

# Diabetes in children and young people

A guide for teachers and parents of children and young people in pre-school, early years, primary and secondary schools

**Produced by the South East Coast & London Diabetes Network** 



## Who is this document for?

This document is intended to enable schools to manage children and young people with diabetes effectively in a school setting.

Recommendations and guidelines contained within are derived from clinical practice at University College London Hospitals, the Hillingdon Hospital, St. Mary's Hospital and East Kent Hospitals and from contributions from stakeholders.

Due for revision: July 2025





## **CONTENTS**

Diabetes at school	4
Be diabetes-ready for school	5
Individual healthcare plan (IHP)	5
What to include in an individual healthcare plan	5
Detailed procedures and advice for schools	6
Responsibilities for helping children with their medical needs in a school or early years settir	ոց 10
Recommendations from the London and South East Coast Policy Guideline Group	13
Children aged five years and under	13
Primary school aged six years and up	14
Secondary school	14
Exceptional funding request	15
More detailed medical advice	15
Legislation	17
Checklist	19
Glossary	20
References	22
Guidance	22
Further reading	22
Further information available from Diabetes UK: www.diabetes.org.uk	23
Acknowledgements	24

## **Summary of recommendations**

- Every pupil with diabetes should have an individual healthcare plan (IHP).
- Each school should have an up-to-date medical conditions policy.
- Children and young people should have appropriate supervision depending on their individual needs.
- Children aged 5 and under will need a named adult and 1:1 support in the absence of parents.
- In primary school (6 years+) pupils will require support to manage their diabetes in school in line with the Children and Families Act 2014; they may need additional hours tailored to the need, age, and age at diagnosis of the child.
- In secondary school the pupil will be largely independent but may require intermittent support.

## **DIABETES AT SCHOOL**

Having diabetes has implications for a pupil's schooling and learning. It impacts on care given within schools and early years settings. Appropriate diabetes care is necessary for a pupil's immediate safety, long-term wellbeing, and optimal academic performance.

While some older pupils may be fully independent with their diabetes care, younger children, those with learning difficulties or those who are newly diagnosed are likely to need support and assistance from school staff during the school day to help them to manage their diabetes in the absence of their parents.

The 2010 Children, Schools and Families Act and the Children and Families Act 2014 introduced a legal duty on schools to look after children with medical conditions. This includes children with diabetes and so it is essential that all school staff and those who support younger children have an awareness of this medical condition and the needs of pupils during the school day.

## Get to know diabetes

## **Key facts**

- Diabetes is a condition in which a person's normal hormonal mechanisms do not control their blood glucose levels.
- About one in 700 school-age children in the UK has diabetes.
- Children with diabetes need daily insulin via injection or pump therapy and need to monitor their blood glucose level and eat regularly.
- In the UK, diabetes in children and young people is increasing.
- In London and the South East Coast there are approximately 6,000 children and young people with type 1 diabetes.
- Over 31,500 young people under the age of 19 in the UK are diagnosed with diabetes. Of these, about 95% have type 1 diabetes (insulin deficiency); the remainder largely have type 2 diabetes, in which insulin is produced but does not act properly.
- Insulin is the treatment for type 1 diabetes; tablet therapy can often be used to manage type 2 diabetes.
- Managing the demands of diabetes in daily life can be challenging.

## BE DIABETES-READY FOR SCHOOL

If a pupil is newly diagnosed with diabetes, their parents and a member of the hospital diabetes team should inform the school as soon as possible so arrangements can be made.

If the pupil is starting a new school, the school should be informed as soon as the place has been confirmed. Parents may wish to arrange an introductory meeting with the school's head teacher or responsible member of staff before the pupil enrols or when the pupil first develops diabetes.

## Individual healthcare plan (IHP)

When a pupil is first diagnosed, the relevant school staff (for example head teacher, nominated school staff or special educational needs coordinator) will need to work with the parents, the member of staff from the specialist diabetes team, school nurse (if available) and the pupil, where appropriate, to draw up a healthcare plan that sets out what support the pupil will need in school.

Example plans can be accessed at:

- University College London Hospitals www.uclh.nhs.uk/our-services/find-service/childrenand-young-peoples-services/children-and-young-peoples-diabetes/living-diabetes
- Diabetes UK www.diabetes.org.uk/resources-s3/2017-09/standalone-care-planicp1%25202-1duk%2520copyright.docx
- Digibete www.digibete.org

## What to include in an individual healthcare plan

An IHP should include the following details:

- Written permission from the parent/carer and the head teacher for insulin to be administered by a member of staff, or self-administered by the pupil during school hours.
- How the insulin dose should be calculated and the procedure for administering it via a pen device or an insulin pump.
- Who will help the pupil with medication and glucose and ketone monitoring and where these tasks can be undertaken safely, ensuring the dignity of the pupil is maintained.
- What help the pupil needs with diabetes management what they can do themselves and what help they need.
- Descriptions of the pupil's symptoms of hypoglycaemia and hyperglycaemia and what staff will do if either of these occurs.
- When a parent or carer should be contacted, and under what circumstances an ambulance should be called.
- What to do in an emergency, including who to contact.
- When a pupil needs to eat meals and snacks. If a pupil needs to go to the front of the lunch queue or have other arrangements at lunchtime these should be noted.
- What should be done before, during, and after physical education (PE) lessons. This might
  include the need for glucose monitoring, a snack or correction bolus if necessary or
  disconnecting a pump (if using one).
- Where insulin and other supplies will be stored and who will have access to them.
- What supplies will be needed, how often the supplies should be checked and by whom.

- Any specific support needed around the pupil's educational, emotional and social needs, e.g., how absences will be managed, support for catching up with lessons or any counselling arrangements.
  - N.B. It is recommended that children and young people attend routine clinic appointments to help them manage their diabetes. The frequency will be determined by their specialist diabetes team and will depend on how they are managing their diabetes.
- The names of trained members of staff along with a description of the training undertaken.
- What plans need to be put in place for exams/tests (if appropriate).
- What plans need to be put in place for any school trips (including overnight) or other school activities outside of the normal timetable.
- The date the plan should be reviewed.

