

POSITION STATEMENT

CARING FOR CHILDREN WITH TYPE 1 DIABETES IN NURSERIES

Last reviewed: April 2016

KEY POINTS:

- All nurseries should look after and support children with Type 1 diabetes so they remain safe, healthy and able to participate in all nursery activities.
- Children with Type 1 diabetes should have access to a nursery place of their parent's choice and be looked after by suitably trained staff to make sure they can participate in all nursery activities.
- All nursery staff caring for children with Type 1 diabetes should 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 nursery to meet their child's needs which relate to their Type 1 diabetes, or be made to feel obliged to support their child during their time at nursery.
- Each child needs 1:1 support, but how this manifests itself will vary from child to child.

Introduction

There are approximately 1700 children under the age of 5 living with Type 1 diabetes in England and Wales¹, and 110 in Scotland². Indeed, the steepest rise in diagnosis of Type 1 diabetes is in this age group, so the number of children with diabetes in nurseries is likely to increase³.

Prior to starting full time education, children may attend a nursery for part or all of the day. In England, parents are currently entitled to 15 hours of free childcare per week when their child is 3 or 4 years of age⁴.

In addition to this, parents of children who have a current statement of special education needs (SEN) or an education, health and care (EHC) plan, or are in receipt of certain benefits such as Disability Living Allowance, are entitled to 15 hours of free childcare per week when their child reaches their second birthday⁵.

Parents can ask for an EHC needs assessment

only if their child has or may have educational needs – not where there are only health or care needs, no matter how severe those needs might be. However, it is possible for Type 1 diabetes to impact on a child's ability to the extent that it can be considered a disability for the purposes of eligibility for both SEN and EHC plans. This may be, for example, if a child's Type 1 diabetes is difficult to manage in such a way as to impact on their ability to learn. This could in turn mean that the child might be defined as having a SEN. Further information on SEN and EHC plans can be found below.

Diabetes UK makes recommendations in the following areas:

- Medical conditions policies
- Individual healthcare plans
- Emergency situations
- Nursery staff training
- Nursery staff availability

Current situation

Children with Type 1 diabetes should be able to attend a nursery of their parent's choice and that nurseries should make all reasonable arrangements to help them to care for the child.

We know that this is achievable and that it is happening, as parents have told us in a recent Diabetes UK survey⁶ and social media discussion⁷.

Parents have told us that nurseries are often able to make the necessary arrangements to care for the child appropriately using existing staff and budgets⁸.

However, we are aware that some nurseries need to improve their practice, as we have also heard from a number of parents who are either having difficulty accessing a nursery place for their child or who are concerned about the quality of care once the child is there⁹.

Given the evidence that many nurseries have successfully made the necessary arrangements to care for a child with Type 1 diabetes, with the right information, procedures and support in place to meet the recommendations set out in this position statement, all nurseries should be expected to provide the appropriate diabetes care.

GOOD PRACTICE

We asked parents in the survey what kind of support their child with Type 1 diabetes receives at their nursery¹⁰. Many of the responses we received revealed that there are great examples of good practice within nurseries.

The following anecdotes are provided from parents' responses to this question about what support their child is receiving. These illustrate the type of practice which Diabetes UK recommends for every nursery in the UK.

"1:1 care key worker but other members of staff are trained to test and administer correction doses / enter carbs into her blood tester... Staff have a small diary which notes how she has been through the session including any blood results, corrections and snacks".

"Named keyworker to ensure she is safe whilst in their care and administer insulin".

"All the teachers and TAs [teaching assistants] are trained (nursery is in a school setting)".

"His key worker is his main support and is available most of the time when needed, but all the staff in his room and the line manager are all trained too and they try taking it in turns in pairs to do his pump, tests and carb counting so they are all confident".

"His key worker undertook all the training along with the pre-school managers, there was never any issue with continuity of care".

"He had a member of staff dedicated to his care – all staff were aware of hypos".

Furthermore, we received several excellent examples of good practice in nursery settings from direct comments posted on our Facebook page in response to our call for comments from parents on their experiences of nursery care for their child with Type 1 diabetes¹¹. These are set out below.

"My nursery is fab with my daughter. Her key worker has fully taken on care and responsibility for the time she is there. Nothing is an issue and she's not afraid to ring to ask or check something with her pump if she is unsure".

