NICE guidance for children and young people with diabetes: What you need to know

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Article points

1. NICE have published new recommendations for diagnosis and management of children and young people (CYP) with type 1 and type 2 diabetes.
2. One of the main updates to the guidance is that CYP with suspected diabetes should be referred immediately (on the same day) to a multidisciplinary paediatric diabetes team for specialist care.
3. Updates to self monitoring recommend CYP with type 1 diabetes should do at least five capillary blood tests a day, and blood ketone testing should replace urine ketone testing.

Key words

- Children and young people
- Glycaemic control
- NICE guidance
- Prompt referral

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In August 2015, NICE published new clinical guidance especially for the care of children and young people with diabetes: *Diabetes (type 1 and type 2) in children and young people: diagnosis and management* (NG18). The new set of recommendations includes important changes for specialist paediatric care, diagnosis and self-monitoring, as well as guidelines on the management of type 2 diabetes in the younger population. This article will describe some of the new and updated recommendations and highlight those that are particularly relevant for primary care clinicians.

In the UK, approximately 29 000 children and young people (CYP) have diabetes (Diabetes UK, 2012). The vast majority have type 1 diabetes, while approximately 500 CYP have type 2 diabetes. Globally, the UK has the fifth largest incidence of type 1 diabetes among children below the age of 14 (Finland, Sweden, Saudi Arabia and Norway all have higher rates [Patterson et al, 2014]).

Despite the fairly high incidence of diabetes among the young, the National Paediatric Diabetes Audit 2013–14 has shown that there is great variation in the outcomes and standards of diabetes paediatric care achieved in UK (Royal College of Paediatrics and Child Health, 2015).

The new 2015 NICE guidance provides a comprehensive guide for the care and management of type 1 and type 2 diabetes in CYP (NICE, 2015), and it is hoped that it will assist in improving standards of care across the UK.

CYP with diabetes receive the vast majority of their care from specialist paediatric diabetes services based in secondary or tertiary care; however, there are aspects of the care pathway where the role of the primary care team is vital in providing support to specialist paediatric teams (i.e. before diagnosis and during intercurrent illness). On average, a large GP practice in the UK will see one child or young person diagnosed with diabetes once every 2 years (Ali et al, 2013). The GP or practice nurse is likely to be the first port of call when a child or young person is presented unwell with the symptoms of diabetes. At this time, they may be at their most unwell, and, in the case of type 1 diabetes, if left undiagnosed and untreated it could prove fatal; it is here where the knowledge of the GP or practice nurse will be most needed.

The new NICE recommendations include, for the first time, guidance on the care and management of CYP with type 2 diabetes. It is, therefore, imperative that primary care clinicians are aware of the NICE recommendations so that they can provide support to specialist paediatric care teams. This article, therefore, aims to highlight the recommendations in the guidance that are especially relevant to primary care professionals.

Diabetes diagnosis

The vast majority of children who are diagnosed with diabetes will initially present at the GP's practice with the typical symptoms (i.e. polyuria, polydipsia, weight loss and recurrent infections). In the updated NICE guideline, excessive tiredness has been added to the list of diabetes characteristics.

The clinical history of a child or young person suspected of type 1 diabetes may not always be straightforward and even when the typical

symptoms are apparent, they are sometimes overlooked. This can be especially common in younger children. For example, excessive urination (which can present as secondary nocturnal enuresis) may be misdiagnosed as a urinary tract infection (Ali et al, 2013). It has been suggested that approximately 30% of newly diagnosed children with diabetes have made at least one related medical visit prior to diagnosis, suggesting the condition is often missed (Bui et al, 2010). This is a cause for concern as the implications of failing to recognise a new case of type 1 diabetes can be fatal. In the hope of reducing the number of missed diagnoses at initial consultation, NICE has updated the recommendation on referring suspected, undiagnosed cases of diabetes to specialist care:

> "**Refer** children and young people with suspected type 1 diabetes immediately (on the same day) to a multidisciplinary paediatric diabetes team with the competencies needed to confirm diagnosis and to provide immediate care." (NICE, 2015)

The guideline on referral in the 2004 guidance was as follows:

> "Children and young people with suspected type 1 diabetes **should be offered** immediate (same day) referral to a multidisciplinary paediatric diabetes care team that has the competencies needed to confirm diagnosis and to provide immediate care." (NICE, 2004)

Recommending that CYP should be immediately referred to specialist care rather than offered a referral is indicative of the importance of a fast referral. This is an updated recommendation that all primary care practitioners should be aware of.

A common reason for a delay in diabetes diagnosis, and thus a delay in starting insulin, is that attempts are made to confirm a diagnosis in primary care (e.g. requesting fasting or random blood glucose [Sundaram et al, 2009]). Capillary blood tests (finger-prick tests) are recommended in this instance to test blood glucose and blood ketones. Although primary care may be the first port of call, diagnosis is to be confirmed by a specialist paediatric diabetes team.