Once the people involved in drawing up this plan are satisfied, the plan should be signed by the school, the parents and a member of the pupil's diabetes team. This should then be available to all relevant members of staff. The plan should be reviewed by the school, parents (and pupil where appropriate) and a member of the children's diabetes team at least every year or whenever the pupil's needs change.

## Detailed procedures and advice for schools

## **Glucose monitoring**

The effectiveness of diabetes management is assessed through monitoring glucose levels. Glucose targets are set at levels designed to protect each pupil's safety, on a day-to-day basis, for their long-term health. Persistent hyperglycaemia (a raised blood glucose over 14 mmol/l) increases the risk of developing long-term problems with nerves, kidneys, blood vessels and eyes.

In general, it is expected that young people check their glucose levels at a minimum of at breaktime, before lunchtime, before and after sport, and before leaving school to go home. This can be done either by finger pricking (self-monitoring blood glucose) or by using a continuous glucose monitoring (CGM) device.

- Self-monitoring blood glucose (SMBG): This is done using a finger-prick device (with a self-contained drum of needles/lancets). These devices are intended for self-monitoring of an individual person only.
- Continuous glucose monitoring (CGM): Many children and young people now use
  continuous monitoring devices, which means they don't have to do as many finger-prick
  tests. A sensor is worn on the body that reads the glucose levels and sends the information
  to a mobile phone or other device. Glucose levels are continually checked, and the phone
  will alert the pupil and/or carer if the glucose level is rising or falling, or is too high or too
  low.

Regardless of how the glucose level is checked, the results need to be interpreted. If they are outside the target range, they need to be acted upon by the young person (if old enough), parents, or, in the school setting, trained carers. Details about the individual's target levels should be available in their individual healthcare plan.

## Insulin calculation (using a bolus advisor within the pump or an app)

Children and young people with diabetes need to balance their insulin with the food that they are eating, their current blood glucose level, and the exercise they are undertaking. This can be done manually or automatically, by using bolus calculators in blood glucose meters, their insulin pump or an app. Increasingly, many people now carry a smartphone loaded with these medical apps and their phone is thus considered to be a medical device.

Insulin needs to be given with all food, snacks and drinks containing carbohydrates unless it is treatment for hypoglycaemia or being used to prevent low blood sugar (hypoglycaemia) when undertaking exercise.

Details about the individual should be found in their individual healthcare plan.

## **Carbohydrate counting**

Children and young people need to eat a healthy and balanced diet. Foods contain varying amounts of carbohydrate, protein, fat, vitamins, minerals and water. Carbohydrates in foods raise blood glucose levels quickly. Therefore, the carbohydrates eaten or drunk need to be matched with insulin; this is done by 'carbohydrate counting'.

Pupils with diabetes can have either packed lunches or school meals. Parents can calculate the amount of carbohydrates in packed lunches. For those wanting to have school lunches, the parents and diabetes team dietitian can help calculate the carbohydrate content using the school menus and by contacting the providers of school meals. Schools should supervise younger children at lunchtimes to ascertain how much of their meal they have eaten, and the carbohydrates consumed. The amount of carbohydrates in the food eaten is used to determine the amount of insulin needed.

## Administration of insulin (using either a pen or a pump)

For a pupil with diabetes, insulin is delivered as either 'basal' insulin or 'bolus' insulin. Basal insulin is a long-acting (slow) insulin injection given in the morning and/or evening. Basal insulin given by injection is usually given at home and is therefore not usually needed within school. On a pump, basal insulin is the background insulin delivered continuously via the insulin pump.

Bolus (fast acting) insulin needs to be given whenever a pupil is having a meal or snack. An insulin bolus may also be given without food whenever the blood glucose level rises higher than the target, to bring the glucose down to within the target range. This insulin is given either via a pen device or by pressing buttons on the insulin pump.

Some pupils manage their diabetes using an approved hybrid closed loop system. This is software run on a smartphone which takes readings from a continuous glucose monitoring sensor (CGMS) and sends automatic instructions to the pupil's insulin pump to increase or decrease the amount of insulin being provided. It is important to note that in these cases the insulin pump is controlled by instructions from the smartphone and therefore the pupil may need to make additional manual adjustments to their insulin using the phone.

DIY closed loop/open source app systems use app software that permit communication between an insulin pump and the CGMS. This enables insulin delivery to be automatically adjusted in response to the glucose level in real time. Although this system is currently not approved by regulatory bodies, the local diabetes team fully supports the family's decision to use this modern technology. As this is an unapproved system, it is the responsibility of the pupil's family to provide 'hands-on' training about its usage. Please direct any queries to the pupil's family. However, your local paediatric diabetes team will continue to provide your school staff with all general education, support and training regarding diabetes management.

Details of individual pupils' insulin regimens should be available in their IHPs.

## Activity and exercise within the school environment

It is important for their long-term health that pupils with diabetes take part in physical education (PE) and other physical activity. The impact of activity on glucose levels will vary depending on the intensity and duration of the activity and on the timing of the activity relative to the timing of insulin dosages. Planning is required in relation to additional glucose monitoring before and after activity or consumption of additional carbohydrates. If the pupil is using an insulin pump, decisions are necessary relating to whether the pump should be disconnected, or whether temporary basal rates should be set.

## Awareness of the impact of stresses within the school environment

Stress (including anxiety about possible bullying or pressure related to exams) can also impact on blood glucose levels. This fluctuation may be outside the pupil's control and therefore needs to be taken into consideration when assessing performance. High blood glucose levels will make students feel tired and thirsty, will make them need to urinate frequently and will generally make concentration difficult. In contrast, low blood glucose levels will have a behavioural and cognitive impact both at the time when they are found to be low and for up to four hours after the level has normalised. Low levels are likely to affect mental flexibility, planning, decision-making, attention to detail and response times.

