Supporting children and young people with diabetes

RCN guidance for nurses in schools and early years settings
Acknowledgements

This publication has been updated and revised by the following members:

Marie Marshall, Children’s Diabetes Nurse Specialist and Co-ordinator of the Children and Young People’s Diabetes Community
Katie Beddows, Children’s Diabetes Nurse Specialist
Louise Collins, Children’s Diabetes Nurse Specialist
Carole Gelder, Children’s Diabetes Nurse Specialist
Amanda Mackin, Children’s Diabetes Nurse Specialist
Grace Parfitt, Children’s Diabetes Nurse Specialist

The RCN sincerely thanks the working party members that produced the first edition of this publication:

Louise Collins, Children’s Diabetes Nurse Specialist
Emma Day, Clinical Nurse Specialist
Joy Winks, School Nurse Advanced Practitioner and Chair of the RCN School Nurses Forum
Supporting children and young people with diabetes

RCN guidance for nurses in schools and early years settings

Contents

1. Introduction 2

2. Relevant legislation and guidance across the UK 2
   England 2
   Wales 3
   Scotland 3
   Northern Ireland 3

3. Policy intent 3

4. Key facts: the Equality Act 2010 4

5. Education and training to meet health needs 4

6. Increasing awareness 5

7. Individualised care plans 5
   Emergency procedures 5

8. Difficulties in accessing support 6
   Responsibility 6
   Statement process 6

9. Essential supplies for children and young people with diabetes 7

10. Summary 9

11. References 9

12. Useful websites and sources of further information 11

Appendix 11
Care pathway for child or young person returning to school following a diagnosis of diabetes 12
Introduction

The RCN is aware of inequality in the care provision for children and young people with diabetes in schools and early years settings. This document outlines the principles that health care professionals and education staff should apply to ensure the needs of children and young people with diabetes are met. The aim is to ensure that children and young people receive appropriate intensive therapies, without prejudicing their health or education.

Relevant legislation and guidance across the UK

England

Several reports published in recent years highlight the importance of diabetes care provision in schools and early years settings. A survey of primary schools and local education authorities – carried out in 2007 by Diabetes UK – revealed that despite 60 per cent of primary schools having written guidance or protocols, few are specific enough to cover blood glucose monitoring, or give or supervise medication administration. It also found that, where children were unable to inject themselves, parents were providing injection support in 70 per cent of schools (Diabetes UK, 2007).

A Department of Health working group examined the current challenges surrounding children and young people with diabetes, producing the report Making every child with diabetes matter (DH, 2007). The need for effective, integrated and accessible services for children and young people and their families was set out in the Every Child Matters documents in 2003 and 2008 (HM Government, 2003; 2008). Managing medicines in schools and early years settings (DH, 2007) also outlined the need for schools to ensure that all children and young people with diabetes have an individualised care plan.

The National Service Framework (NSF) for diabetes is made up of 12 standards all of which relate to children and young people with diabetes. Standard five specifically identifies the care that they should receive in order to optimise their blood glucose control, and their physical, psychological, intellectual, educational and social development (DH, 2001). More recently, the Children and Young People’s Health Outcomes Forum highlighted the need to address support for children and young people with long-term conditions such as diabetes in light of poorer outcomes in comparison with other European countries (Children and Young People’s Health Outcomes Forum, 2012). Relevant legislation includes the Special Educational Needs and Disability Act 2001 (amendment of Disability Discrimination Act 1995). This is described in more detail on page four.

Diabetes UK has also worked in collaboration with Asthma UK, the Anaphylaxis Campaign and Epilepsy Action to produce guidance on how to develop a school-wide policy for children with long-term medical conditions.

The guidance, entitled Medical conditions at school: A policy resource pack, is available from www.medicalconditionsatschool.org.uk
**Wales**

The Welsh Assembly has produced a new guidance document: *Access to education and support for pupils with medical needs*. In May 2007, *Designed for the management of type 1 diabetes in children and young people in Wales: consensus guidelines – standards 5 and 6 National Service Framework* was also developed. This document makes specific reference to diabetes in schools, reinforcing the need for children and young people to receive appropriate individualised care and support, within educational settings.

**Scotland**

The Education (Additional support for learning) (Scotland) Act (2004) places duties on education authorities to identify, meet and keep under review the additional support needs of all pupils for whom they are responsible, including pupils with diabetes. The Education (Disability Strategies and Pupils’ Educational Records (Scotland) Act (2003) also places duties on bodies responsible for schools to prepare an accessibility strategy which sets out their plans to ensure access to the curriculum, physical environment of schools and school information. There are also examples of good practice – for example, in 2008 Fife Council Education Service produced a policy for the management of diabetes in schools, which may be used country-wide.

