn't want to eat all of the food provided in the lunch box!! Or is too full to eat more. If a child is on a fixed regimen does s/he understand the importance of eating all or most of the meal or snack provided?

Insulin Delivery - being able to dial up an insulin pen without any mistakes. Many children are not ready for the responsibility of measuring insulin nor do they understand the consequences of an error. This may also involve operating an insulin pump and having to problem solve on-line (e.g., bolus should be 5.3 units, insulin pump delivers "bolus stopped" message - therefore having to go into the pump bolus memory to determine how much was delivered and how much of the balance needs to be bolused for again). Again, if they can't remember whether they have bolused or not, they need to access the pump memory.

Administering the insulin - A child may need help with this. A young child will need someone to check the amount dialed, up or drawn up in a syringe (though insulin pen devices are frequently used these days) Again many children are not ready for the responsibility of doing their own injections. Also insulin pens are big and difficult to hold and use for small children.

Checking Pump Alarms -A pump alarm will need attention, someone needs to be able to read a pump alarm, "No delivery" or "battery low" warnings etc. Can a child change their own pump battery, or decide if they have enough insulin left when a low reservoir warning shows up. Do they know what all the alarms mean and can they act on them?

Thinking Ahead - understanding that if exercise is due, PE, games etc, that the basal rate on the pump may need changing, or the pump may need detaching. If on an injection regimen, or pump, an extra snack may be require to prevent hypos.

Can a young child remember to do all of the above, in a timely fashion, without forgetting or getting distracted by everyday children's thoughts?

Can a teacher be expected to do all of the above without extra help and support in the classroom? Some classes may have 30 children. Even with a classroom assistant, a young child with diabetes may need one to one support for at least part of the school day.

Children and young people with diabetes are proportionately at greater risk during their lives because their bodies have to cope with the condition longer.

If teachers or support staff do not volunteer to do blood tests and or injections and the LEA or the school will not pay for the support needed, does this mean that parents will have to give up their jobs to ensure that their child receives the treatment as prescribed by their consultants? Many parents are torn, worrying whether they should give up their jobs or continue to worry all the time about whether their child's health and education is suffering. Many parents have been unable to return to paid employment because they have to be available to go into schools to do blood tests and injections when a school refuses to help with these matters.

Young children with diabetes need more support in the classroom in those very early years, but this is not happening. Without the extra help, care plans for younger children are going to be very difficult to work. Teachers already have many educational targets to reach. The quality of life for a young child with diabetes is going to be badly effected if schools are not given extra support to care for the youngest of the children going into education.

A parent of a five year old said:

"None of these things is terribly complicated or difficult, but they do come on top of all the usual responsibilities of teaching and caring for small children. Taking care of a young diabetic child takes more one-on-one time than taking care of a similar child without diabetes, and schools should take this into account when planning class sizes and assigning classroom and lunchroom aides." Rachel.

Currently there is no consistency.

Some schools cope really well by having extra help at certain times of the day from midmorning to after the lunch period for instance. This person ensures that if blood tests are required that the child's hands are washed and that the results of any blood glucose tests are interpreted and acted upon. The results of the blood tests and any treatment given needs to be logged. They will ensure that all essential snacks and meals are eaten. They may also give or supervise any insulin injections or bolusing an insulin pump. Sometimes a school pays an extra weekly amount to one of the staff that already works at the school to undertake these extra duties. This member or members of staff who carries out these duties will usually know about any extra activities that need taking into account.

There is some evidence that some diabetes clinics are worried about changing a child's insulin regimen to a more suitable one when a twice a day insulin regimen is failing, because of the problems of finding someone to administer insulin injections in school. If this is the case it means that a child's diabetes treatment is being dictated by the needs of the school and not the clinical needs of the child.

Changes in the level of care needed

Diabetes care has changed significantly in the past 10 years. At one time, children with diabetes were sent to school with only lows to worry about. Frequently, the blood sugar levels were left to run high to prevent hypos at school. It has now been shown beyond doubt that high blood glucose levels are the main cause of diabetic complications. There were no small portable blood glucose monitors to check what was happening. Now we have small blood glucose monitors, multiple daily injections and insulin pumps. We have more technology, more knowledge of good diabetes management. Sadly this does not mean that the school system or the general public is any more aware than they were 15 years ago.

3.5 What happens when a child's BG is not controlled?

We now know much more about diabetes than we did in previous years. We know that in the short-term hyperglycaemia (high blood glucose levels and not enough insulin) can cause a child to have blurred vision and be unable to concentrate on their schoolwork or any other tasks at hand. Research has shown us that hypoglycaemia (low blood glucose level caused by too much insulin in the body) leaves a child weak and disoriented. When the blood sugar is out of the normal range children can feel unwell and be unable to learn properly. This affects their ongoing education. If staff members are not properly educated to be aware of these conditions, problems can escalate and, in the case of hypoglycaemia, the child can have a seizure with the most serious consequences. There also needs to be enough staff to give the support.

By the time some of the youngest children are 25 they will have had type 1 diabetes for over 20 years. If the control has been poor over these years at school, by this time these children could already be experiencing complications due to poor control. Any steps taken now will help to reduce the possibility of complications developing and diminish the effects of any that do. Treating complications is a potentially expensive business. Effective treatment now and support in schools will not only improve the quality of life now and in the future but is also likely to save the NHS money in the long run.

3.6 Choose health, choose life, choose to save money!

Children have been muddling through, with mediocre or poor support in school for umpteen years; we need to address these issues now so that children with diabetes have a better quality of life now and a future with less risk of complications. **Complications cost the NHS a vast amount of money; anything done now to improve control will save money later.**

A school's duty is to provide education in a safe non-restrictive environment for children with diabetes. How can a school

successfully educate our children, if it cannot provide a setting that is conducive to learning?

In “Choosing health” (2004 p55) the government stated “Children spend on average a quarter of their waking lives in school. The school environment, attitudes of staff and other pupils, as well as what children learn in the class room, have a major influence on the development of their knowledge and understanding of health.”

Diabetes must be managed 24 hours a day seven days a week. We cannot ignore it during school hours just because it is inconvenient.

A Series of Unfortunate Events

4.1 Examples of negative experiences at school

◆ Sasha was 4 years old and the head teacher would not allow staff to help with blood glucose testing at school. Sasha could not tell the difference between high or low blood sugar. This refusal to help with blood tests meant that whenever Sasha felt unwell, the school treated this as hypoglycaemia and gave sugary drinks or biscuits, this meant that on very many days Sasha would spend much of the day with extremely high blood glucose levels frequently as high as 16-20 mmols.

◆ The school that Tim was supposed to be going to (after attending the linked pre-school) refused to do any care for him at all. The absolute most that they would do, they said, was to call an ambulance if he was unconscious. We decided to change school. We are very happy with the new school.

◆ Our daughter wears an insulin pump that she was prescribed in the USA. The school is willing to administer glucose and handle her insulin pump, if appropriate training is provided for them. But the NHS nurse is unwilling to permit them to do so: and she will only permit the staff to do testing "if the child is feeling hypoglycemic", and not as part of a regular program of testing and providing a bolus (insulin given via the pump). The nurse is not willing to authorize it as part of a daily regime without a parent present. This presents a problem: our whole reason for being in England is for my wife to attend graduate school, and I need to work to pay for that graduate school. The school has been lovely about it, now I have to negotiate things with this nurse.