Other types of diabetes diagnosis

The NICE guidance stresses that when diagnosing diabetes in a child or young person, it is important to assume type 1 diabetes unless there are strong indications to suggest type 2 diabetes or monogenic diabetes. However, with the seriousness of type 1 diabetes it may be wise to be over-cautious and assume type 1 diabetes until diagnosis has been confirmed by a specialist paediatric care team.

In a new addition to the guidance, the possibility of type 2 diabetes should be considered in CYP with suspected diabetes with the following characteristics:

- Obese at presentation.
- Of black or Asian family origin.
- Having a strong family history of type 2 diabetes.
- Showing evidence of insulin resistance (e.g. acanthosis nigricans).
- Having either no insulin requirement or insulin requirement of less than 0.5 units/kg after the period of partial remission.

Rarer types of diabetes (e.g. maturity onset diabetes of the young, insulin resistance syndromes and molecular or enzymatic abnormalities) are to be considered in infants who present with diabetes; CYP who rarely or never produce ketones during episodes of hyperglycaemia; and those who have associated features, such as retinitis pigmentosa or deafness.

Diabetic ketoacidosis diagnosis, management and monitoring

Diabetic ketoacidosis in CYP with undiagnosed diabetes

An immediate referral to secondary care is imperative because CYP with undiagnosed type 1 diabetes can develop diabetic ketoacidosis (DKA), if they have not already. DKA remains the commonest cause of death in CYP with type 1 diabetes (Dunger et al, 2004), and any child or young person with suspected DKA should be immediately sent to a hospital with acute paediatric facilities. The symptoms of DKA include the following:

- Nausea or vomiting.
- Abdominal pain.

Page points

1. NICE has updated the guidance so that children and young people suspected of having type 1 diabetes are to be immediately referred (on the same day) to a multidisciplinary paediatric diabetes team with the competencies needed to confirm diagnosis and to provide immediate care.
2. The NICE guidance stresses that when diagnosing diabetes in a child or young person, it is important to assume type 1 diabetes unless there are strong indications to suggest type 2 diabetes or monogenic diabetes.
3. Guidance on the diagnosis of type 2 diabetes in children and young people is now included.

Page points

1. An important update to the guidance is that it is now advised that blood ketone monitoring should be used rather than urine ketone monitoring (unless blood ketone testing is not available).
2. A new addition to the guidance is that children and young people (CYP) with type 1 diabetes should be offered level 3 carbohydrate counting education.
3. According to the new NICE guidance, standard-release metformin should be offered to CYP with type 2 diabetes from diagnosis, and HbA_{1c} should be measured every 3 months.

- Hyperventilation.
- Dehydration.
- Reduced level of consciousness.

It is important to note here that children with undiagnosed diabetes do not always present with DKA and that DKA can develop very quickly. DKA is an emergency and any child with undiagnosed diabetes presenting in DKA must be transferred to hospital for urgent medical treatment.

DKA in CYP with diagnosed diabetes

Errors in insulin dosage and improper management of intercurrent illness are the most common causes of DKA in CYP with established diabetes (Lawrence, 2005). The NICE recommendations encourage that CYP and their parents or carers should be taught how to monitor ketone levels during illness or periods of hyperglycaemia in order to detect elevated levels and take preventative action before DKA occurs (NICE, 2015).

Ketone monitoring

An important update to the guidance is that it is now advised that blood ketone monitoring should be used instead of urine ketone monitoring (unless blood ketone testing is not available). Blood ketone tests measure beta-hydroxybutyrate, which is the predominant ketone body produced during DKA, thereby providing a measure of ketone levels at the time of testing. Urine ketone tests, on the other hand, measure only acetoacetate. Urine ketone tests have a high false positive and false negative rate (Laffel, 1999) – so the results can remain positive long after DKA has resolved giving the false impression that DKA is not responding to treatment (Laffel, 2000).

Following this update, GPs should be prepared to prescribe blood ketone test strips to CYP with type 1 diabetes and be able to test for blood ketones in the surgery. It is important to note here that not all blood monitoring meters measure blood ketones, so ensuring there are appropriate meters at the surgery is paramount.

The overall message from NICE is that if type 1 diabetes or DKA is suspected, carry out a finger-prick test and refer immediately to a multidisciplinary paediatric diabetes team.

Management of diabetes

Type 1 diabetes: Recommended insulin regimen

The guidance recommends that CYP with type 1 diabetes are offered basal–bolus multiple daily injection (MDI) therapy from diagnosis. In CYP in whom MDI therapy is not suitable, then continuous subcutaneous insulin infusion (or insulin pump) therapy should be considered.