## Assistance if feeling unwell due to low blood glucose hypoglycaemia

At all ages, pupils with diabetes may require help to perform a glucose test when the blood glucose is low. In addition, many pupils with diabetes need a reminder to eat or drink during hypoglycaemia and must not be left unsupervised until such treatment has taken place and the blood glucose value has returned to the normal range.

## **Emergency management of severe hypoglycaemia (low blood glucose levels)**

Hypoglycaemia is often accompanied by specific signs and symptoms such as trembling, fast heart rate, pallor, sweatiness and/or difficulty concentrating, blurred vision, difficulty hearing, slurred speech, poor judgement and problems with short term memory (neurological dysfunction). The blood glucose level at which signs and symptoms occur may vary according to the individual. Young people may also exhibit behavioural or mood changes when their blood glucose levels fall but remain within or above normal range.

The severity of hypoglycaemic episodes can be described on a scale of mild, moderate and severe.

If a pupil has previously experienced severe hypoglycaemia it may be recommended by the pupil's healthcare team that the school keep glucagon on the premises. Glucagon is a hormone that raises blood glucose rapidly. Additional advice will be provided by the diabetes team, and volunteers or first aiders will need to be trained in how to give this.

In severe hypoglycaemia, the young person may not be able to assist in their own care and may become semi-conscious or unconscious. Urgent treatment is required but it is unsafe to give any treatment by mouth. In this instance, the school should ring 999 and then contact the parents.

## Assistance if unwell due to high blood glucose levels/illness

Special consideration must be given to pupils who appear unwell or who become unwell during the school day due to either high glucose levels or illness. For some children and young people progression into diabetic ketoacidosis (DKA) can be rapid and can result in death.

Pupils at a higher risk of DKA include those where there are known safeguarding and social concerns and those where compliance with diabetes management within the home is poor. Specific concerns, when known by the diabetes team, will be communicated with school staff during school care planning. Specific instructions to be taken by school staff acting in loco parentis will be documented within the school care plan and this will include blood ketone testing as standard practice when the pupil is unwell/has high blood glucose levels (hyperglycaemia). Pupils will have been issued a blood ketone meter following diagnosis and instructed to test for ketones during periods of illness/feeling unwell.

Staff requiring additional advice and support should be encouraged to contact the parents in the first instance. Where parents/guardians are unavailable or where information is deemed inappropriate or unreliable, or where documented guidance appears unclear, school staff are encouraged to contact their local diabetes team for advice. The course of action to be followed can be discussed, thus maximising the safety of the pupil and preventing development of DKA.

Where a pupil is sent home from school unwell, handover must be to a responsible adult who has received training in the management of diabetes; this will include having access to both glucose and blood ketone monitoring equipment.

## **Exams and technology**

Diabetes technology has advanced significantly over the last few years, and this has changed the way children and young people with diabetes are supported with managing their condition in school.

This is particularly important during exams, as appropriate use of technology will enable the pupil to perform to the best of their ability on the day. By monitoring their glucose levels during exams, pupils can correct glucose levels that are too low or too high, or that are dropping or rising too quickly.

There may be concerns about the use of mobile phones at school, and particularly in exams. When the connection between the diabetes device and the phone is via Bluetooth, the phone will still work as a receiver without Wi-Fi and with the phone in airplane mode. The mobile will need to be within six meters of the student with appropriate alerts on. Alerts relating to glucose levels that are too high or too low can be put on vibrate, so as not to disturb others. Only urgent alerts that require immediate attention cannot be muted. Do speak to the pupil or contact the diabetes team to discuss any concerns further.

Restricted access to mobile phones would prevent the pupil from managing their diabetes. This would increase the risk of serious immediate and long-term problems. Therefore, where possible, alternative sanctions may be required for inappropriate use of mobile phones.

In order for pupils to use mobile phones as medical devices during exams, the individual school's exam officer must make an application under access arrangements before 31 March in the year of the examination. More information about access arrangements and reasonable adjustments is available at <a href="https://www.jcq.org.uk/wp-content/uploads/2020/10/AA\_regs\_20-21\_FINAL.pdf">www.jcq.org.uk/wp-content/uploads/2020/10/AA\_regs\_20-21\_FINAL.pdf</a>.

Additional information for school staff is readily available via the Diabetes UK website.

## Residential trips

Pupils with diabetes should not be excluded from extra-curricular activities and residential trips.

Additional planning and staff training may be needed before planned residential trips. This can be provided in collaboration with the family and the specialist diabetes team.

Additional information on school trips can be found on the Diabetes UK website at www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/school-staff/school-trips

# Responsibilities for helping children with their medical needs in a school or early years setting

#### Head teacher

We recommend that the head teacher of the school or early years setting is responsible for ensuring:

- The school has an up-to-date medical conditions policy statement in place. A template can be accessed at www.diabetes.org.uk/resources-s3/2018-11/1201BD\_Sample%20 medical%20conditions%20policy\_DIGITAL.pdf
- Policy states the designated senior member of staff and the procedures for pupils who have been diagnosed with diabetes.
- All school/setting employees are aware of a pupil having diabetes, are able to obtain the
  pupil's individual healthcare plan in the school setting and know how to assist them when
  necessary in a diabetes emergency (especially hypoglycaemia).
- A minimum of two staff members are selected for training in the management of each individual pupil's diabetes. The local diabetes team can provide training to school staff. These members of staff may be asked to supervise or perform:
  - glucose testing/monitoring,
  - calculations of insulin doses,
  - o insulin injections using an insulin pen,
  - giving an insulin dose using a subcutaneous insulin infusion pump, as outlined in the IHP.
- Safe storage of diabetes containers (containing, if necessary, insulin injection devices as well as hypoglycaemic treatment) is established, together with the safe disposal of used needles/'sharps'.
- The school and its employees do not discriminate against pupils with diabetes, thereby enabling pupils with diabetes to participate fully in all aspects of school life, including physical and extra-curricular activities.