**Northern Ireland**

The Department for Education in Northern Ireland has issued guidance relating to the administration of medicines in schools. In addition, recently updated disability discrimination acts provide protection for young people with diabetes.

**Policy intent**

Government policy on children and young people aims to be inclusive and child-centred. The prevalence of type 1, type 2 and other forms of diabetes amongst children and young people is increasing (Diabetes UK, 2008). It should be noted that the management of diabetes in children and young people is very different and more complex than it is for adults (DH, 2007 Gaudieri et al 2008). Most noticeable in recent years has been the increasing incidence in type 1 diabetes in the under five-year-olds (Patterson et al. 2009). It is vital that all schools actively support children and young people with diabetes to manage their life-long condition during school life. The most recent document from Diabetes UK calls for partnership working between schools, local authorities and primary care trusts (Diabetes UK, 2008). It has been estimated that children spend about 15,000 hours at school, between the ages of five and 16 years (Llahana, Poulton and Coates, 2001).

Good diabetes control means that children are:

- at a reduced risk of complications
- not disadvantaged in their learning and academic achievement
- not prevented from participation in school and extra curricular activities.

Diabetes should not be the cause for a child being excluded from any type of activity, nor for non-attendance at nursery, school or college. Research suggests that children with diabetes miss significantly more school than both their non-diabetic siblings and their peers (Glaab, Brown and Daneman, 2004). Education and social integration within school and early years settings are of fundamental importance to a child or young person with diabetes (DH, 2007).

This guidance provides support and direction to individuals who are caring for children and young people with diabetes in schools and early years settings by:

- looking at what underpins practice
- signposting to various fundamental resources
- increasing awareness of roles, responsibilities and the formulation of individualised management plans.
**Key facts: the Equality Act 2010**

It is important for nurses to ensure that schools are aware of the Equality Act 2010 which has replaced the Disability Discrimination Act 1995. This act describes the principles that education providers should follow in their treatment of people with diabetes and applies in England, Scotland and Wales but not in Northern Ireland.

It should be acknowledged that many people do not classify diabetes as being a disability, however the condition can still be covered by the act because it is a life-long condition and can seriously affect a person's ability to do normal day-to-day things. According to the act the education provider has a duty to make reasonable adjustments to enable children and young people with diabetes to have their needs met. It should be acknowledged that some adjustments are simple to make but others may require more organisation or planning. Diabetes UK (2011) suggested the following as the type of adjustments that education providers should be able to make in order to meet the needs of children and young people with diabetes:

1. Being able to plan and access meals, as more and more children are on intensive insulin regimens, then each education provider should be able to supply the nutritional information that children and young people with diabetes require.
2. Being prepared to make reasonable adjustments to exam and course work conditions if necessary – for external exams, it is imperative that the education provider is aware of the child or young person with diabetes sitting the exam as soon as possible so that the examination board can also be made aware.
3. Be able to provide an appropriate place to administer medication and test blood glucose levels and ketones as deemed necessary.

**Education and training to meet health needs**

The RCN believes it is imperative for children and young people in schools and early years settings to receive appropriate health care and support for their diabetes:

- staff in schools and early years settings should receive appropriate and consistent training, advice and support from health services and children's diabetes specialist services
- a child or young person's diabetes should be managed effectively in school and early years settings, ensuring optimal glycaemic control
- training and guidance should be offered to schools when a child or young person is newly diagnosed. Regular updates should be offered according to local policy, but at least annually
- schools and early years settings should be able to access training from children's diabetes specialist nurses (CDSN), school nurses or community children's nurses, according to local service provision.
6
Increasing awareness

What does having a child/young person with diabetes in school involve? The management of their condition should include the following essential elements:

- monitoring blood glucose levels and when appropriate blood ketone monitoring
- taking medications and supporting changing treatment regimens
- treating emergency situations, such as hypoglycaemia or illness that has an associated effect on diabetes
- access to a healthy balanced diet
- participating in physical activity programmes
- participating in extra curricular and social activities.

- the care plan should be universally available to all school personnel. It should be signed off by a Children’s Diabetes Specialist Nurse*, parents/carers and school/nursery staff
- individualised care plans should be regularly updated, at least on an annual basis or whenever there are any changes to the child or young person’s care.

The individualised care plan should include:

- guidance and interpretation of blood glucose monitoring and targets
- guidance and interpretation of blood ketone monitoring
- provision of a clean environment, availability of hand washing facilities
- guidance surrounding the administration or supervision of and adjustment of insulin doses if required in school
- hypoglycaemia, hyperglycaemia, illness management, individualised treatment plan and the provision of emergency supply boxes
- sport and exercise management, including potential off-site activities such as playing sport at other schools
- support of administration of insulin including treatment changes (in order to prevent exclusion or transitional difficulties)
- food and dietary management, facilitation of carbohydrate counting
- emergency procedures.