◆ Nasseem's teachers and head teachers ignored, or seemed disinterested in our warnings about the seriousness of hypos and the importance of eating snacks on time and testing the blood sugar. Then another young child with diabetes started at the school and shortly afterward had a severe hypo and seizure. The staff were shocked by this event and later kept telling us that they didn't really understand the seriousness of the condition before. It is

unfortunate that it took a serious incident like this before they took notice. Also, our DSN didn't agree with blood testing at school. The school were confused by the different advice. After the incident with the other child, the school were willing to do any blood tests needed. Jill

◆ I spoke to Rose's teacher as she starts school soon in January, she wants Rose really to be able to do all her blood glucose tests herself. I did explain that it maybe possible, but when she is low she gets very shaky and so will not be able to. She suggested I talk to the parent of the other boy in reception with type 1 to see how she got her son to self-test. I pointed out that he was diagnosed nearly 3 and half years ago and Rose only since Jan. We're having another meeting soon to discuss her care plan etc. Even if Rose could do her own tests most of the times, there will be times when she may be unable to do them. Also she cannot read and write yet and would be unable to interpret the results and act on them safely. I feel that at 4 years old this is far too much responsibility. B

◆ Edward uses an insulin pump and he is not capable of doing any of his own diabetes care. Needless to say, this was quite an issue when he started nursery school last January. The headmistress and staff at our local school (where Edward's brothers attend) were, understandably, shocked and scared to hear about the level of care required to help and protect a very young child using an insulin pump at school. **There was a flat refusal to take on any of the responsibility whatsoever** and so we approached the local Parent Partnership Association who liaises between parents and schools where disabilities and special needs are required. From there we were directed to the school nursing department and several school nurses were trained by myself and Edward's DSN and an appropriate care plan was drawn up. The nurses spent time at our home watching how I managed Edward. (At this point I should say that Edward's glucose levels are particularly unpredictable as is often the case in very young children.) The nurses would have worked on a rota basis providing one to one care for Edward whilst at school. **Literally the day before he was due to start school I had a message to say that the nurses would not go in to help. They felt that the level of care required was too high and they were going to approach their nursing union for further advice. I have asked but have never been told what the outcome was.**

◆ My 23 month old son Jamie was diagnosed with type 1 diabetes last Thursday I feel like we're coping ok, Jamie's been amazing, tells me where to jab him etc hasn't cried once and is on the 4 injections a day. But I'm having problems with work. I work in a nursery where my son comes with me; they phoned yesterday to say they didn't want the responsibility of having him at the school and having injections there. Are they allowed to do this? It's a private prep school? This has made me feel worse than finding out about the diabetes, as if they can, **it leaves me jobless. I'm a single mother.**

◆ When Charlie started reception we had a major fight on our hands with the headmaster who expected Charlie to do all his own blood testing, choose an appropriate snack and go and get it from the store cupboard – all at the age of 4 and only having been diagnosed 4 months previously! In the end we

decided to by-pass the headmaster and arranged an appointment with the reception teacher direct. **When we arrived at school's front door the school secretary actually blocked the corridor by standing with her arms and legs spread-eagled so we couldn't get past to go to the classroom** – this is despite the fact that the reception teacher was expecting us and my husband, is Chairman of Governors at the school!

◆ Unfortunately, when we had a meeting with the school and our DSN, (who we thought was there to support us) it made matters worse. **The DSN seemed to do her utmost to discourage the school from taking on procedures such as testing, her attitude being that schools should not have to take on such levels of care.** We were quite surprised and hurt at her attitude. It made us feel very much on our own in the pursuit of a good standard of care for a young child starting school. Anthony.

◆ **We had contacted the school months before the meeting and left information for them to read.** The first aider was the worst, as usual, she knows ALL about diabetes!!! having been on a 2-day first aid course!! The school nurse pointed out they have a policy on insulin pumps, but that no child attending school in our town has a pump. I told her she was wrong, as there are a number of children using insulin pumps. I couldn't help myself. I could have put my head in my hands it was so bad. **The teacher said "so if he starts to have a hypo, I have to put the insulin in his mouth then"!!** The bursar? was taking the minutes, I feel like asking for a copy so I can post it on here!!! I was thinking, my child is supposed to be coming here soon, and you have not looked into this one bit, the SENCO needs the sack as the head teacher said he had never seen the diabetes in schools document and asked me where I got mine from. When I said the LEA website his face was a picture.

A further meeting, with a large number of representatives from various agencies attending, has still failed to reach any decisions about suitable arrangements for a child to have his insulin injection. **One suggestion that the child be driven by car across town every lunchtime to go to his own GP's to receive his injection** was rejected by the family as being unsafe, a ridiculous waste of money and resources and discriminatory. He may have had to be driven by a different driver each day who would know nothing of dealing with diabetes emergencies and the child would have no time to play with his friends and would have to eat his lunch on his lap in the car!!!

◆ 9-year-old Sam was left to wander the corridors in search of the school's first aider when he went low, as the staff felt that diabetes related issues were his responsibility.

◆ Our child needed a lunchtime injection to control his blood glucose. No one at the school was willing to help.

◆ **I removed my daughter from the state education system** in february (2005) and now home educate her and I consider this to be proof that our children (with diabetes) are being not only failed, and are at risk within our education system . Since leaving school her HBA1C's have risen to a level the clinic are happy with whereas, previously they were so low the consultant considered her to be at high risk of severe hypoglycaemia, obviously she must have been extremely low at school for much of the time. Overall her care has improved immeasurably and not because I do much more for her, but because the home educating community saw my daughter's diabetes as an opportunity to learn about the condition and parents and children alike took it upon themselves to make sure they were able to handle any situation that may develop. What a difference from school where her fellow pupils were not told of her condition and the head treated her as nothing more than a nuisance.
Elaine

◆ When I came to collect our child from nursery school the staff said that she was tired and was lying on a cushion in the "book corner" alone. She didn't normally fall asleep at school. When I tested her blood glucose level, it was 2.5 mmols. The staff's said that they hadn't tested because she hadn't said that she felt low.

◆ Joshua shows all the same signs when he's running really high and really low and Joshua's nursery are finding it really difficult to decide which cause of action to take, to feed or not. Joshua is only 2 1/2 so cannot say either way. At Joshua's nursery they will not test blood sugars because they say that they are not covered in their insurance to do so. So Joshua usually comes out of Nursery sky high!

◆ We have struggled with Ryan's school since he started, not wanting to take an active role in his diabetes. If Ryan looks pale/ill or says his tummy is hurting the school is straight on the phone asking me to come and take him home, I work for my husband in the office, but if I had a 'proper job' I think I would of been sacked by now the amount of time off I have had.

With 2 stressful years behind us, this year we thought, Great, a teacher who is interested, and lets me know if anything has happened etc.

We found out yesterday she will be taking the head teacher's job, so Ryan is having ANOTHER new class teacher. She is in her final term of teaching practice (whatever that means) and knows nothing about diabetes. She took the class for the first time yesterday (I found out after the fact) Ryan went low, She sent him off on his own to find a teacher who would supervise his test! By the time he had found a teacher and carried out the test he was 2.9 mmol any thing could of happened to him! I feel like going in and kicking up such a stink but where does that get you they are even more reluctant to look after him.

◆ I had to have a word with Abbie's teacher today, to gently explain the procedure for treating a hypo. We only went over this about a week ago and she seemed to understand. Anyway on Friday, I collected Abbie after school at

3pm and her teacher came to me and said that Abbie had insisted she was "wiggly" (dizzy and low) even though she looked fine, so she gave her three dextrose tablets followed by the full carton of Ribena which is kept in her emergency box!!!! I tested at home and her blood sugar was now 25.4

◆Lilly needed to start having a lunchtime injection after other attempts to control the blood sugar with different insulin regimens didn't work. **Her parents were told that the teachers could not possibly inject "because of insurance" and that there was nobody else who could.** We went to the Education Department; Social Services weren't of any help.

◆**After weeks of saying that they would be happy to check my child's blood glucose they suddenly decided that they would not check him at all. Due to "health and safety reasons"** This was two days before the end of the summer term before Oliver was due to start in September. There was no way that we could send him to this school and in our opinion he would not have been safe.

