Looking after children with Type 1 diabetes in schools (aged 4 – 18)

Key points

- All schools should look after and support children with Type 1 diabetes in schools, so they remain safe, healthy and able to participate in all aspects of school life.

- No child should be excluded from any part of school life because of their Type 1 diabetes. This includes PE, extra-curricular activities and school trips – including residential trips.

- All schools should have a medical conditions policy, which recognises the severity of medical conditions in children, the impact they can have on a child’s ability to learn and make clear every child with a medical condition should be treated as an individual. It should make explicit who is responsible for the policy and its implementation.

- All children with diabetes will need an Individual Healthcare Plan (IHP). This should be agreed in discussion with the child’s parents, the paediatric diabetes specialist nurse and the relevant staff. If appropriate the child should also be present. It should also state exactly the support a child needs, who will give that support and when.

- All school staff caring for children with diabetes must receive suitable specialist training, be signed off as competent and receive additional training as appropriate to meet a child’s changing needs.

- No parent should be required to go into schools to meet their child’s needs around their diabetes, or be made to feel obliged to support their child during the school day.

Introduction

1 In England, the legal duty to look after children with medical conditions in schools applies from when a child is in year one. However, Diabetes UK believe this standard of care should be made available to all children in the UK from when they start primary school.
Type 1 diabetes is a complex condition, which needs careful management by people with the appropriate understanding and skill set.

There are about 35,000 children and young people with diabetes under the age of 19 in the UK (1). 93% of these have Type 1 diabetes (2).

A Diabetes UK survey in early 2014, showed wide variety in the provision of support for children with diabetes in schools. Whilst some schools have excellent policies and procedures, in other cases children are unable to actively participate in activities and school trips, and parents are having to take a key role in managing their child’s diabetes during the school day (3).

Following a long campaign by the Health Conditions in Schools Alliance², from September 2014 schools in England have a legal duty to support and care for all children with medical conditions in schools. This provides the legal basis for all children in England to be properly supported in schools, enabling them to participate fully and get the most out of their time at school. While this is a legal duty only in England, it is still best practice in Scotland, Wales and Northern Ireland.

Of course, the legal duty is just the first step. Looking after children with diabetes in school requires the coordinated effort of the headteacher, school staff, the school nurse, specialist nursing staff and the child’s parents to make sure the necessary training, knowledge and information is in place to look after children with diabetes.

Outlined below in ‘calls to action’ are the roles and responsibilities for each of these groups, with reference to the legal requirements which support the organisational cooperation needed to make this happen.

**Current situation**

**England**
The Children and Families Act 2014 introduced the duty to make arrangements for pupils with medical conditions. The duty applies to all maintained schools and academies in England, and the requirements are explained in guidance issued by the Secretary of State. This duty came into force from September 2014.

Diabetes UK are campaigning to make sure that the individuals and organisations involved in the care of children in school are aware of, and understand their role in supporting children with diabetes in schools.

**Wales**

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² The Health Conditions in Schools Alliance is a coalition of over 30 organisations, representing the interests of children with a range of health conditions and chaired by Diabetes UK.
Welsh Government guidance explaining the support to be provided to children with diabetes in school can be found in the May 2010 paper, ‘Access to Education and Support for Children and Young People with Medical Needs’.

It has been produced for schools and local authorities across Wales and represents a key guidance publication for head teachers, school nurses and all school staff to ensure the children under their care are looked after properly. Diabetes UK Cymru believes it is also useful for parents because it provides a clear and accessible explanation of what care the school should provide for their child.

While the guidance document covers information on all medical conditions, a specific section on diabetes can be found on pages 85–87.

Scotland
There are various pieces of legislation that relate in some way to the rights of children with diabetes at school:
- Children and Young Person (Scotland) Bill (passed on 19 February 2014 but not yet in force);
- NHS (Scotland) Act 1978; The Functions of Health Boards (Scotland) Order 1991;
- the Education (Disability Strategies and Pupils’ Educational Records (Scotland) Act (2003);
- Standards in Scotland’s Schools etc Act 2000;
- Education (Scotland) Act 1980;

The last of these has the most current relevance for parents of children with diabetes at school. The concept of ‘additional support needs’ refers to any child or young person who, for whatever reason, requires additional support for learning. These needs can arise from any factor which causes a barrier to learning - social, emotional, cognitive, linguistic, disability, or family and care circumstances. Issues arising from managing diabetes while at school can, therefore, constitute an additional support need.

Impact will vary from child to child. However, it is how these factors impact on the individual child’s learning that is important and this will determine the level of support required.