"The preschool nursery our daughter attends has been fantastic. One week after diagnosis, all staff had received training to recognise signs of hypos and hypers, test blood and administer insulin. They count and keep a log of the carbs she eats each day and the blood test results which we have to sign off at end of day. If she has a low test result they are confident, just four months on, to treat it. We couldn't be more at ease and confident with their level of care.

"My son's nursery was amazing – [they] offered to pay for training to monitor his sugar levels and treat hypos initially, but then the NHS actually went out to give them a morning of training where they could ask as many questions as they wanted and get to know how to use the monitor and testing strips, and how to spot signs of hypos – they were amazing and have since trained the rest of their nursery staff up on how to look after my son".

"[My son's nursery] have been absolutely fantastic with him. Giving extra snacks and extra testing when running a little low, giving corrections when high, ringing me whenever they have any doubts about anything. I have been very pleased and relieved!"

"They were amazing! Took all the training on board, made sure all nursery staff and administrator trained by nurses. Took guidance from me too. Full communication of all glucose, ketones, activity, foods eaten... Always truly concerned and interested in [my son's] wellbeing. Obtained funding for inclusion to ensure [he] had a second member of staff to help with his care. Follow all statutory guidance and laws too. Not fazed by pump or continuous glucose monitoring when introduced part way through the year".

"All the staff were fantastic with her and a couple volunteered to check her blood levels and deliver her insulin... as long as I detailed the amount of

carbs in her lunch box. It worked really well for us all and I only remember receiving one phone call that they couldn't cope".

"[My son] attends two different pre-school / nursery settings, and both have been totally amazing. With the support and dedication of our diabetic nurse, the staff have all been trained and [my son] is now back being tested by them at set times throughout the day".

POOR PRACTICE

A concern which was raised to us related to the attitude and behaviour of nursery staff. A parent who responded to the survey highlighted "staff reluctance for retraining" when staff who were trained to look after children with Type 1 diabetes ended their employment with the nursery.

Another individual, for example, referred to those who worked at their child's nursery as being "frightened of [their] son's condition and overwhelmed". They also pointed to the importance of nursery workers demonstrating compassion towards their child.

Current situation: legal

This section explains the legal requirements on nurseries to look after children with Type 1 diabetes. Although these represent a number of ways in which to hold nurseries to account legally as a last resort if they consistently fail to meet fundamental standards, parents should first work closely with the nursery team to discuss what could be improved.

THE EQUALITY ACT 2010

Under the Equality Act, nurseries in England, Scotland and Wales have legal duties to children with Type 1 diabetes, who fall within the legal definition of disabled persons. Nursery schools maintained by the local authority and nursery education provided by schools both have the same obligations as schools under the Act. Other early years providers (such as private nurseries and play groups) are additionally covered by the Act as service providers.

Under the Act, all nurseries have a duty to make reasonable adjustments for disabled children to prevent them being put at a substantial disadvantage compared with their peers. Importantly, this duty is anticipatory, which means that adjustments must be put in place in advance to prevent disadvantage from occurring at all.

This is particularly relevant to nurseries in making

sure they have enough staff trained so that a child with Type 1 diabetes can take part in all aspects of nursery life. If all the trained staff were to leave, contingency plans must be in place to train replacements quickly.

The Act also states children with disabilities must not be discriminated against, harassed or victimised.

You can find out more about the Act on the [Equality and Human Rights Commission](#) website.

THE DISABILITY DISCRIMINATION ACT 1995 (NORTHERN IRELAND)

In Northern Ireland, the equivalent legislation to the Equality Act is the Disability Discrimination Act 1995 (Northern Ireland).

This piece of legislation imposes a duty on service providers to make reasonable adjustments for disabled people of all ages to help them to overcome barriers that they may face in accessing and using services.

THE EARLY YEARS FOUNDATION STAGE STATUTORY FRAMEWORK

In England, it is mandatory for nurseries (as registered early years providers) to meet the standard outlined in the [Early Years Foundation Stage Statutory Framework](#). This framework sets the standards for learning, development and care for children from birth to the age of five.

Under this framework, nurseries must meet certain requirements in relation to health and medicines. Providers must have, and implement, a policy and procedures for administering medicines, and "training must be provided for staff where the administration of medicine requires medical or technical knowledge".