Type 1 diabetes: Dietary advice

CYP with type 1 diabetes and their parents and carers should be offered level 3 carbohydrate counting education. This is a new addition to the guidance and involves carbohydrate counting with adjustment of insulin dosage according to an insulin:carbohydrate ratio, which is individualised according to age, sex, pubertal status, duration of diabetes, time of day and activity.

As well as carbohydrate counting education, CYP and their families and carers should be supported to develop a good knowledge of nutrition, including how eating healthy foods with low glycaemic index (and fruit and vegetables) may help to reduce cardiovascular risk and to manage blood glucose control. It is important to take in to account social and cultural considerations when discussing diet and lifestyle changes and to provide guidance to reduce the risk of hyperglycaemic episodes. Carbohydrate counting education is provided by specialist paediatric dietitians who are part of the paediatric diabetes multidisciplinary team, but primary care clinicians can support dietary knowledge and education during routine appointments.

Type 2 diabetes: Medication and lifestyle advice

According to the new NICE guidance, standard-release metformin should be offered to CYP with type 2 diabetes from diagnosis, and HbA_{1c} should be measured every 3 months. There is an emphasis on education and dietary management for CYP with type 2 diabetes and their parents and carers:

- HbA_{1c} monitoring and targets.
- The effects of diet, physical activity, body

weight and intercurrent illness on blood glucose control.
- The aims of metformin therapy and possible adverse effects.
- The complications of type 2 diabetes and how they can be prevented.

Recommended blood glucose targets

Although there are no studies on the optimal HbA_{1c} target for children, there is evidence that lower HbA_{1c} significantly reduces the risk of long-term complications (The Diabetes Control and Complications Trial Research Group, 1993). The new NICE guidance has recommended a target HbA_{1c} of 48 mmol/mol (6.5%) or lower for CYP with type 1 and type 2 diabetes. This represents a tighter glycaemic control than previously advised in the 2004 guidance (58 mmol/mol [7.5%]).

The new recommended HbA_{1c} level will pose a big challenge to CYP, their families and carers, and healthcare professionals as the *National Paediatric Diabetes Audit 2013–14* showed that only 16% of CYP in UK achieved an HbA_{1c} of less than 58 mmol/mol (7.5%; Royal College of Paediatrics and Child Health, 2015). In view of this, the guidance advises that healthcare professionals agree an individualised, lowest achievable HbA_{1c} target with each child or young person who has diabetes and their family members and carers, taking into account factors such as daily activities, individual life goals, complications, comorbidities and the risk of hypoglycaemia.

To achieve tighter glycaemic control, lower optimal target ranges for short-term plasma glucose control are recommended for CYP with type 1 diabetes:
- Pre-prandial blood glucose (at waking and before meals) of 4–7 mmol/L.
- Post-prandial blood glucose of 5–9 mmol/L.
- Those able to drive should aim for a plasma glucose level of at least 5 mmol/L when driving.

Self-monitoring

The guideline recommends that CYP with type 1 diabetes complete at least five finger-prick tests a day to monitor their blood glucose. This is a new recommendation and is derived from several studies that have shown there is a correlation between frequency of capillary blood glucose testing and glycaemic control (Dorchy et al, 1997; Helgeson et al, 2011; Miller et al, 2013; Campbell et al, 2014), and a large study that showed the positive association between glycaemic control and frequency of blood glucose testing plateaued after five tests per day (Ziegler et al, 2011).

The cost of increased capillary blood glucose monitoring (which includes the cost of the testing strips and the cost of delivering the education needed to ensure that testing is undertaken safely and the results are interpreted correctly to inform effective diabetes management) will be offset by the long-term health benefit of improved diabetes control.

The timing of blood glucose monitoring will depend on individual circumstances and will, therefore, be agreed between the CYP, their parents or carers and their healthcare professionals. Primary care professionals should be aware of the increased requirement of blood glucose test strips (and blood ketone strips where appropriate) for CYP with diabetes on prescription.

Dealing with diabetic emergencies

CYP with diabetes may present to their GP or practice nurse during periods of intercurrent illness. As part of the new guidance, secondary care teams are recommended to explain the "sick-day rules" with CYP and their families and carers. It would be useful for members of the primary care team to be aware of these rules so that they can provide consistent advice. The "Sick-day rules" include:
- Frequent monitoring of blood glucose.
- Monitoring and interpreting blood ketones.
- Adjusting their insulin regimen.
- Food and fluid intake.
- When and where to seek further advice or help.