Visit the Diabetes UK website for more information: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/school-staff/responsibilities-headteachers-school-governors-responsible-bodies

#### School staff

We recommend trained members of school staff are responsible for carrying out or supervising:

- Glucose monitoring just before a meal or snack according to the training received.
- Insulin dose calculation with meals according to the training received.
- Mealtime insulin via pen or insulin pump according to the training received.

The specialist diabetes team recommend an initial practice period of two weeks, with the volunteer member of school staff observing the parent for one week and then the parent observing the volunteer, until both are confident.

Visit the Diabetes UK website for more information: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/school-staff/responsibilities-teachers

## **Child/young person**

Children and young people should be allowed, as much as possible, to manage their own diabetes at school with relevant parental consent, to the extent that is appropriate for the child's developmental stage and his or her experience with diabetes.

The extent of a young pupil's ability to participate in their own diabetes care should be agreed upon by senior school staff, the parent/carer, the pupil and the specialist diabetes team. The ages at which a pupil is able to perform self-care tasks are very individual and variable, and the capabilities and willingness to provide self-care should be acknowledged in each pupil's IHP.

Visit the Diabetes UK website for more information: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools

## Specialist diabetes team

The specialist diabetes team will offer training to the volunteers from the school setting, to include (as required by the individual healthcare plan):

- Training on the individual healthcare plan
- Training on glucose monitoring
- Training on insulin dose calculation
- Training on insulin administration

The team will also assist parents in assessing staff competency and provide support with care planning including trips.

## **Training**

Ongoing training should be provided annually where required by the specialist diabetes team. This can be delivered either face-to-face, or virtually where appropriate to do so.

This will include:

- Overview of diabetes
- Treatment of hypoglycaemia and hyperglycaemia
- Managing exercise
- When to seek help
- Documentation and training requirements
- Delivering insulin and monitoring glucose

A record should be made when training has completed.

Additional training can be provided at the school's request.

#### Parent or carer

Parents or carers who have legal responsibility for the young person with diabetes are strongly encouraged to liaise with the head of the school/establishment and the specialist diabetes team to provide the school/establishment/setting with adequate, up-to-date information about the pupil's diabetes and treatment.

They will be responsible for providing the school with:

 Sufficient information about their child/young person's diabetes and how it is managed, including what help they will need and how any treatment changes and day-to-day events might affect their diabetes at school.

- All materials and equipment necessary for diabetes care tasks, including glucose
  monitoring and insulin administration (if needed). The parent/carer is responsible for the
  maintenance of glucose monitoring equipment (i.e., cleaning and performing controlled
  testing as per the manufacturer's instructions).
- Supplies to treat hypoglycaemia.
- Information about their child/young person's meal/snack schedule. The parent should work
  with the school to coordinate this schedule with that of other pupils as far as possible. For
  young children, instructions should be given in the individual healthcare plan for when food
  is provided during school parties and other activities.
- Information about the carbohydrate content of the pupil's lunch if they are taking a packed lunch. If the pupil is eating school meals the catering company will need to provide this information to the person calculating the carbohydrate content. A 'carbs and calories' book may help to work it out.
- Emergency phone numbers for the parents/guardians and the diabetes team so that school/establishment personnel can make contact in times of emergency or where there are any queries.
- Specific advice for school staff regarding school trips, exams and so on as appropriate, for inclusion in the IHP.

Where volunteers are being trained to supervise or perform any diabetes tasks, the parent or carer will sign the IHP to show that they have agreed to this arrangement.

Visit the Diabetes UK website for more information: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/parents/what-are-my-responsibilities

#### Children's services/social worker

Children and young people with type 1 diabetes and their families may need additional support:

- Living with type 1 diabetes can stretch the resources of the family and can be a source of anxiety or stress within the household.
- A secure home environment and healthy family relationships will help the family and young
  person undertake the intensive self-management necessary to look after their diabetes.
  Support in these areas may therefore be required to prevent a negative impact on their
  health and education.

School staff and healthcare professionals, supported by their respective safeguarding teams, should ensure that they communicate with each other when potential concerns are identified. Strong communication will enable identification of families who would benefit from additional support and allow referrals to children's services to be comprehensive.

When support from children's services is being provided to a child/young person and their family, school staff and healthcare professionals will work closely with social workers to promote positive interactions between home life, education and health (physical and mental).

# RECOMMENDATIONS FROM THE LONDON AND SOUTH EAST COAST POLICY GUIDELINE GROUP

Pupils have differing support needs depending on their age, their stage of diabetes and whether they have any learning difficulties. There is currently no nationally agreed funding structure to support the funding of additional support staff.

The information below is an example of good practice relating to funding allocation within the Borough of Islington and can be referred to as a general guide.

There are different ways one-on-one support can be provided depending on an individual's need. This could be from a named member of staff who is trained and available to help through the day as needed. Alternatively, it could be from a trained person who only has responsibility for the child and is physically with them at all times throughout the day. If it is decided by the school and/or child's parent that the second option is appropriate, this can be funded through an education, health and care plan from the local authority. The specific number of hours a child needs will vary and should be agreed on an individual basis.