Northern Ireland
Joint guidance, published by the Department of Education (DE) and the Department of Health, Social Services and Public Safety (DHSSPS) in 2008, sets out the key roles and responsibilities pertaining to the medication needs of school pupils in Northern Ireland. You can download ‘Supporting pupils with Medication Needs 2008’ on the Department of Education Northern Ireland website.
This requires schools to have in place a policy for ensuring that children with medication needs, such as insulin, will receive appropriate care and support at school.

Further information on the legal position in all nations is available on our website: http://www.diabetes.org.uk/Guide-to-diabetes/Schools/Diabetes-in-schools-legal-information/

To help those involved in looking after children with diabetes in schools Diabetes UK have developed specific resources for parents, schools and healthcare professionals:

http://www.diabetes.org.uk/schools

Diabetes UK calls to action

Providing children with the support they need to participate in all aspects of school life requires a coordinated effort, with the below individuals and organisations having the following responsibility:

Schools
The new duty (In England) gives responsibility to the governing body to make arrangements to support children with medical conditions in schools.

- **Headteachers, school governors and responsible bodies:**
  - must ensure that the school develops a medical conditions policy, which recognises that every child with a medical condition is different and must be treated as an individual. The medical conditions policy must acknowledge that medical conditions can be life threatening and can have an impact on a child’s ability to learn. The policy must clearly identify the roles and responsibilities of all those involved in supporting pupils at school with diabetes and must be regularly reviewed.
  - must ensure that sufficient staff have received suitable training and are competent before they take on responsibility to support children with diabetes. The medical conditions policy should make clear that the training delivered supports the needs of each child with diabetes. Training should be carried out by a paediatric diabetes specialist nurse.
  - must ensure that a child’s Individual Healthcare Plan is reviewed at least annually, or earlier if the child’s needs change – for example if they move from injections to an insulin pump. In this circumstance the staff member will also need new training.
- have overall responsibility for the development of individual healthcare plans for every child with diabetes. The headteacher will need to coordinate a meeting (or delegate coordination to a staff member) to discuss the child’s IHP with key school staff, the child and their parents and the paediatric diabetes specialist nurse.

- must make sure that all staff who need to know are aware that a child has diabetes. The headteacher must also make sure that all staff are aware of the policy for supporting pupils with medical conditions and their role in implementing it. All staff should be aware of a child’s Type 1 diabetes and all staff should know what to do in an emergency.

- have responsibility for ensuring sufficient trained staff are available to implement the policy and deliver against the individual healthcare plans. The headteacher will need to make sure the appropriate number of staff are always available, and make preparations for staff absence and turnover. They must make sure that staff are trained and signed off as competent by appropriately qualified medical staff (generally the PDSN) and that staff training is updated regularly, as a child’s care needs change. Diabetes UK recommends at least two members of staff being trained to support a child with diabetes at school.

- have responsibility for ensuring that school staff are appropriately insured and aware that they are insured to support children with diabetes.

- **Trained members of staff:**

  - Any member of staff can volunteer to look after a child with diabetes, whether they are a teacher, teaching assistant, a SENCO, pastoral year head, a deputy head or Headteacher.

  - There should be at least two trained members of staff to look after a child with diabetes, and staff should be trained and signed off as competent by a paediatric diabetes specialist nurse.

Further information for governors, responsible bodies and headteachers, including recommended content for the individual healthcare plan for children with diabetes, is available on the Diabetes UK website.

Further information for trained staff, including guidance on storing medication for children, and responding to emergency situations is available on the Diabetes UK website.

Further information for SENCOs and teachers is also available on the website.
Local Authorities:

In England:
- School nurses have a key role in coordinating support for children with diabetes. The local authority will need to be responsive through commissioning to the needs of schools and make sure there are sufficient school nurses to do this.

- Local authorities have a duty (under the Children Act 2004) to work with relevant partners to improve the health and wellbeing of a child in relation to their physical and mental health and education. Local authorities will therefore need to make sure that schools are well able to access nursing support for training from both school nurses and paediatric diabetes specialist nurses.

In Wales:
- Local authorities, local health boards and governing bodies should work together to ensure that children and young people with medical needs and school staff have effective support in schools.

- Local authorities provide a general policy framework of good practice to guide schools in drawing up their own policies on supporting children and young people with medical needs.

- All children and young people with complex health needs should have an identified key worker or care co-ordinator. The role is responsible for ensuring the delivery of an inter-agency care plan for the child and the family.

In Scotland:
- Local authority staff can undertake the administration of insulin for children/young people who are unable to do so themselves. Where a member of staff is not identified, the Quality Improvement Officer for Education (or equivalent) will assist the head teacher to make appropriate arrangements to ensure the health care needs of the child/young person are met.

- Local authority staff should be released to attend the necessary training in diabetes. Local authority staff who assist in the health care needs of a child/young person with diabetes will be fully supported by the local authority.