◆When our daughter Kirsty started school at the age of 4, our daughter was unable to monitor her own blood nor was she able to administer her own injections when running high. She had no awareness of hypos and had poor diabetic control on a two injection a day regime The Health Visitor would not assist with our problems at school since she felt it was the duty of the School Nurse who in turn indicated that because of our daughter's age, she felt it was the duty of the Health Visitor. We had to rely on the community nurses to deal with any problems when they were available. **The Head teacher indicated that in terms of the Schools Act there was no obligation on a member of staff to assist a child with administering of any medication. She further told the staff that the teachers union had advised them not to volunteer to assist with any of the care since it affected the insurance of the school and further that the school would not support them if there was any litigation.** So our problem of high blood glucose levels continued for a period of three years until she had finished infant school. **"I try not to think about the long- term damage this might have caused"**. During this period her HbA1c rose to 11.2%!

◆Ellie was 8 when she needed to add a lunchtime injection of insulin. She had been diagnosed 10 months previously. The school were happy for this to happen as long as Ellie took full responsibility. This meant that no one was willing to remind her to inject, or check the dose, or check she had done the injection, or even check that she had eaten any of her lunch. We bought Ellie a mobile 'phone and she 'phoned me every lunchtime to tell me what she had eaten so we could calculate the dose of insulin based on her blood sugar and any planned exercise as well as her carbohydrate intake. She would dial up the dose on her insulin pen and inject it while I was on the line so I knew it had been given. If she did not 'phone me by a given time I would call the school to ask them to check that she was all right and remind her to 'phone me. This system worked as she is a conscientious child. Ellie's school were very supportive of the care plans we devised for her in school. They were always willing to have relevant training and the Head

ensured that if the care plan was not followed this was dealt with swiftly. However the school depended on me as a parent to continue to supervise Ellie's diabetic self- management even while she was in their care. I feel that this was not ideal. I wonder whether it is appropriate to ask parents to do this when the school staff will administer other drugs in school and do not expect other pupils to take responsibility for self-medication. I feel that it was a great deal of responsibility for an eight year old.

◆ On Thursday Tim had pasta and a carton for milk for his packed lunch. When he was opening his milk he spilt some of it in his pasta. He told the dinner lady and asked her for help. She told him to find Penny and ask her for her lunch!!! Tim found Penny and she'd already finished hers so Tim went back to the dinner lady and told her. Her response: well I don't know what to do so go out and play. Nobody else was told, Tim thought it must be ok because the dinner lady "said so" and needless to say Tim was 2.5mmol when I picked him up at home time. I don't know how he didn't go lower. Luckily, I suppose, he's had a couple of afternoons of going higher than normal, so I guess this must have helped him. I was going to speak to the head on Friday but he wasn't in so this meant that I had to drop everything and be in school all afternoon. Tim only has help from the head and a teaching assistant who only works mornings. This means that every time the head is at a meeting (so far 8 times this term) I have to be in school for Tim. It's really starting to annoy me. I enjoy being in school but I really feel that they're taking advantage. It's a good job I don't work!!

Kirsten, mum to Tim aged 5.

◆ I'm the dad of Archie who was diagnosed Type 1 diabetes a couple of months before his 2nd birthday (Sept 03). He was in a fantastic nursery school who kept right on top of his condition. **He has just started 'big school', which cannot/will not monitor him and provide the care he needs. To get him through the first week my wife (Maria) and her mother took it in turns to go to school with Archie**, which is a massive drain (Maria has a college course and her Mum other grandchildren to care for). In his first week Archie had two hypos - something he has rarely had before. Archie is not yet 'hypo aware' so my question is; are the council obliged to provide full time support to keep Archie in school - the alternative looks like we'll have to take him out which will be a massive shame, as he loves it.

◆ I got a telephone call telling me my daughter was crying but that she had had a snack, when I got her home she was 2.2 mmol and obviously hypo when she recovered I asked why I couldn't see any food missing from her snack bag and she said that she couldn't see it because her eyes wouldn't work and had managed to grab her pop bottle but didn't remember how to drink it! The next day I took her to school and calmly asked the teacher what she had eaten for the snack only to be told " I noticed Jenny's eyes rolling, so I sent her for her snack, I did see her with a bottle of pop" **THEY HAD STOOD WITH MY DAUGHTER CRYING INCONSOLABLY FOR 20 MINS AND DONE NOTHING!** I explained to the teacher and the head that they had witnessed a

hypo and should have given her food whenever in doubt, but she still comes out hypo at least every other day, Elaine

◆ **Danielle 10 years was excluded from her final swimming lesson because the teacher didn't have time to check her blood was ok before she went into the pool.** I couldn't wait to see her smiling face coming out of school with her certificate and badge, but instead I was greeted with her crying her eyes out! The teacher came over to me and told me that 'there had been "some tears today'. I can't tell you what, thinking I am still fuming. Danielle was definitely scarred by this.

◆ A teacher took my child's class out of school for the afternoon down to the local library and forgot to ensure that she had taken any of her Lucozade, hypogel, glucose tablets, biscuits or blood glucose meter. My husband had to go up to the Library to take extra hypo supplies and the meter. The teacher didn't seem to realize the seriousness of the situation if Sasha had gone low.

◆ The headmistress asked me to 'pop' into her office for a chat when I had 'finished with Edward'. This was to tell me that Sheila, (Edward's support worker) needs to reduce her hours (knew about this, it is to do with her personal circumstances at home and issues relating to her contract, or rather lack of, arrangements at school, she is unhappy with this). **I have been asked to collect Ed an hour early every Friday afternoon because there is no one to look after him and 'he'll only be missing playtime and story time'**. This apparently will "suit me perfectly", because I can go straight to the juniors to collect George and Arnie'. I said no, I would like Edward to be at school for the same length of time as the other children. So we are 'having another little chat' when I 'have had time to think about it'. Just rang the DSN and she said stick to my guns and she will back me up. It amounts to discrimination.

◆ **Teachers seemed to think that if I had hypos that it was because I wasn't looking after myself properly and that if my blood sugar was high it was because I had eaten sweets.**

◆ My son's school was arranging a school residential trip. I asked to be able to come along on the trip because of his needs. Insulin injections and monitoring of blood sugars and food. I knew from past experience that the school would be unable to manage my son's condition without additional support. The head told us that our son could not come on the school trip and that I could not come either because "all the other kids would want their mothers"!! He wouldn't back down. We offered to stay nearby rather than at the site but this offer was rejected and my son and another child with diabetes at the school did not go on the school trip.

◆ Our daughter was diagnosed when 4 she started on injections, which did not agree with her. She was moved from her school due to appalling care, her second school was more understanding if not a little dangerous in their care, (left sitting in a corridor on her own while having a severe hypo - she lost

consciousness while unattended). At the end of her first year in juniors she received her pump and the school was fully supportive. 2nd year Junior school started badly after being taken over by a new head who decided that she couldn't be on campus without one of her parents - small problem due to us both working full time. It was made perfectly clear that the pump and blood monitoring equipment was not welcome and she was asked to leave until an arrangement was made. **After a suggestion of a special needs school and nearly 3 months of no communication we withdrew her; her father gave up work and she is now home educated.**

It's not been easy and there is no financial help with her education, however, her HbA1c is 7, her health is fantastic and she is happy. Wouldn't change that for the world. KayleighHawkin

◆ I thought that the saga of the school trips was over until last Thursday. I went to parents evening and was told that the TA (teaching assistant) that was going with Jake on the trip in June to Kingswood, **can only go for the first two days and could Jake be collected early!!** Well I really didn't know what to say. We have a clinic appointment next Thursday so I will speak to Jake's DSN.

I did say that I would go for the remaining days as I have an enhanced CRB certificate, but his teacher said **that they don't like parents going.**

The school have been really supportive since Jake had been there and it just seems such a shame that they are letting us down, just when Jake is about to leave the school.