## Children aged five years and under

Child/young person	Care required	Funding
The pre-school/reception age child is unable to perform any diabetes tasks.  The child will need one-on-one support of some description from a named adult who is trained to undertake these tasks. How this looks will vary from child to child.	<ul> <li>An adult to administer insulin (via a pen or pump).</li> <li>An adult to carry out, monitor, record and act on blood glucose readings.</li> <li>Additional observation and/or intermittent problem-solving interventions when the signs and symptoms of diabetes ensue.</li> <li>Supervision to assess for signs and symptoms of hypo- and hyperglycaemia.</li> <li>Supervision at meal or snack times to assess how much carbohydrate is consumed.</li> <li>Staff should be trained in interventions required if a young person is hypoglycaemic.</li> </ul>	<ul> <li>School allocation</li> <li>Exceptional funding request</li> <li>50/50 split between the local council and the local ICS</li> </ul>

## Primary school aged six years and up

Child/young person	Care required	Funding
The primary school aged child is unable to manage independently.  The care required is such that a child requires the support of a trained adult to manage their diabetes in school.  The child is expected to cooperate with staff in ensuring that diabetes tasks are performed within school (unless hypoglycaemic).	<ul> <li>An adult to administer insulin (via a pen or pump).</li> <li>An adult to carry out, monitor, record and act on blood glucose readings and in some cases to carry out blood glucose testing.</li> <li>Supervision at meal or snack times to assess how much carbohydrate is consumed.</li> <li>Supervision to assess for signs and symptoms of hypo- and hyperglycaemia.</li> <li>Adult supervision if the child is hypo- and hyperglycaemic unaware.</li> <li>Staff trained in interventions if a young person is hypoglycaemic.</li> </ul>	<ul> <li>School funding. This level of support should be provided by the school, in line with the Children and Families Act 2014, and funded from the school's existing budgets.</li> <li>Exceptional funding request</li> </ul>

## **Secondary school**

Child/young person	Care required	Funding
The student requires regular but time-limited adult support to supervise/oversee largely independent management of their diabetes.  Children with additional needs may require further help and support.	<ul> <li>Reminders to administer insulin and test blood glucose levels.</li> <li>Staff should be trained in interventions required if a young person is hypoglycaemic.</li> <li>Support to allow blood glucose testing in class and treatment of hypoglycaemia.</li> <li>More intensive support and supervision for periods of time if the young person is struggling to manage their diabetes and/or during exams and residential trips.</li> <li>Specific adherence to individualised care plans for pupils where safeguarding concerns relating to diabetes management have been identified and the pupil may be at increased risk of acute diabetes-related complications.</li> </ul>	School allocation

## **Exceptional funding request**

- In exceptional circumstances some children may require additional support whilst attending school – for example, children who have hypoglycaemia (low blood glucose) without visible symptoms or children who are non-compliant with their diabetes management. If a child has exceptional circumstances and requires higher levels of support whilst attending school, additional funding can be applied for.
- Funding requests must be made to the local Education, Health and Care Management Board with a supporting letter from the child's specialist diabetes team outlining why the child has exceptional needs and is requiring additional support whilst attending school.
- The additional funding will be time limited depending on the child's support needs and will be reviewed in the time period specified at the Education, Health and Care Management Board. It will be expected that schools will continue the care of these children once additional funding has been stopped in the time specified.
- Exclusion and inclusion criteria may apply; for example, funding may only be available for children registered with a GP within the funding authority and those who are resident elsewhere but looked after by the local authority.

## More detailed medical advice

## Hypoglycaemia and seizures (fits)

Approximately 31% of children with type 1 diabetes experience severe hypoglycaemia at some point due to the difficulty in balancing insulin with activity and diet in a growing child. Very young children may be unable to identify symptoms or to verbalise them, and as activity levels are harder to predict, they are at greater risk of severe hypoglycaemic episodes. This is especially problematic as the early years are also the time of most rapid brain development with critical periods for the development of various skills and abilities.

Learning and memory are the abilities most likely to be affected by hypoglycaemia as well as motor speed, visuospatial skills, attention, memory and executive function.

Mild symptomatic or asymptomatic hypoglycaemic episodes, which all pupils with diabetes experience, may cause transient cognitive deficits, especially in planning and cognitive flexibility, sustained attention span, and reaction time, with a cumulative, negative effect on the pupil's performance in the classroom setting.

Children diagnosed at a young age may have more seizures due to the behavioural and medical challenges of disease management in young children.

Seizures are related to the smallest overall cognitive effects but may be greater for children who have chronic poor metabolic control (who have been shown to have lower scores on psychometric tests in individual studies).

## Hyperglycaemia

Repeated hyperglycaemia causes a rise in a blood test marker known as HbA1c. A persistent raised HbA1c demonstrates poor control of glucose levels over the previous three months. This contributes to an increased risk of complications of diabetes, including problems with eyes (retinopathy), kidneys (nephropathy) and tingling in hands and feet due to nerve damage (neuropathy). Extreme hyperglycaemia due to lack of insulin can cause diabetic ketoacidosis (DKA). This is a condition that occurs when insulin is missing and the body compensates by breaking down fat and creating acids in the blood. This can lead to acute illness, loss of consciousness and even coma or death. Severe DKA may result in central nervous system damage. Whilst it was originally thought that non-DKA episodes of hyperglycaemia were likely to

have little or no effect on cognitive function, research is now beginning to suggest that there may indeed be consequences through disruption of brain structures and neurotransmitter regulation in the developing brain.

Children with elevated glucose levels have problems with memory and executive functioning, fine motor control and motor reaction tasks. Hyperglycaemia has also been found to specifically affect verbal intelligence and spatial intelligence, information processing speed and sustained attention.

## Individual variables – age at onset of diabetes

Hypoglycaemia and hyperglycaemia have different effects on cognitive function determined partly by the amount of exposure during development, but not by age of onset. The most potent predictor of learning is disease duration. Cumulative and chronic exposure to the metabolic abnormalities typical of diabetes is a major risk factor related to poorer learning over time. Episodes of severe hypoglycaemia have been shown to significantly predict lower verbal and full-scale IQ at six years after diagnosis. In studies, spatial intelligence and delayed recall were reduced following repeated hypoglycaemia, especially when episodes began before the age of five years.