THE SPECIAL EDUCATIONAL NEEDS AND DISABILITY CODE OF PRACTICE: 0 TO 25 YEARS

This [Code of Practice](#) is statutory guidance for organisations which work with and support children and young people who have special educational needs (SEN) or disabilities.

The key points of relevance to this position statement, relating to access for children with diabetes and the provision of appropriate care, are covered in the Equality Act 2010 and the Framework respectively.

WHERE NURSERY CARE IS INADEQUATE

If parents feel that the care and support that their child's nursery provides is failing to meet these legal duties and standards, they should raise this with the nursery staff and discuss opportunities for improving the care provided in order to meet these duties. If nursery staff consistently refuse to engage with these discussions, or there is a consistent failure to meet these standards despite such discussions, then parents could consider a legal solution as a last resort.

Recommendations

This section sets out Diabetes UK's recommendations for nurseries on the level and nature of care which needs to be in place in all nurseries. There should be specific legislation or statutory guidance which incorporates, at a minimum, these recommendations. However, in the absence of such legislation or statutory guidance, the below recommendations provide the framework of guidance for nurseries and parents using their services about what they should expect.

These recommendations have been developed by taking into account the views of parents and healthcare professionals that were gathered in the survey¹², the social media responses¹³ and in recent collaborative guidance¹⁴.

MEDICAL CONDITIONS POLICIES

The nursery should have a medical conditions policy, which recognises that every child with a medical condition is different and must be treated as an individual.

Type 1 diabetes is a complex condition which needs careful management by people with the appropriate level of understanding and skills.

- The policy must acknowledge that medical conditions can be life-threatening, and can impact upon a child's development.
- It must clearly identify the roles and responsibilities of all those involved in supporting the child with diabetes whilst they are at nursery.
- It must be regularly reviewed.

INDIVIDUAL HEALTHCARE PLANS

The nursery should have in place an individual healthcare plan for every child with Type 1 diabetes.

The nursery needs to coordinate a meeting between the child's parents and the paediatric

diabetes specialist nurse (PDSN) to discuss the child's specific needs and the care that needs to be provided. They must then draw up an individual healthcare plan together which includes the child's full care needs and how they will be met in each case.

EMERGENCY SITUATIONS

The nursery should ensure that all staff are aware of a child's Type 1 diabetes and that all staff know what to do in an emergency.

NURSERY STAFF TRAINING

The nursery should ensure that sufficient staff receive adequate training from a PDSN to enable them to look after children with Type 1 diabetes.

There should always be a sufficient amount of staff who have the right skills and knowledge to provide an adequate level of care and support for all children in the nursery who have Type 1 diabetes. This must include ensuring that there enough adequately trained staff at all times, including when there are staff absences and during times of staff turnover.

The exact number of adequately trained staff that is appropriate will vary between nurseries. However, there should be at least two such members of staff per nursery who are trained to administer insulin and check blood glucose levels. Furthermore, the numbers of staff who are trained should not significantly exceed this number to ensure that those who are trained are able to practise their skills frequently, and thus maintain their competence and build trust with the children.

The PDSN at the nursery should ensure that all such members of staff are able to provide adequate care and support for children with Type 1 diabetes before they take on the role by providing support, education and guidance. The ultimate responsibility for ensuring that children are cared for by staff who are competent for their roles, however, lies with the nursery itself.

NURSERY STAFF AVAILABILITY

The nursery should ensure that sufficient staff are available at all times to care for the child with Type 1 diabetes.

Due to the high support needs of children in this age group, all children with Type 1 diabetes should have 1:1 support whilst they are at nursery, in the sense that there should always be a trained member of staff available throughout the day to support the child. However, the way in which 1:1 support is provided may vary, depending on the specific needs of the child. Additionally, it should be

agreed between the parents, the PDSN and the nursery.

Anecdotal evidence has been gathered from clinical experts from Spain, Sweden, Portugal, Belgium, Ireland and Canada through the SWEET diabetes network, which is composed of European and national diabetes organisations.¹⁵ This demonstrates that the consensus is that most cases of 1:1 support is provided in the form of a trained named member of staff (for example, the child's key worker) who is available to help throughout the day as needed. It is not common practice for support to be provided in the form of a trained person who has responsibility for one child only and is physically with them at all times throughout the day. This is not only because it is difficult for nurseries to financially support, but also because it makes it harder for a child to be normalised within the nursery environment and increases the risk of discrimination.