I feel really upset for Jake as he was looking forward to going. My husband is not impressed and wants to demand a full refund (£280) and permission to take Jake out of school for the week, he has said that he will take him camping for the week. It looks like he may well get his way!

Michelle

Mum to Jake(10) dx99 pumping Jan05 Attends Addenbrookes Hospital,

◆ When Brandon's blood sugar level goes high he cannot concentrate and is restless and unsettled and cannot sit still. Brandon's head teacher punishes Brandon when he behaves like this, even though it isn't his fault. The school will not help with blood glucose testing. The head teacher has told his mother that having diabetes is no excuse!!! There are other children at the school who have a statement of special needs and one child in particular hits Brandon but they are "excused" because they are "statemented". Bradon and his family feel that he is being unfairly treated and Brandon is fed up with school.

◆ **Jamie, aged 9, at junior school;** the teacher would not tell Jamie when it was time for a snack (he was on an old insulin regimen at the time), did not allow him to wear a watch with an alarm, so I provided a clock for the classroom wall. A few months later, same problem, the batteries had run out and the teacher had thrown the clock out.

Same teacher; half the school went to a community hall in town for a town wide music festival. Jamie's teacher, who refused to read the school care plan because she 'knew all about diabetes', her old uncle had had it, forgot to take the Lucozade with them. **Jamie asked to eat his snack and she told him 'no'.** As his class was coming off the stage, Jamie collapsed unconscious

in a serious hypo. The teacher had also forgotten my emergency contact number. Jamie did not come round, so she drove back to the school 3 miles away, got my phone number, rang me up, and when I arrived, Jamie was unconscious and they were trying to feed him chocolate and sugar free squash with undissolved sugar cubes in!!

When Jamie returned to school, everyone asked how he was, told him what he looked like when he collapsed, Jamie was devastated (he's a shy boy) and from then until he got his pump, apart from being taken to school, refused to leave the house/garden and became withdrawn at school. The teacher mentioned he'd lost his memory, and had relearn the multiplication tables!

I complained to the head of school governors, the teacher got the message.

On MDI, Jamie had to do his lunchtime injection in the busy dining hall in front of everyone there, the girls especially used to comment or make a fuss.

In secondary school, Jamie has not been allowed to go on any school residential trip, most school day trips, including a geography field trip that was part of the curriculum (along with another boy with diabetes) and the Duke of Edinburgh Award. When threatened with using the Disability discrimination Act, and having consulted an educational solicitor, and offering to go with them on the trip (I am a children's nurse) they cancelled the trip, firstly the thought the trip was 'oversubscribed', subsequently, they said it was 'undersubscribed'.

Jamie was put in the bottom GCSE geography group, as part of the assessment for the group, which was done on performance of the field trip that he was not allowed to attend, therefore he had not done the required work! Double punishment. (Yet in the exam he came 3rd in the year).

There are many subtle ways your child is discriminated against at school for having diabetes; bags have to be left outside dining room, outside library etc, Jamie's bags have been stolen on several occasions, his blood meter stolen, lunch box stolen, lucozade bottle opened in his bag and its gone over his blood glucose meter and books. There is now a new headmaster at the school, and he has allowed children with diabetes to take their bags with them. This shows sometimes it only requires small things to be done, to make life at school better. The difference to the child in having staff that will listen and bend rules is also a quality of life issue; before this head we felt as if some of the teachers were bullies. This in turn leads to a child becoming disaffected with the school. Once this happens, it is hard to alter.

◆ Last week Joel went swimming, which is offsite, without any hypo supplies, no meter, no nothing, pump left on chair in changing room!! This wasn't his usual teacher but one from the school - the usual ones have been off sick for a couple of weeks. This teacher doesn't have a clue... I couldn't understand why Joel was so high at school for several days running. I went in to check his hypo box in the classroom - 2 packets of glucose tablets and several biscuits were gone - he hadn't been low so there was no need to use them. This teacher said oh yes, the supplies will need replenishing, Joel's been high a lot this week hasn't he... so he's needed to take quite a bit from the box...' O my god, I thought, please - no, I said, he doesn't need to eat when he's high', I couldn't say anything else, I just walked out.....

We've also had issues with Joel forgetting to bolus at lunchtime, this is since they staggered the lunchtime last term. Joel was going out to play at 12 then having to go to the classroom at 12.30, do his bloods and bolus, and go to lunch. He was forgetting. I asked the (temporary) head if someone could remind him on a daily basis (he couldn't hear the alarm if I set it on the pump). The head said, 'oh no, we couldn't possibly expect anyone to remember to do that everyday, as they may forget and that one day may be the one that something happens to Joel, then you would sue the school'. Oh all right then, that's ok, don't worry about Joel... doesn't he realise that we'd be more likely to sue the school if they refuse to help him and something happens to him. Then we realised this term that Joel was actually on his own in the classroom testing his bloods at lunchtime, he'd had a couple of 2.5's as well, he could've collapsed and no one would've known until 1pm. New permanent head in place this term. He said 'oh no, this can't happen, Joel must go to the office at lunchtime to do his stuff (as he calls it, he seems a nice bloke actually, so far anyway...). Ok so that's in place, but now Joel is forgetting to go to the office and no one is bothering, and when he does go to the office he's still forgetting the bolus. So now I phone at 1pm everyday to make sure he's been and done his 'stuff'. I had a conversation with the nice office staff, well they thought that Joel didn't need an injection everyday at lunchtime, thought it depended on his BGs. AGGGGHHHHHH And do they not realise he uses a pump now, obviously not. What's the point of having a nice photo of Joel on the wall with his care plan and not looking at it??!!

As some of you will remember, I asked the head on Nov 1 last year if he would use Glucagon in the school - he said no problem. Well time went on and I didn't hear anything about it, so I phoned the school nurse and asked her if she'd heard from the head about it. Well, she didn't have a clue what Glucagon was and I had to explain to her! I don't know what she said to him but she must've put him off. So I asked the DSN if she could train the staff but the hospital are not in agreement with using it in school, saying that it was more important to call an ambulance. At Joel's last clinic they said they would speak to the head about using it though, as we still would rather have it in place than not.

Had a meeting with the head last week about the serious lack of awareness of Joel's condition in the school. He seemed very positive. He said Joel is on the agenda for the next staff meeting. He said the main problem is that the staff doesn't understand the guidelines and there's just too much information to take in. This is true. Joel's guidelines aren't really written for him, they are too generic. He wants basic (Idiot's guides) sheets about hypos and everyday reminders for Joel and the teachers to be put on the classroom door. I have also been busy putting together some new guidelines for Joel, there will be no excuse by the time I'm finished! I asked him about the Glucagon, he said he had spoken to the DSN who has advised him not to have it in the school and he must go by what they advise. Well thanks a lot Clare (DSN), thanks for not telling me you were going to say that to him! Why do DSNs always have to do that? She told me that the head was not happy to have his staff trained to administer Glucagon. Danni

Older children's negative experiences

◆ "I am so angry that I feel that you might be interested in the following. Alex (14) has not been happy for a couple of days and today I found out why. Last week during a science lesson, the teacher decided to talk about Diabetes. 'Most diabetics are **fat**' was her opening comment. She then, asked about reasons why people became diabetics they were, according to her -

- 1) too many cigarettes
- 2) too much alcohol
- 3) too much sugar.

At this point Alex told her he was diabetic - she just said sorry.

What ignorance! I have written and been in to school to explain and yet this teacher was even unaware that he was diabetic. I specifically wrote at the beginning of the year to ask that all teachers be aware of this. I am now going to write in very strong terms about the difference between type 1 & 2 and how angry, hurt and upset Alex and I were by these comments".

◆ My name is Angela Read and I am a parent of a 14 year girl who was diagnosed with type 1 diabetes 5.5 years ago. She is now on an insulin pump and deals with the highs and low blood sugars herself but I have had a mixed reaction from the senior schoolteachers in how to deal with Amy when she is poorly.