## **Developmental course**

The brain is thought to be particularly vulnerable to the effects of hypoglycaemia. The cognitive effects from hypoglycaemia, although mild, appear relatively quickly following diagnosis.

Puberty is considered an independent risk factor for the complications of diabetes due to hormonal changes that may lead to increased risk of hyperglycaemia. Executive function deficits are seen in adolescents with diabetes, regardless of the age of onset. Those who developed diabetes during later childhood and adolescence also showed poorer scores on tests of vocabulary and general knowledge.

## Impact on functioning at school

Medical research studies help us to understand the impact of diabetes on the ability of children to function and learn at school.

Although boys and girls with diabetes have been reported to achieve IQ scores in the average to high average ranges, the group mean has been found to be three to seven points lower than that of a control group. These mild difficulties may have a cumulative effect and in particular may create subtle difficulties for specific groups of children.

It is unclear whether the impact on intelligence, memory and other cognitive functions is reflected in everyday cognitive, social or academic functioning. Mild hypoglycaemic episodes have an influence on attention, psychomotor speed and memory. Teachers may not be aware if a pupil is experiencing hypoglycaemic attention difficulties and so may fail to provide appropriate support.

There is evidence of poorer school achievement among children with diabetes, especially in reading and spelling. Children with diabetes, and especially those who have experienced severe hypoglycaemia, have more learning difficulties reported by parents and need more part-time special education than unaffected children. Up to one third of boys with diabetes are reported by their parents to have had learning difficulties at some point in their school career. In one study, 17% had received a formal diagnosis of learning difficulty or hyperactivity and 29% had resource room instruction at some point. 40% of the boys with diabetes had either had special input, repeated a school year, or both. 4% of the girls had repeated a year and 12% had received special intervention. The number of girls receiving special instruction was double that of those without diabetes.

There may be both direct and indirect effects on day-to-day functioning that become apparent over time. It is essential therefore to monitor and detect change with an individual pupil over time. It is also important to make sure that any progress is sufficient and adequate for the individual.

## **LEGISLATION**

## The Children and Families Act 2014

Section 100 of the Children and Families Act 2014 introduced a legal duty on schools to look after children with medical conditions. This includes children with diabetes. Schools must make arrangements to support pupils at school with medical conditions and have regard to the statutory quidance.

#### The Education Act 2002

Sections 21 and 175 detail how governing bodies of maintained schools must promote the wellbeing of pupils and take a view to the safeguarding of children at the school.

## Section 3 of the Children Act 1989

This places a duty on a person with the care of a child to do all that is reasonable in the circumstances for the purposes of safeguarding and promoting the child's wellbeing. In relation to a child with diabetes, this will mean knowing what to do in the event of an emergency.

## Legal duties on local authorities

Local authorities have legal responsibilities to help make sure schools can meet the duties relating to children with diabetes. These duties refer to all children in the local authority and they do not depend on the kind of school the child attends.

#### Section 10 of the Children Act 2004

This is a particularly important piece of legislation if schools are struggling to get the support and training they need to look after a child with diabetes properly.

Section 10 essentially means the local authority must make arrangements to promote cooperation between the authority and relevant partners. Relevant partners include the governing body of a maintained school, the proprietor of an academy, clinical commissioning groups (CCGs)\* and NHS England. They must make arrangements with a view to improving the wellbeing of children, including their physical and mental health, protection from harm and neglect, and education.

## **Working Together to Safeguard Children 2018**

This sets out the safeguarding responsibilities for all agencies working with children. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/942454/Working\_together\_to\_safeguard\_children\_inter\_agency\_guidance.pdf

#### Section 17 of the Children Act 1989

This gives local authorities a general duty to safeguard and promote the welfare of children in need in their area. If a school is looking after a child with diabetes so poorly that the child is put in danger, the local authority must step in.

## Section 3 of the NHS Act 2006

This gives clinical commissioning groups (CCGs)\* a duty to arrange for the provision of health services to the extent the CCG considers it necessary to meet the reasonable needs of the persons for whom it is responsible. What this means is that CCGs should provide the healthcare the people in its area need, if these needs are reasonable.

This section also provides for CCGs to arrange such services as it considers appropriate to secure improvements in physical and mental health of, and in the prevention, diagnosis and treatment of illness in, the persons for whom it is responsible.

In relation to children with diabetes, this means that a CCG should, within reason, make sure support and healthcare is in place to improve their health or at least keep them healthy. Poor management of diabetes at school will obviously affect the health of a child. If a school is unable to get the support it needs to help manage a child's diabetes successfully then both the local authority and the local CCG have a responsibility to the child's health and welfare.

## **Equality Act (2010)**

The equality act says that types of discrimination are illegal, defining discrimination as when a person with a disability is treated less favourably, because of his or her disability, than a person who does not have a disability. The Equality Act 2010 defines a disability as a 'physical or mental impairment' that has 'a substantial and long-term adverse effect' on an individual's ability to carry out 'normal day-to-day activities'. A substantial adverse effect is a negative effect that is more than trivial, and the effect is long-term if it has lasted or is expected to last for more than twelve months. Whilst only a court or tribunal can decide whether a person with diabetes is covered by the definition, in many cases diabetes is covered by the definition in the Act.

Education and early years providers have a duty to make reasonable adjustment for people with disabilities and failure to make reasonable adjustments is a form of discrimination. The Act covers all schools and providers of early years settings that are covered by the early years' framework in England, including maintained (non-fee paying) and fee-paying schools.

\*Note: On 1 July 2022, 42 integrated care systems were established across England on a statutory basis. Integrated care systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area. ICSs include integrated care partnerships (ICPs), integrated care boards (ICBs), local authorities, place-based partnerships and provider collaboratives. The establishment of ICBs resulted in clinical commissioning groups (CCGs) being closed down.