Examples of current school management can be seen on the RCN’s website: www.rcn.org.uk/cyp_diabetes_community

The individualised care plan should describe all parties’ responsibilities regarding diabetes supplies and provisions.

7
Individualised care plans

The RCN believes that:

- all children and young people with diabetes should have an agreed individualised care plan (DH, 2007)
- care plans should be formulated jointly by the child or young person, parents/carers, community nurse or Children’s Diabetes Specialist Nurse, and school nurse, and agreed by a designated person – usually the head teacher or special educational needs co-ordinator (SENCO), within the school or early years setting

* In conjunction with the child’s school nurse and/or community children’s nurse, according to local service provision.

Emergency procedures

The RCN believes that:

- all early years and school settings should have arrangements in place for dealing with emergency procedures, as part of their general risk management processes
UK (2011) underlines the fact that parents always have the main responsibility for the health care of children and young people with diabetes in the school environment but also reason that this should not mean that school expect parents to come into school to meet their regular medical needs on a daily basis. Parents are responsible for keeping the education provider informed about the medical needs of their children and ensuring the school is supplied with all essential medical supplies.

There is no legal duty for members of staff in schools to give regular medical assistance unless it forms part of their job description. School staff, have a common law duty of care towards pupils and students. This duty does not include the administration of regular insulin injections. However schools must make reasonable adjustments to enable children and young people with diabetes not to be at a disadvantage which may well include employing someone with the skills required to administer insulin during the school day.

Volunteers

If the education provider does not employ members of staff whose job descriptions include administration of medication then a reasonable adjustment would be to ask for members of staff to volunteer. It is then essential that these volunteers receive appropriate training from the children's diabetes team.

Statement process

The statement process may allow for an application to be made to the local authority to provide financial support for extra staff for children and young people with diabetes who need extra support. While every local authority has its own criteria, many schools currently use school action and school action plus to denote children who need different levels of intervention in the classroom. These can be used to enable a child with diabetes to get extra support. This is funded via the existing special educational needs budget in schools.

More information can be found at: www.parentpartnership.org.uk

Parents may also find the following document a useful resource, Special educational needs, a guide for parents and carers (DCSF, 2009).
Essential supplies for children and young people with diabetes

Information should be in the child or young person's individualised care plan.

<table>
<thead>
<tr>
<th>Item</th>
<th>Parents’ responsibility</th>
<th>Early years/ school responsibility</th>
<th>Child/young person’s responsibility when deemed competent</th>
<th>Paediatric diabetes specialist nurse</th>
<th>School nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individualised care plan</td>
<td>Formulation of plan and to update information when necessary</td>
<td>All school personnel to be aware of plan and what care it includes</td>
<td>Formulation of the plan and to update information when necessary</td>
<td>Formulation of plan and provide training in order for information to be disseminated</td>
<td>Dietician to be involved where available</td>
</tr>
<tr>
<td>Emergency supply box</td>
<td>To provide box and contents</td>
<td>To make accessible to child/young person/staff To make parents aware when supplies are low</td>
<td>To make parents aware when supplies are low</td>
<td>To provide training as to the correct use of the box</td>
<td>May provide training as to correct use of box</td>
</tr>
<tr>
<td>Insulin injection and pump supplies</td>
<td>To provide all supplies of insulin, pens, needles, reservoirs and cannulas, batteries</td>
<td>Provision of fridge space for spare supplies of insulin Provide clean and private environment</td>
<td>To make parents aware when supplies are low</td>
<td>To guide parents as to when supplies may need to be replenished</td>
<td>None</td>
</tr>
<tr>
<td>Blood glucose and ketone testing supplies</td>
<td>To provide supplies of lancets, blood glucose strips and quality control (QO) solutions To be aware when replenishment of supplies is necessary</td>
<td>Provide correct storage of supplies where necessary and request for extra supplies or training when required Provide clean and private environment To give permission for the child/young person to test whenever required</td>
<td>To make parents aware when supplies are low</td>
<td>To provide training in order to initiate blood glucose testing</td>
<td>None</td>
</tr>
</tbody>
</table>
## Essential supplies for children and young people with diabetes