The difference between junior school and senior school attitude is unreal. Amy has had a lot of time off over the past year as she has had DKA 4 times and has been hospitalised. When it came to the parents evening meeting, my husband and myself were dumbfounded to find that her head of year was asking us why Amy had not been at school all the time! She did not even know that Amy was diabetic!!!! Apparently there are pictures of children with any medical condition in the staffroom on the wall with their specific condition but, we were told that " no-one really looks at them" which I find very disturbing. We worry about substitute teachers knowing even less!

◆ "I was called into school today because Danielle was dizzy and shaking. The receptionist asked me if I could call in with her 'thingy' the receptionist didn't know what to do. The receptionist thought it was an Epi pen or something. (Which has nothing to do with diabetes and is used for treating anaphylactic shock) Another receptionist had given her 2 Quality Street Chocolates but nobody had been to her medical box, which was full of glucose tablets. Chocolate should only be given to treat a hypo if there is nothing else available. The high fat content of Chocolate means that any sugar is absorbed too slowly and the blood glucose level in the brain will continue to fall. Fast acting glucose is needed immediately to safely treat hypoglycaemia to prevent the symptoms worsening".

◆ After being delayed due to completing some tests in a previous lesson, the class had no time to go outside to eat their morning snacks. At this school lunch is not served until 1.30 pm, many children do not get to eat until almost 2.00 pm. The children went to queue for their next lesson. Sasha got out her snack and bolused the insulin through the pump and began to eat her snack. The other children were eating their snacks too and a teacher came along and started shouting and ranting at the children for eating in the corridor. They were told to stop eating and put away the food the teacher would not listen when Sasha or her friends tried to explain the teacher that Sasha needed to eat NOW because she had given the insulin.

◆ **A parent's letter sent to a school about an incident:**

I am writing to you about an incident that took place this afternoon in the year 7 drama club. I went to collect my daughter and was met by one of her friends who told me my daughter was 'hypo' (i.e. hypoglycaemic, a dangerously low blood sugar requiring immediate action) in 'the pit' where they have Drama club. When I arrived there she was sat alone. It seems that she tried to tell the teacher she was hypo but the teacher would not listen. My daughter had asked a friend to find her some Lucozade, as she didn't have any with her: the friend refused, as she didn't want to miss the final game being played. She asked another friend who agreed to go to the PE office where my daughter has supplies. The friend was told by staff there, that they did not have any diabetic supplies for my daughter (although they had been there earlier in the day during Ellie's PE lesson). They offered her some coke and apple juice which she took to Ellie. In the meantime the drama teacher and other students left.

I am very concerned that the drama teacher did not realise how serious this situation was. An untreated hypo would have resulted in my daughter quickly becoming unconscious, fitting, and finally brain damage and death. I would have hoped that the teacher could have directed another student to fetch diabetic supplies from one of the school diabetic stores (I believe there is one very close to the pit). We can only be very grateful that my daughter retained enough sense to direct a second friend to the PE office, and that she was willing to help. As you will know from my daughter's diabetes notes, low blood sugar causes the brain to malfunction, leading to confusion and memory loss. This means that my daughter cannot always remember how to treat herself when she is hypo. She should never be left alone when hypo and an adult should always check that she has actually taken her hypo treatment.

I would like to know that all my daughter's teachers are aware that she is diabetic (Mrs XXXX is my daughter's class drama teacher, as well as taking the drama club) and that they know what to do if a diabetic student says they are hypo. I would also like to see the other students made aware of how to find diabetic supplies if they are asked for them. I look forward to hearing from you.

Enc. My daughter's diabetes information

Cc school nurse

PS

The school has now apologised and has expressed regret and have taken steps to make sure that this type of incident is less likely to happen again.

♦ I dropped my 12 year old son off at school early this morning as he's off on a history trip and went to check with one of the teachers if anyone had thought to get Danny's hypo kit from the office. He has glucose on him but I like the kit to go as extra everything is in it if needed. Not really surprised that nobody had got it but was so cross when this teacher the head of history who taught him last school year when diagnosed asked me to point him out and then said there was no point him going to the office to get it as the office was locked and he wouldn't know where it was anyway! Well good job it wasn't ever needed in his lesson last year! I assumed all teachers knew where the kits are kept as the secretary surely isn't in the office all day even if she's only let out for the loo! The bus was leaving at 0815 and apparently the secretary arrives at 0830! Luckily I found a lady in school who had a spare key to the office, didn't know either where to find the kit, but luckily it was in the first drawer she opened. I then ran with it to the bus as I'd been told they were leaving 0815 prompt and couldn't wait!!! This same teacher made a comment that there's "another boy somewhere says he needs to inject at dinner too" (there is another type 1 in Danny's year) but is that how he sees it, they just need to inject and everything is then tickety boo!! He didn't seem interested or aware of his responsibility. I was trying to explain to him just so he was aware that Danny had given more insulin than usual before breakfast as he was high 9.9 this morning post last nights meal out but he walked off as I was telling him! Danny should be ok as we checked it again in the car one hour after and it was still 8.2 and he had one and a half hours sitting on the bus to come. I'm just trying to calm down before I ring the school to politely point out that I feel it is essential that all staff members know where the hypo kits are and that some teachers seem unaware of the implications of intensive insulin therapy.

♦ Just to relate a sad tale of what happened to Philip this week. I arranged to go in and see the 3 teachers who were accompanying the 30 children to the Pyrenees leaving a week today last Tuesday morning, with the two D nurse. Just so that they were clear on what help Philip might need. Nothing basic about diabetes I assumed they were clued up on that, Philip having a care plan in school etc. etc. I wrote out four things to watch out for that would indicate the need for help i.e. unable to treat a hypo, (how to identify and what to give) - seizure, what to do - hypers and when help is needed (i.e. he is so sick he cannot treat himself) and if there is a bug going round the group so he gets too ill to look after himself. The final suggestion in all cases was of course that they should call an ambulance as you would in the UK or at school if Philip was to collapse with a hypo or seizure, or instead of being sent home if very high and sick.

Anyway, they asked us to come back yesterday, I thought to show them how to do a blood glucose test again (which I had with me and demonstrated first time, which we were suggesting they do, if Philip was low/high and could not manage himself) This time they also had the guy who does health and safety risk assessments for school trips. Apparently they had done one 6 months ago on the trip but had not identified any problems. They had taken someone with diabetes before and "just pushed a mars bar down him before he went down the ski slope" in their words. (I had informed

the trip leader of Philip's diabetes when he was signed up about a year ago.) The health and safety guy now announced they were all really worried that Philip was a very high risk and that they didn't have enough staff to look after the other children if he were taken ill. (But of course, any of the children or staff could be taken ill!) The upshot was: either I go with him or the trip is cancelled for him, until next year, when they will have it all sorted in good time and an extra member of staff to look out for him specifically.

Philip was very quiet in the meeting, only saying how much he wanted to go on the trip, but afterwards was extreeeeemely upset to say the least. What he said about the school/staff is unrepeatabe! He finally decided he didn't want me with him (although I was quite happy to go, paying in full), but would wait a year. That seems about the best solution, and we are in time to have a full refund from the company organising the trip. I am sharing this just so that if any other parents/children are planning to go on such a trip, arrangements are be made with the school well in advance. i.e. at least 6 months.

I feel so bad that he has been disappointed and, in his words, "has been kicked out of the ski trip because he is diabetic". He calmed down later and was OK this morning. We will have to make it up to him big time over half term and of course, his big brother is still going on the ski trip! Anne Mum to Philip, aged 12 diagnosed 4.8.2002 pumping since Nov. 2005,

Discrimination?

J was not allowed to go on the Year 9 Geography field trip that formed part of the course curriculum because he had diabetes and the risk assessment said it was too risky.