At the time of writing, the relevant pieces of legislation included here had not yet been updated to reflect this change.

## **CHECKLIST**

		Yes	No	Requires action by whom/when
1	Has the school got a medical conditions policy? A template can be accessed from Diabetes UK: www.diabetes.org.uk/resources-s3/2018-11/1201BD _Sample%20medical%20conditions%20policy_DIGITAL.pdf			
2	Has the individual healthcare plan been agreed by the parents, school and diabetes team?			
3	Does a risk assessment need to be completed e.g., disposal of sharps/safe storage of insulin?			
4	Are there two nominated individuals to support with care required?			
5	<ul> <li>Is the pupil of nursery/primary school age? If so:</li> <li>Is one-on-one support available for this child?</li> <li>Is an educational health and care plan application needed via the local authority?</li> </ul>			
6	Have the nominated individuals accessed training to enable them to support the young person appropriately?			
7	Is there a system to cascade important information to all relevant staff members? Have they had awareness training?			
8	Are there any staffing implications?			
9	Have learning needs been reviewed?			
10	Have the parents/carers provided emergency supplies to be available on site?			

## **G**LOSSARY

Term	Description
Basal insulin	Basal insulin, also known as background insulin, is a slow-acting type of insulin. Its role is to keep blood glucose levels consistent during periods of fasting.
Blood ketones	Ketones are substances made by the body when the cells don't get enough glucose (blood sugar). Glucose is the body's main source of energy. Ketones can show up in blood or urine. High ketone levels may indicate diabetic ketoacidosis (DKA), a complication of diabetes that can lead to a coma or even death.
Bolus insulin	A bolus dose is insulin that is specifically taken at meal times to keep blood glucose levels under control following a meal. Bolus insulin needs to act quickly, and so short-acting or rapid-acting insulin will be used.
Carbohydrate	Carbohydrates are found in a wide array of both healthy and unhealthy foods – bread, beans, milk, popcorn, potatoes, biscuits, spaghetti, soft drinks etc. The healthiest sources of carbohydrates are unprocessed or minimally processed whole grains, vegetables and fruits.
Continuous glucose monitoring sensor (CGMS)	A small medical device that is worn at all times; it gives a continuous readout of estimated blood glucose levels. It measures the amount of glucose in the fluid that surrounds the body cells, called interstitial fluid (not the actual blood glucose). Depending on the technology used, the glucose level can be transmitted in real time to view on a screen within an insulin pump, a separate linked 'reader' device or an app on a smartphone, meaning that 'real time' estimated glucose levels are available any time of day or night without having to perform a finger prick blood test. CGM systems can alert the user when the glucose level is either too high or too low.
Continuous subcutaneous insulin infusion (CSII)	CSII or insulin pump therapy involves wearing a device (insulin pump) which provides a steady stream of insulin into the body.
СҮР	Children and young people
Diabetic ketoacidosis (DKA)	A serious condition that can lead to diabetic coma (passing out for a long time) or even death. When the body's cells don't get the glucose they need for energy, the body begins to burn fat for energy, which produces ketones. When ketones build up in the blood, they make it more acidic. High levels of ketones can poison the body.
ЕНСР	Education, health and care plan

Flash glucose monitor (FGM)	A small medical device that is worn at all times, containing a sensor that estimates blood glucose. It is most commonly inserted into the back of the upper arm with the tiny sensor sitting just under the skin. It measures the amount of glucose in the fluid that surrounds the body cells, called interstitial fluid (not the actual blood glucose). A handheld 'reader' device or app on a smartphone can be swiped over the sensor at any time for an estimated glucose reading, meaning that glucose levels are available any time of day or night without having to perform a finger prick blood test. The device can be enabled to alert the user when the glucose level is too high or too low.
Glycaemia	The presence of glucose in blood.
HbA1c	An important average measure of how well a person's diabetes has been controlled over the previous two to three months.
Hyperglycaemia	High blood sugar levels
Hypoglycaemia	Low blood sugar levels
IHP	Individual healthcare plan
Insulin	A hormone made by the pancreas that allows the body to use sugar (glucose) from carbohydrates in the food. In people with diabetes, this may need to be given by injection.
Lancets	A blood lancet is a pricking needle used to obtain drops of blood. It is often used within a device.
Nephropathy	Diabetic nephropathy (or diabetic kidney disease) is a progressive kidney disease caused by damage to the capillaries in the kidneys.
Neuropathy	Damage to or dysfunction of nerves. Neuropathy typically results in numbness, tingling, muscle weakness and/or pain. Diabetes can cause neuropathy as a result of high blood glucose levels damaging the small blood vessels which supply the nerves.
Retinopathy	Also known as diabetic eye disease, is when damage occurs to the retina due to diabetes. It can eventually lead to blindness.
'Sharp'	Any object that could readily puncture or cut the skin of an individual when encountered.
Type 1 diabetes	People with type 1 diabetes cannot make insulin because the beta cells in their pancreas are damaged or destroyed. Therefore, these people need insulin injections to allow their body to process glucose and avoid complications from hyperglycaemia.
Type 2 diabetes	People with type 2 diabetes do not respond well or are resistant to insulin. They may need insulin injections to help them process sugar and to prevent long-term complications from this disease. People with type 2 diabetes may first be treated with oral medications, along with changes to their diet and exercise.