<table>
<thead>
<tr>
<th>Item</th>
<th>Parents’ responsibility</th>
<th>Early years/school responsibility</th>
<th>Child/young person’s responsibility when deemed competent</th>
<th>Paediatric diabetes specialist nurse</th>
<th>School nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality control of blood glucose meter</td>
<td>To carry this out according to local policy</td>
<td>None</td>
<td>None</td>
<td>To train parents to carry out, following local guidelines</td>
<td>To support if required</td>
</tr>
<tr>
<td>Sharps disposal</td>
<td>To provide sharps bin (refer to local policy)</td>
<td>To make parents aware when sharps bin is two-thirds full</td>
<td>To make parents aware when sharps bin is two-thirds full</td>
<td>To provide parents with information about local policy</td>
<td>To provide parents with information about local policy</td>
</tr>
<tr>
<td>Extra food</td>
<td>To provide food for snacks and exercise as required</td>
<td>To make parents aware if running out of food for snacks and exercise. To give permission for child/young person to eat whenever required</td>
<td>To make parents aware when more food supplies are required</td>
<td>Information can be included about supply during treatment</td>
<td>None</td>
</tr>
<tr>
<td>Risk assessment</td>
<td>To provide information to facilitate risk assessment</td>
<td>To initiate and complete risk assessment documentation</td>
<td>To participate in risk assessment where possible</td>
<td>To provide specialist information as required</td>
<td>To provide specialist information as required</td>
</tr>
</tbody>
</table>

In order for the above to be achieved, children’s diabetes services must work closely with local children’s services to ensure that all children are able to access safe and appropriate care in school and early years settings. Local protocols should be in place, which should be drawn up jointly by health services and local authorities.
Summary

The RCN believes that:

- the needs of children and young people with diabetes are paramount
- treatment regimens should be led by clinical need, rather than the level of support available in schools and early years settings
- children and young people with diabetes should have equitable access to all curricular and extra curricular activities
- where support is required, training should be provided to identified personnel by appropriately trained health care professionals*
- a child or young person with diabetes should have sufficient support to ensure optimal glycaemic control within the school environment, enabling them to meet their full academic capability.

The RCN calls for:

- all education staff involved with children and young people with diabetes to receive specific training to facilitate individual needs
- every school and early years setting to have an agreed guidance document on the management of diabetes in school
- every child or young person with diabetes to have an individualised management plan, agreed by relevant parties
- every child and young person with diabetes to be able to participate in all curricular and extra curricular activity
- every child and young person with diabetes to receive support to manage their diabetes to ensure glycaemia control.

Examples of current school management plans can be accessed via www.rcn.org.uk/cyp_diabetes_community

References


Department for Children, Schools and Families (2009) Special educational needs, a guide for parents and carers, London: DCSF.


Diabetes UK (2011) Education and diabetes Your rights in early years settings, schools, and further and higher education.


* These may be children’s diabetes specialist nurses, school nurses or community children’s nurses, according to local service provision.


Useful websites and sources of further information

Department for Education
www.dfe.gov.uk

Department of Health
www.dh.gov.uk/government/organisations/department-of-health
Tel: 020 7210 4850

Diabetes UK
www.diabetes.org.uk

Diabetes UK Care line: 0845 120 2960
www.diabetes.org.uk/sharedpractice

Disability Rights Commission merged into the newly created Equality and Human Rights Commission in 2007
www.equalityhumanrights.com

Medical Conditions at School
www.medicalconditionsatschool.org.uk
A partnership of organisations – including Diabetes UK – working collaboratively to support schools to provide a safe environment for children and young people with medical conditions. A policy resource pack is available.

Juvenile Diabetes Research Foundation
www.jdrf.org.uk
Tel: 020 7713 2030

Medicalert
www.medicalert.org.uk
Tel: 0800 581 420

National Institute for Health and Care Excellence (NICE)
www.nice.org.uk

TeacherNet
www.teachernet.gov.uk
The education site for teachers and school managers.

The Equality Act 2010 full test is available to view and download from www.legislation.gov.uk
Appendix

Care pathway for child or young person returning to school following a diagnosis of diabetes

This pathway represents good practice of what should happen when a child or young person has been newly diagnosed with diabetes.

CYP newly diagnosed with diabetes

Identify school or early years service, notify school nurse/health visitor of diagnosis

Identify personnel to be trained within school or early years service

Designate day of return for child or young person

Child or young person not requiring insulin in school

On day of return, paediatric diabetes specialist nurse attends to teach diabetes care. Ensure negotiated care plan is formulated and school staff are adequately trained to adhere to plan

Parents to be made aware of need to support school until training can be offered by professional

Child or young person requiring insulin either via injection or CSII in school

Support by parent/carers for lunchtime insulin until training can be accessed

Updates

Annually when child or young person changes class or as required for trips/events
The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

August 2013
Updated and reprinted in November 2013

RCN Online
www.rcn.org.uk

RCN Direct
www.rcn.org.uk/direct
0345 772 6100

Published by the Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

020 7409 3333

Publication code 003 318

ISBN 978-1-908782-77-9