Observations

1. The field trip was “an important part of your eventual level in Geography at Key stage 3..... the work done on the day will be used .. to complete a fieldwork write-up when you return to school. Some aspects will also form part of the summer exam in geography”
2. The risk assessment was flawed in many ways; it was not person specific to J, mentioned injections when he was on a pump, did not have any involvement or information from J, his parents, his GP, his consultant (who had written a letter saying that J had good control and there was no reason why he should not take part in any school trip) or DSN, mentioned risks that would apply to everyone else and were not disease specific.
3. J had to sit in the school library all day the rest of the year were on the trip, looking up books, with another child with diabetes. The other child walked out of school and went home, J sat there all day bored. He could not complete the workbook as it involved being in the Peak District doing practical exercises. This action he saw as punishment.
4. In Year 10, the start of GCSE geography, J was put in the bottom geography group – he missed the trip and the work taught that day, which was not made up by staff, so, as warned on the trip paper he did not have the completed field trip to form part of his key stage 3 or the peak district teaching for the summer exam. He would therefore have been entered at foundation level for GCSE, not higher level, directly as a result of school barring him from the trip as he was diabetic, and not providing the teaching he did not receive making up the work.
5. On being advised he could not take part in the Year 10/11geography field trip (a residential one this time – he has never been on a school residential trip in his life), J wanted to take this further. We involved our local MP and councillor (himself diabetic), I offered to accompany J on the trip (I am now a children’s nurse); firstly the school said the trip was oversubscribed and I would not be able to come, then they said it was under-subscribed and the trip was cancelled.

The Disability Rights Commission were involved in the first trip, commented things may change when the head retired.

The Northern Peak District

Year 9 geography field trip **Monday 16th May 2005**

Exercise 1

Exercise 2

An investigation into the possible effects of a new limestone quarry near Castletown.

This form a very important part of your eventual level in Geography at Key stage 3, and an exercise based on the information you collect here will be completed when you return to school.

Exercise 3

Exercise 4

The work done on the day will be used by you to complete a fieldwork 'write-up' when you return to school. Some aspects will also form part of the summer exam in geography.

RISK ASSESSEMENT RECORD

ESTABLISHMENT/WORKPLACE: The Kxxxxx Txxxxx School, Baldock		
WORK ACTIVITY: Year 9 Geography Field Trip, Peak District – Jxxx Mxxxx		
DESCRIPTION OF ACTIVITY: Jamie is a diabetic and suffers from asthma. The trip to the Peak District includes a visit to the Blue John Cavern, a steep underground mine. The area to be visited is very hilly with steep inclines, and rough terrain. The trip is being carried out in one day which includes long coach journeys and all day at the Peak District. FREQUENCY: DURATION: 1 day Approx.13 hours	PEOPLE AT RISK: Jxxxx	
SIGNIFICANT HAZARDS: Insufficient/irregular eating Missed insulin intake Long journey Irregular hours Strenuous exercise Long periods outdoors in possible inclement weather Effects of diabetes Steep access to mine Remote location	ADVERSE EFFECTS: Fatigue Stress/Anxiety Fainting Low blood sugar levels Coma Possible physical injuries Hypothermia	
EXISTING CONTROL MEASURES: Existing generic RA's for trip activities in accordance with Offsite Visits Policy. GP/Specialist advice. School's knowledge and experience of his condition. Supervision.		
RISK FACTOR = 8		
ACTION AND TIMESCALE(S): Arrange for additional support to be provided on trip to assist JXXX support to assist Jxxx id he needs to rest or cannot keep up with the group Alternative arrangements to be organised (eg visitors centre etc) if Blue John Cavern or Winnats Pass assessed as inappropriate for Jxxx once at the location Mother to agree that a dynamic assessment at the location may limit or alter Jxx's participation in events and the Group Leader has final decision. Jxx to be monitored to ensure he takes his time and takes regular breaks Jxx to be monitored to ensure he takes his medication as necessary Jxx to ensure he carries appropriate food at all times and eats regularly Jx to be monitored to ensure he takes blood count at correct intervals. Head Teacher/Group Leader to consider procedures should Jxx collapse – i.e call ambulance, medical assistance. Jxx's mother to inform the school of any GP/Specialist advice regarding emergencies. Note:Undertake a further Risk Assessment following the introduction of additional control measures.		
ASSESSED BY - REVIEWED BY – J.Hambrook, Health, Safety and Risk Manager	SIGNATURE – _____	Date- CSF 12/05/05
-		

RISK ASSESSEMENT RECORD

<p>ESTABLISHMENT/WORKPLACE: The Kxxxxx Txxxxx School, Baldock</p> <p>WORK ACTIVITY: Year 9 Geography Field Trip, Peak District – Review of risk associated with Jxxx Mcxxx</p>	
<p>DESCRIPTION OF ACTIVITY: Jamie is a diabetic and suffers from asthma. The trip to the Peak District includes a visit to the Blue John Cavern, a steep underground mine. The area to be visited is very hilly with steep inclines, and rough terrain. The trip is being carried out in one day which includes long coach journeys and all day at the Peak District. In the last year Jxx has missed a considerable amount of school due to illness, including a recent spell during S.A.T.s.</p>	<p>PEOPLE AT RISK: Jxxxx</p>
<p>FREQUENCY: DURATION: 1 day Approx. 13 hours</p>	
<p>SIGNIFICANT HAZARDS: Impacts from the following being significantly increased due to Jxx's recent ill health: Insufficient/irregular eating Missed insulin intake Long journey Irregular hours Strenuous exercise Long periods outdoors in possible inclement weather Effects of diabetes Steep access to mine Remote location</p>	<p>ADVERSE EFFECTS: Fatigue Stress/Anxiety Fainting Low blood sugar levels Coma Possible physical injuries</p>
<p>EXISTING CONTROL MEASURES: Existing generic RA's for trip activities in accordance with Offsite Visits Policy. GP/Specialist advice. School's knowledge and experience of his condition. Supervision. Previous arrangement for additional support to be provided on trips to assist Jxx Jxx to be monitored to ensure he takes his time and takes regular breaks Jxx to be monitored to ensure he takes his medication as necessary Jxx to ensure he carries appropriate food at all times and eats regularly Jx to be monitored to ensure he takes blood count at correct intervals. Head Teacher/Group Leader to consider procedures should Jxx collapse – i.e call ambulance, medical assistance. Jxx's mother to inform the school of any GP/Specialist advice regarding emergencies</p>	

RISK FACTOR = 16**ACTION AND TIMESCALE(S):**

Given recent circumstances the ability of Jxxx to attend this trip has altered. Jxxx has experienced a significant amount of ill health recently which suggests he is not at his physical best and has a history of experiencing difficulties on a much less strenuous trip in the past.

Under normal circumstances the school try to provide additional support for Jxxx to ensure inclusion. On the last trip this was covered by his mother.

However, MrsBxxxxx cannot attend this time and the school have not been able to resource additional support in time.

The risks to Jxxx are therefore significantly raised due to:

Inability to provide 1-1 support

Inability for this support to stay with Jxx if he is unable to keep up with the group

Higher risk, due to recent ill health, of complications should Jxx require emergency aid in the mine.

Higher risk, due to recent ill health, because of the remoteness of location and previous experience of timing for emergency services to respond

Given the above factors, the level of risk for Jxxx to attend this trip is too high, and as such would preclude his attendance on this particular occasion

Note:Undertake a further Risk Assessment following the introduction of additional control measures

ASSESSED BY -

SIGNATURE –

Date-

REVIEWED BY – J.Hambrook, Health, Safety and Risk Manager CSF 12/05/05

Examples of positive School Experiences

Some of the schools mentioned are private schools with small class sizes.