## REFERENCES

## Guidance

- Osha.europa.eu. European Agency for Safety and Health at Work. Union Directive 2010/32/EU - prevention from sharp injuries in the hospital and healthcare sector; 2014. Available from: https://osha.europa.eu/en/legislation/directives/council-directive-2010-32-eu-prevention-from-sharp-injuries-in-the-hospital-and-healthcare-sector
- Gov.uk. UK Government. Supporting pupils at school with medical conditions; 2014.
   Available from: www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3
- Hse.gov.uk. Health and Safety Executive. Health and safety (Sharp instruments in healthcare) Regulations www.hse.gov.uk/research/rrhtm/rr1127.htm
- Guidance for employers and employees; 2013. Available from: www.hse.gov.uk/pubns/hsis7.pdf
- uclh.nhs.uk Living with diabetes: Sample care plan; 2015. Available from: www.uclh.nhs.uk/our-services/find-service/children-and-young-peoples-services/children-and-young-peoples-diabetes/living-diabetes

## **Further reading**

- Cameron FJ, Northam EA and Inder TE. Diabetes and the developing brain. In: (eds Dattani M, Hindmarsh P, Carr L, Robinson ICAF). Neuroendocrine disorders in children. Mac Keith Press, London. 2016.
- Cato MA, Mauras N, Ambrosino J, et al. Cognitive functioning in young children with type 1 diabetes. J Int Neuropsychol Soc. 2014;20(2):238-247. doi:10.1017/S1355617713001434
- Fleming M, Fitton CA, Steiner MFC, et al. Educational and Health Outcomes of Children Treated for Type 1 Diabetes: Scotland-Wide Record Linkage Study of 766,047 Children. *Diabetes Care*. 2019;42(9):1700-1707. doi:10.2337/dc18-2423
- Gaudieri PA, Chen R, Greer TF, Holmes CS. Cognitive function in children with type 1 diabetes: a meta-analysis. *Diabetes Care*. 2008;31(9):1892-1897. doi:10.2337/dc07-2132
- Hannonen R, Komulainen J, Riikonen R, et al. Academic skills in children with early-onset type 1 diabetes: the effects of diabetes-related risk factors. *Dev Med Child Neurol*. 2012;54(5):457-463. doi:10.1111/j.1469-8749.2012.04248.x
- Shalimova A, Graff B, Gąsecki D, et al. Cognitive Dysfunction in Type 1 Diabetes Mellitus. J Clin Endocrinol Metab. 2019;104(6):2239-2249. doi:10.1210/jc.2018-01315

# Further information available from Diabetes UK: www.diabetes.org.uk

- Children with diabetes at school: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools
- Treating diabetes information for school staff: www.diabetes.org.uk/guide-todiabetes/your-child-and-diabetes/school-staff
- Diabetes in schools the IHP a child's individual healthcare plan: /www.diabetes.org.uk/resources-s3/2017-09/standalone-care-plan-icp1%25202-1duk%2520copyright.docx
- Diabetes in schools responsibilities of headteachers, school governors and responsible bodies: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/school-staff/responsibilities-headteachers-school-governors-responsible-bodies
- Sample medical conditions policy: www.diabetes.org.uk/resources-s3/2018-11/1201BD\_Sample medical conditions policy\_DIGITAL.pdf
- Diabetes in schools responsibilities of trained staff: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/school-staff/responsibilities-teachers
- Diabetes in schools information for parents: www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/parents/what-are-my-responsibilities

## **ACKNOWLEDGEMENTS**

This policy was originally developed through collaboration with Healthy London Partnership (children and young people programme), Diabetes UK and the five London paediatric diabetes networks. It has since been updated by the South East Coast and London CYP Diabetes Partnership.

We would particularly like to express our appreciation to the initial working group:

- Heather Bird, Senior Policy Officer, Diabetes UK
- Elle Dormer, Parent
- Ashley Dartnell, Parent
- Libby Dowling, Senior Clinical Advisor, Diabetes UK
- Professor Peter Hindmarsh (Chair), South East Coast and London Diabetes Partnership Board, Professor of Paediatric Endocrinology and Divisional Clinical Director for Paediatrics and Adolescents at UCLH
- Dr Jaikumar Ganapathi Paediatric Clinical Lead, The Hillingdon Hospital NHS Foundation Trust
- Kate Fazakerley, Parent
- Charles Gostling, GP and Diabetes Clinical Director Health Innovation Network
- Sally Lydamore, School Nursing Service Manager, Camden
- Sara Nelson, Assistant Programme Lead, Children and Young People's programme, Healthy London Partnership
- Bridget Turner, Director of Policy and Care Improvement, Diabetes UK,
- Chris Owen, Programme Manager, Schools Health & Wellbeing Research Network, UCLP
- Usha Parkash, SEC and London Paediatric Diabetes Partnership Manager
- Tracy Parr, Head of Children and Young People's programme, Healthy London Partnership Network, and Consultant in Adolescent Medicine, University College Hospital
- Roz Rosenblatt, London Region Manager, Diabetes UK
- Professor Russell Viner, Clinical Director, Healthy London Partnership and Consultant in Adolescent Medicine, University College Hospital
- Helen Walter, Head of Health, Greater London Authority

Thank you to the following for their contribution to the revised edition (2022):

- Chris Bound, Lead Nurse, Children's Diabetes Team, St. Mary's Hospital
- Jennifer Brunsdon, Lead Nurse, Children's Diabetes Team, East Kent Hospitals University Foundation Trust
- Dr Peter Christian, Paediatric Clinical Lead, East Kent Hospitals University Foundation Trust
- Anne Corbett, Head of Richard Cloudesley Outreach Service, Islington
- Steve Green, Deputy Head Teacher and Examinations Officer, Royal Free Hospital Children's School
- Rebecca Martin, Nurse Consultant, University College London Hospitals Foundation Trust
- Dr Abigail Price, Paediatric Consultant, East Kent Hospitals University Foundation Trust
- Andrew Simpson, SENCO, Brockhill Park Performing Arts College, Kent

#### Thanks also go to:

- The Wessex Diabetes Network for their work to produce a position statement on the use of mobile phones for diabetes management in schools
- The Children and Young People's Wales Diabetes Network schools working group for their work on an all-Wales policy on the use of DIY closed loop/opensource apps for the treatment of type 1 diabetes in a school or educational environment.