- **School Nurse**
  - The role of the school nurse is to work with the PDSN to make sure that there are enough teachers trained to look after children with medical conditions. For children with diabetes this may mean assisting with training members of staff.
- The school nurse should also have an up to date record of every child with diabetes in the schools they cover and a copy of their IHP. They may be involved in developing the IHPs.

Further information for school nurses is available on the Diabetes UK website.

**Local commissioning bodies (health boards in Wales, Scotland and Northern Ireland; CCGs in England):**

- The local commissioning body has a responsibility to make sure that commissioning is responsive to children’s needs, and that health services (usually PDSNs) are able to cooperate with schools supporting children with diabetes.

- **Paediatric Diabetes Specialist Nurses (PDSNs)**
  - PDSNs will need to provide training for all staff with responsibility for looking after children with diabetes. This will need to be tailored to the individual needs of the child.
  - PDSNs must be involved in developing and signing off the child’s IHP. They should attend the initial meeting to do this with the child, their parents and school staff and any subsequent meetings to amend the IHP.
  - Where required PDSNs may also be asked to provide general diabetes awareness training for the wider school staff.

Further information for PDSNs and the paediatric diabetes healthcare team is available on the Diabetes UK website.

**Parents and children**

- **Children**
  - Children with diabetes will often be best placed to provide information about how their condition affects them, and should be fully involved with discussions about their diabetes support needs and the development of their IHP wherever possible.

Dedicated information for secondary and primary school pupils is available on the Diabetes UK website.

- **Parents**
For parents, the key role is making sure that the school is up to date on managing their child’s diabetes, making sure the school has enough and appropriate equipment and giving consent for any medical treatment to be given at school. Parents may also have a role in delivering training for school staff and in helping draw up the Individual Healthcare Plan.

Further information for parents, including what they can expect from schools is available on the [Diabetes UK website](http://www.diabetes.org.uk/schools).

### Further information

- Diabetes UK information for schools, nurses and parents: [www.diabetes.org.uk/schools](http://www.diabetes.org.uk/schools)

### References

2) HSCIC (2012) National Diabetes Audit
3) Diabetes UK schools survey (2014)
Appendix one

What care to expect and unacceptable practice

Diabetes UK believes that every child with Type 1 diabetes deserves to have the same education as their classmates. This means:

- No child with Type 1 diabetes should be excluded from any part of the school curriculum.
- Every child with Type 1 diabetes should have access to extracurricular activities, including overnight stays and trips abroad.
- Schools, local authorities and health services should work together to make sure they meet the needs of children with Type 1 diabetes.
- Paediatric diabetes teams should provide training and support to schools, so school staff have the skills and confidence they need to look after a child with Type 1 diabetes.
- No parent should be relied on to go into school to treat their child’s diabetes.
- Every child with Type 1 diabetes should be allowed to inject insulin, in public or private, depending on their wishes.
- Every school should have a ‘medical conditions at school’ policy, which is updated every year.
- Every child with Type 1 diabetes should have an individual healthcare plan (IHCP), which details exactly what their needs are and who will help them.
- Parents should provide up-to-date information about their child’s needs and all the supplies needed to manage diabetes in school.
- Not assuming that all children with Type 1 diabetes have the same needs.
- All school staff should know what to do in case of emergency and at least two people should be trained in how to care for a child with Type 1 diabetes. Planned staff absences should be coordinated so that there is always one trained person in school.
- Schools and parents should agree on a clear method of communication.
- Children with Type 1 diabetes should never be left alone when hypo or be prevented from eating or drinking to prevent or treat a hypo.
- Children with Type 1 diabetes should never be prevented from blood testing or taking insulin and should be able to look after their equipment themselves.
- When children with Type 1 diabetes have exams, specific plans should be included in that year’s IHCP and agreed between the school, the child and their parents.
- Children with Type 1 diabetes should not be frequently sent home or penalised for poor attendance when absence is related to their diabetes.
- Every child with Type 1 diabetes should be listened to and their views taken into account.
Unacceptable practice

Only allowing a child with diabetes to take part in an extra-curricular activity or trip if one of their parents or carers accompanies them is not acceptable practice.

There are other unacceptable practices heads and governors must make sure do not take place in their school:

- No child should be prevented from treating themselves or managing their diabetes when and where necessary.
- No school should assume a child’s diabetes is the same as another child’s and requires the same treatment.
- The views of children with diabetes and their parents should not be ignored.
- Children with diabetes should not be sent home unnecessarily.
- If a child with diabetes requires treatment they should never be left unaccompanied or sent off to the medical room alone.
- A child should never have their attendance penalised for attending medical appointments to do with their diabetes. Their IHP should make clear how these are entered in the register so they are not penalised.
- Schools must not require parents to provide support in school for their child or make them feel obliged to do so.