◆ Finn has funding from the LEA. It's not statementing. It is funding for medical needs. The paperwork is much simpler apparently and comes from a different pot of money. I rang the LEA myself to find if it existed and it is dealt with within the special needs department.

It is reviewed annually and he gets 7 1/2 hours per week. This is purely for his diabetes needs.

All it took was a letter from his DSN explaining he is unable to recognise and treat hypos, needs to eat lunch.

I know of at least 2 other children in Lincolnshire who get exactly the same purely for diabetes. I think it is par for the course here for the younger children with diabetes.

Marie, mum to Findley, 6, diagnosed 2001, minimed pump,

◆ In a pre-school setting, Sophie's nursery was second to none in her diabetes care. Diagnosed at 2, I was just about to start a new job, and Sophie was already in nursery. Once we had settled into her injection routine we talked to nursery, trained them on tests etc and they were off, 10 days after her

diagnosis! After about a month they asked if they could learn to do her injections, as I kept having to drive there from work. So we trained them on that too - there were about 5 staff who could do them. Sophie was there 4 days a week and they were probably more fastidious than me in her tests and making sure she was OK. I cried when she left because I knew she was unlikely to have that kind of care from a third party ever again!
Penny

◆ I cannot complain about Poppy's school because they have been great - even better now that Becky (DSN) came to give them a talk - all 5 first aiders were more than willing to do blood tests, injections and now supervise Poppy doing her pump settings. I would like to complain about many of the other Milton Keynes schools, but I did a survey with the parents in our group (in conjunction with the local council) - and most were complimentary about their child's school. Most children in our area do hardly any blood tests and only 2 injections! Having said that the council's report did conclude that there is a need for a more unified approach.

◆ **An example of good practice, written by Ben with help from mum.**

My Name Is Ben and I am 7 years old. In September 2005 I was taken into hospital and diagnosed with Type 1 Diabetes.

Before I returned to school my mum and dad went into school to talk to my teachers about the condition and what they could do to help me. Both my teacher and teaching assistant were very helpful and wanted to do as much as they could to ensure that my school life wasn't affected.

They help me to do a blood test when I need to as I don't always remember to wash my hands and sometimes I'm in a rush and don't think to do everything that I am supposed to. When I started to have a problem with my blood sugars my teacher agreed to help me test every lunchtime, as there were times when I was going low when coming out of school.

Sometimes I recognise my own hypo symptoms like having a headache or stomach ache but I don't always relate it to having a hypo. My teacher picks up on my behaviour in the class and helps me to test if she thinks she needs to. My teacher has tested me herself when I was so low that I felt very weak.
Luckily my mum helps out at my school and on the days she is there the teacher always fetches mum to help me.

I always take part in PE lessons at school and do after school football. My mum puts an extra snack in my lunchbox for these activities. On special days like Sports Day, I have extra snacks so that I can run my fastest, this year I came first in 3 of the races which made me feel very happy.

For lunch my mum sends me with sandwiches. My dinner lady and my teacher always make sure that I have eaten everything that is in my lunch box. Sometimes I have dropped a sandwich on the floor so they have given me a biscuit out of my special box. Mum thinks I do this on purpose sometimes just to get a biscuit but I don't honest!!

My diabetes does not stop me from going on school trips, mum just puts extra snacks in because of all the walking and sometimes mum has come with us on the trips. My teacher always carries my special box which contains hypo treatments and snacks. In October 2008 there is a 3 day trip to London which I want to go on. My mum approached the teacher organising it and he said not to worry and that it's up to school to make sure that I have the same chance as every other child in the school. They asked my mum if she would like to go or whether she would like to train a member of staff to be with me. My mum jumped at the chance of going!

My DSN went into school at the end of last term to talk to my new teachers. Mum says they were both very interested and told her not to worry and that they would look after me.

My life at school is OK since having Diabetes my friends think it's cool when I have to have a drink of coke and extra snack. My school has been fantastic and has done everything my mum and dad has asked them to. Ben Aged 7

◆ Penny Robinson's experience

When we first started on this list last summer we had a load of really helpful tips and advice about diabetes care in school. Sophie (4) is now settled in school, after we trained all the relevant staff, school secretary, the head and 2 teaching assistants. Our specialist nurse came along but to be frank did not really add any value to the training, as all he focused on was hypos, and the staff wanted to understand more. They now turn to me for all their advice. They do her blood tests mid morning and before lunch, make sure she has her snacks, and I have been in to do the occasional injection when she's very high. The head has agreed to do the next injection - as there are not many they don't get the practice but I have given them a spare pen and suggested they use an apple!

I was advised to get her certified for special medical needs, and I investigated this. The local authority explained that in North Yorkshire all the schools have already had this money allocated as a slush fund, i.e. they should be able to deal with extra work by utilising the teaching assistants they have. In my case I am lucky as the school is great, and they are very keen to help, regardless of risk assessment paperwork that the Authority keeps sending them! Sophie likes having her tests as she gets to chat to the school secretary in the office, who is the nicest lady in the world. They also call me on my mobile with any issues.

I can breathe a sigh of relief after the first half term, and I am hoping that DUK will use schools like mine as an example to help other parents. Even within North Yorkshire the care varies enormously. Another "reception Mum" I know can't get her school to do anything except 'call an ambulance if he collapses' and that child has very variable sugars.

I took the decision to change my job considerably from when she started school as I knew I would have to be more hands on with school. At nursery they cared for her as I would have: tests, injections, the lot. I now work fewer hours, can pick her up every day and don't work school holidays. I couldn't face trying to train the after school clubs as well as the school staff. I'm glad I did it, although work is more boring I don't worry about Sophie's diabetes as much.

DUK were not very useful at all in the process, the papers they publish and even the government papers in this area are vague and don't put any positive obligations on to the schools. So you just get the luck of the draw with schools it seems.

Our next plan is to do a Denim For Diabetes fundraising day at school (I have done this at 2 other schools and this involves doing assemblies for the kids) and invite the parents, so that they'll all learn a bit about diabetes. I think spreading knowledge and awareness may be a good way to ensure our children are looked after by their friends and others if need be.

Penny Robinson

mum to Sophie 4 (dxd 2004), Harry 11, stepmum to Fiona 14 and Douglas 13, wife to Glynn.

◆Nathan has a helper called Jo to support him at school.

My name is Nathan and I go to Manorcroft Primary School. I am nearly seven years old and have had diabetes since I was five.

At school I have a blood test and an insulin injection before lunch. I can pretty much manage this myself but I do need some help from a lovely lady called Jo. She reminds me to wash my hands before the finger prick and watches me do my blood test. She knows how much insulin I need depending on the reading and checks I have dialled up the correct amount on my insulin pen. If I get an error reading I wouldn't know what to do but Jo does. She can also help if I am fumbling to get the needle on or off the pen. Jo looks after all my diabetic kit and tells my mum when supplies need replacing. She also records my readings so my mum can make changes to my regime if needed.

I am given special permission to wear a watch to school which alerts me when it's time to go and do my finger prick. My teacher thinks this is great because she worries she would sometimes forget with 29 other kids to think about too! My watch also sounds at 2pm because I need an afternoon snack.

I am very good at recognising my own hypo symptoms and I tell my teacher if I am feeling low. She has had training from my DSN and knows what to do. She always takes me to Jo who has supplies of sugary Ribena in her fridge and biscuits for me. If Jo isn't around there is another nominated person who also knows what to do. Not all my friends can recognise their symptoms so well so it's important for their teachers to know how to spot a hypo and how to deal with it.

I take part in swimming and PE lessons at school and do after school football. My mum puts a snack inside my swimming hat so I can't forget to eat it! My teacher and the swimming teacher know that I need a snack anyway and that there will be a hypo drink in my swimming bag just in case.