In periods of hypoglycaemia, the recommendations from NICE remain similar to the 2004 guidance. To ensure the primary care team can provide consistent information to that of the specialised paediatric diabetes team, it is useful to remember the following recommendations:

Page points

1. The new NICE guidance has recommended a new, lower target HbA_{1c} of ≤48 mmol/mol (6.5%) for children and young people (CYP) with type 1 and type 2 diabetes, reduced from 58 mmol/mol (7.5%) in the 2004 guidance.
2. The guideline recommends that CYP with type 1 diabetes complete at least five finger-prick tests a day to monitor their blood glucose.
3. As part of the new guidance, secondary care teams are recommended to explain the "sick-day rules" with CYP and their families and carers. It would be useful for members of the primary care team to be aware of these rules so that they can provide consistent advice.

Box 1. Summary of changes to the NICE guidance for children and young people with type 1 and type 2 diabetes relevant to primary care practitioners.

- The referral process for a suspected case of diabetes or an episode of diabetic ketoacidosis (DKA) is updated to ensure immediate, same day, referral to a specialist paediatric diabetes service. It is not within the remit of the primary care team to make a diagnosis, but it is within the remit to recognise the symptoms and perform a capillary blood test (finger-prick test) before referring.
- Blood ketone testing is now recommended instead of urine testing for diagnosis, prevention and management of DKA, so GPs and practice nurses will need to be able to perform blood ketone testing in the surgery (noting that not all meters can measure for ketones) and be aware that specialised ketone blood strips (which are different to standard blood glucose strips) will need to be prescribed to individuals.
- Blood glucose testing by finger-prick test is now recommended at least five times a day; therefore, an increase in test strip prescriptions is likely.
- HbA_{1c} target is now recommended at 48 mmol/mol (6.5%) or lower for children and young people (CYP) with type 1 and type 2 diabetes. This represents tighter glycaemic control than previously advised in the 2004 guidance (58 mmol/mol [7.5%]).
- It is within the remit of the primary care team to maintain the level of knowledge and to encourage adherence of treatment, self-monitoring and attendance to specialist appointments of the child or young person with diabetes and their parents and carers. This includes information on insulin regimens and frequency of blood glucose testing for type 1 diabetes, sick day rules in order to prevent development of DKA during episodes of inter-current infections for type 1 diabetes, and exercise and weight management for CYP with type 2 diabetes.

Page points

1. Thyroid function tests are now recommended at diagnosis and annually thereafter, and all children aged 12 years and above should have annual retinopathy screening, foot examinations and microalbuminuria tests.
2. The majority of the guidance is most relevant to specialist paediatric diabetes teams, but primary care practitioners will often be the first port of call for children and young people with diabetes, so it is important for primary care to be aware and comfortable with the changes.

- Explain to CYP with type 1 diabetes and their parents and carers that it is important to have appropriate knowledge of avoiding and managing hypoglycaemia.
- Encourage CYP with type 1 diabetes and their family members or carers to always have access to an immediate source of fast-acting glucose and blood glucose monitoring equipment to confirm and manage hypoglycaemia.
- Fast-acting glucose (for example, 10–20 g) taken by mouth either in liquid or solid form is the recommended way to treat mild to moderate hypoglycaemia in CYP with type 1 diabetes.

Blood glucose should be rechecked every 15 minutes after an episode of hypoglycaemia and as symptoms resolve, an oral complex long-acting carbohydrate should be consumed to maintain blood glucose levels, unless the child or young person is about to have a snack or meal or they use an insulin pump.

Screening for complications

The screening for long-term complications and associated disorders will be carried out by the specialised paediatric diabetes team. Remaining from the 2004 guidance, CYP who have persistently suboptimal blood glucose control should be offered screening for anxiety and depression. From 2015, thyroid function tests are recommended at diagnosis and annually thereafter, and all children aged 12 years and above should have annual retinopathy screening, feet examination and microalbuminuria tests. The guidance also advises screening for coeliac disease at type 1 diabetes diagnosis or if they have suggestive symptoms.

In accordance with the recommendation of the Department of Health "Green Book" (2006), all CYP with diabetes should be immunised against pneumococcal infection, and those over the age of 6 months should be offered annual immunisation against influenza.

Take home messages for primary care professionals

The new NICE guidance is intended to update and clarify the optimal assessment and management of CYP with diabetes. The majority of the guidance is most relevant to specialist paediatric diabetes teams, but primary care practitioners will often be the first port of call for these individuals. *Box 1* includes the most relevant guidance and take-home messages for primary care practitioners. It is important to be aware

of the updates and new recommendations to follow clinical pathways correctly, and to provide efficient support to secondary specialist care and consistent advice to CYP and their families and carers. ■

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"Primary healthcare practitioners need to be aware of the updates and new recommendations to the NICE guidance on the diagnosis and management of diabetes in children and young people to provide efficient support to secondary specialist care and consistent advice to young people and their families and carers."