If 1:1 support involving one person with sole responsibility for a child with diabetes is considered, it should be a decision which is made on a case-by-case basis and is tailored to meet the child's clinical, emotional and physical care needs.

The role of parents

Parents should not be required to go into nursery to meet their child's needs which relate to their Type 1 diabetes, such as visiting the nursery on a regular basis to administer insulin, or be made to feel obliged to support their child during their time at nursery.

However, it is reasonable for nurseries to anticipate that parents provide them with their contact details in case of emergency, alongside all other necessary information about their child which enables the staff to provide them with adequate care. This could take place at an initial meeting with nursery staff at the point when the child commences their attendance at the nursery.

EHC plans

Where parents feel that the arrangements made or proposed by the nursery are insufficient, they and the nursery may decide to apply for an Education, Health and Care (EHC) plan to meet the needs of the child.

EHC plans replaced Statements of SEN for Children, and Learning Difficulties Assessments for Young People with SEN, in September 2014. Parents can ask for an EHC needs assessment if their child has or may have educational needs – it does not apply where there are only health or care needs, no matter how severe those needs might be. However, if a child's Type 1 diabetes is difficult to manage, this could impact on their ability to learn

and so could mean that the child might be defined as having an SEN.

Parents who feel that their child's Type 1 diabetes is causing them to be held back at nursery, and who believe that the nursery is not able to provide the help and support they need, can request an EHC assessment. This is done by contacting the local authority where the nursery is based. Parents who do this themselves should let the nursery know. The local authority will then decide whether to issue an EHC plan for that child based on the evidence provided on the child's educational needs. Local authorities should work closely with the local paediatric diabetes team and the child's family to ensure that the individual needs of children are taken into account when making decisions on EHC plans.

Children who attend nurseries that are able to follow the recommendations set out above will hopefully not need extra support. If parents do feel that an EHC plan is necessary however, they could contact the Independent Parental Special Education Advice (IPSEA), whose website is provided below.

Further information

- For more information on the Diabetes UK Advocacy Service, please go to www.diabetes.org.uk/How_we_help/Advocacy/
- Additionally, information on Diabetes UK's Care in School Helpline can be found at www.diabetes.org.uk/Guide-to-diabetes/Schools/Care-in-School-Helpline/
- Please see IPSEA's website, which offers free information, advice and support to help get the right education for children and young people with all kinds of SEN and disabilities at www.ipsea.org.uk/
- Please see also the website of ACE Education, which provides independent advice for parents and carers on state education in England, at www.ace-ed.org.uk/

References

- ¹ National Paediatric Diabetes Audit 2013-14 Report 1: Care Processes and Outcomes, <http://www.rcpch.ac.uk/system/files/protected/page/Revised%20Sept%202014%20NPDA%20Report%201%20FINAL.pdf>
- ² NHS Scotland, Scottish Diabetes Survey 2014, <http://www.diabetesinscotland.org.uk/Publications/SDS2014.pdf>
- ³ Bristol University, Dramatic increase of Type 1 diabetes in under-fives, <http://www.bristol.ac.uk/news/2007/5349.html>, presented at the Diabetes UK Professional Conference 2007
- ⁴ Help paying for children, <https://www.gov.uk/help-with-childcare-costs/free-childcare-and-education-for-2-to-4-year-olds>
- ⁵ See reference 4
- ⁶ Diabetes UK, Nurseries Survey, <https://www.surveymonkey.com/r/TYMQYPX>
- ⁷ Diabetes UK, How do nurseries manage the needs of children with Type 1 diabetes?, (24 April 2015), <https://www.facebook.com/diabetesuk/photos/a.10150174129820167.410496.20583485166/10155400790495167/?type=1&theater>
- ⁸ See references 6 and 7
- ⁹ See references 6 and 7
- ¹⁰ See reference 6
- ¹¹ See reference 7
- ¹² See reference 6
- ¹³ See reference 7
- ¹⁴ Healthy London Partnership, Diabetes UK and South East Coast and London Diabetes Partnership Board, London policy/guideline for the care of children and young people with diabetes in the pre-school, early years primary and secondary school, (November 2015)
- ¹⁵ SWEET Project, <http://www.sweet-project.eu/relaunch/>