On special occasions such as Sports Day, I have extra snacks. So long as the school tell my mum in advance, she can make arrangements for this. Towards the end of last term we had loads of different things going on, such as picnics and school productions. I didn't miss a thing because the school made

sure my mum knew what was happening and when and could sure I had extra food, insulin or whatever was needed to cope with the change in routine. Sometimes things happened fairly last minute, like the day when the PTA sent in ice lollies for us but the school just rang my mum and she sorted something out. Yum. The cook and her staff know I have diabetes and the cook even makes me extra bread specially to go with my lunch because that is what I need.

I went on a day trip with my school last year. Jo came along and my mum gave instructions for what to do if lunch was delayed or something else went wrong. My friend who is much older than me went on a residential trip and our DSN spoke to all the staff who were going on the trip to explain the importance of regular meal times and what to do if they were changed. She told them what to do to cope with increased activity levels and illness and all sorts of eventualities.

My mum says my DSN is going to speak to my new teacher before the next school year starts. My mum thinks it's great that they are all so keen to learn and be involved in my care. She says it can be daunting for a teacher knowing they will have a child with diabetes in their class and she says my class teacher was terrified the first time I told her I was feeling hypo in class. But she didn't tell me that and neither she nor anyone else at school ever stopped me taking part just like everyone else. Usually it just takes a bit of forethought and planning. Some children will need much more help than me, especially if they are younger or have no hypo awareness but if your school is willing, it makes such a difference to your school life. And mum doesn't have to go around in a tizz all the time worrying about me when I'm at school. Some parents she knows had to give up work to be able to give the lunchtime injection because the school wouldn't help. Some parents have to go on every school trip or their child is excluded. Things like that should not happen.

Diabetes is with me every day and for life and sometimes I hate it, but I'm glad that school life doesn't constantly remind me of that and make me hate it even more. I hope and wish all my friends with diabetes get the same care at school as I do.

◆ I think 'wonderful' might be a strong word but Isobel's school is not bad. It's a private school so I'm not sure how helpful that is for this discussion but as far as good practice goes they allow Isobel to test in class whenever she needs to and always at lunchtime. If she feels low, she and the teacher have supplies of sugar and if it is before lunch, she is also sent to lunch early with a buddy in case of faintness on the way. The teacher keeps her afternoon snack on her desk and has an alarm clock go off to remind her and Isobel to eat the snack as no one else in the class has anything to eat in the afternoon. She doesn't inject at lunchtime owing to the consultant's reluctance to let her but, if and when she does, she will go to the school nurses' office to do the injection and there will always be either a nurse or a first aider to supervise. She also has a written care plan which is checked at least annually.

Kate (Mum to Isobel, aged 9,

◆ My son Daniel was diagnosed in February 2005 and is currently on Novorapid and Lantus. He started school full time in January 2007. Our

experience has been nothing but positive. We have full support from the school. I first approached them in May/June last year in order to get the ball rolling. I also contacted the school nurse and Daniel's DSN. They have also both been very supportive and helpful throughout the whole process. Between the school nurse, the DSN and myself we drew up a care plan. Daniel is the first child in Dudley LEA to have MDI and therefore need an injection at lunchtime, of primary school age. In December last the three of us meet with 4 members of staff from the school to do some training on taking his blood sugar, giving his injection and going through his care plan. The members of staff involved were his classroom teacher, the head of the nursery, the deputy head and a classroom assistant. Daniel's classroom teacher is his the main carer during each day. Both her and the head of nursery take responsibility for giving him his injection, with one giving and the other one checking. They alternate each day so they are both confident to give the injections. His classroom assistant tests his blood sugar mid morning. This means that there are basically 3 members of staff that are actively involved.

So far they have been great, they always contact me with problems, however small. We have a communication book which they record his blood sugar levels each day and also what he has eaten. They also use this to ask for any supplies needed.

I feel very confident and comfortable leaving Daniel in their care during school hours. Also I have no worries about talking to them about any problems or concerns I have. Obviously it is early days as Daniel has only done 7 weeks so far, but if the school continues with the same positive attitude towards Daniel and his diabetes then I'm sure we will all have a happy future. Jenny Mom to Daniel 4 dx'05 and Isabelle 17 months.

◆ **Private school.**

All our school experiences have been positive. We have found common sense and caring, and systems that worked well for us without pedantic rigid regulations/obstacles. At all schools he has been allowed to test in class. They have always encouraged him to join trips, including overnight trips, allowing us the option to accompany him, but saying it wasn't necessary. (He went on 2 residential week long school trips without us). From Kindergarten to aged 7 the school were excellent and the teachers would help him do 2 tests a day, writing the results in a little book with any comments. He was on 2 injections of Mixtard 30 so no injections at school were needed.

At aged 7 he changed school, and they were also good. He had a little box of glucose tablets and biscuits kept in every classroom he went in. When he eventually started pumping they were supportive.

He is now at senior school where there is a lovely matron who has experience of children with diabetes, and is very supportive. He's got a pass for him and a friend to queue jump at lunch if necessary. He's allowed to have his mobile turned on so we can text throughout the day if necessary- although he always waits for break on the few occasions he has done this. There are 2 other diabetics in his year, one girl is also on a pump.

Rosie

James, 13 dx at 3.5 years

◆ Statements

When William was due to start school we discussed with the head teacher how best to care for William in school, he was already on MDI so needing a lunchtime injection. He was only 4 years old and completely unaware of his hypos. The head teacher had come along to the nursery attached to the school several times to observe William there.

From the outset the head was adamant that she would not take the responsibility of managing Williams care, she recognized that this was a life threatening condition and that she would not allow anything to happen to him in her care. She insisted that extra help was needed and advised us to apply for a statement of special educational needs which we did with her full support and backing. It was a very protracted process, which we started in March 2003 when his place at the school was confirmed.

Approval had still not been given by the time he started school in the September so the Head teacher applied for and obtained interim funding from the schools reintegration team.

In the November William was granted a teaching assistant for 25 hours per week. As a member of staff was specifically recruited to care for William it was included in the job specification that they must be prepared to learn all that is required to care for a child with type 1 diabetes in school and undertake, with training, lunchtime injections and regular blood tests. The school has been fantastic. Williams teaching assistant does not 'breathe down his neck' but keeps a watchful eye from a distance whilst helping out generally with the rest of the class.

William is encouraged to do as much for himself as possible including thinking about things like site rotation, disposal of sharps and planning ahead for PE. William has now moved on to an insulin pump and throughout the transition the staff were fully involved and supportive.

My daughter Georgia was diagnosed 2 weeks after her eighth birthday in Dec 2005 and went straight onto MDI. When she initially returned to school a teaching assistant was assigned to her to help her settle down. Georgia was initially very anxious and wanted to test her blood a lot. The teaching assistant was very gentle with her and allowed her to test whenever she wanted. As a result Georgia quickly grew in confidence and soon learned to recognize a hypo and not to panic or be overly anxious about it happening.

Georgia's extra help was only in place for one term when a review meeting was held and it was agreed with all including Georgia that she could now manage during the day on her own but that Williams assistant would supervise her lunchtime blood test and injection, which she has done for herself from day 1. Her teacher also remains vigilant to Georgia's needs.

Both my children have received outstanding care at school which has allowed

them to lead as normal a school life as possible. They both have an HbA1c of below 7.5% a result which would not have been possible without the support they have received. They are happy self-confident children who have been allowed a childhood without the burden of having to manage a devastating and life threatening condition. I find it appalling that this care is not standard for all young children with type 1 diabetes.

Angela mum of William aged 7 diagnosed at 18mnths pumping since Nov 05.
Georgia aged 8 diagnosed Dec 05. Also has hypothyroidism which was diagnosed Nov 06

Jackie Jacombs
List Owner/Manager
UK Children With Diabetes Advocacy Group
An On Line Mailing Support Group



Every Child Does Matter, including those with diabetes.



UK Children with diabetes Advocacy Group
© J.Jacombs D.Beskine 2007