# New NICE guidance: Changes in practice for multidisciplinary teams. Part 1: Type 1 diabetes in children and young people

# Helen Thornton

This is the first of two articles on the 2015 NICE NG18 guideline, *Diabetes (Type 1 and Type 2) in Children and Young People: Diagnosis and Management*. The second will follow in a later issue of this journal. In the current article, the management of type 1 diabetes in this age group is explored. The author comments on the key recommendations in contrast to the adult guidelines and considers how, as teams, practitioners should ensure a consistent message to achieve the holy grail of improved control.

he new NICE guidance on the management of diabetes in children and young people, NG18, was released in August last year (NICE, 2015a). There have been considerable changes in technology and treatments for the management of type 1 diabetes since the original CG15 guidance in 2004. I have had the opportunity to review and comment on both versions during their consultation periods. Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how the recommendations are developed. There were 473 pages of comments and responses during the most recent consultation period, and these comments had significant influence on the final document and the tone of some of its recommendations.

Some of the most important feedback was from the Families with Diabetes National Network, and I would recommend that readers spend time looking at this (available at: http://bit.ly/11RpT3U) when considering the implementation of NG18 into their clinical practice and what their team messages are. All good sales training will explain that you need to believe 125% in your product to be a successful salesperson. Healthcare professionals in diabetes operate as "salespeople" – we have to sell the diabetes lifestyle to the children and young people we see, as well as their families. Unless we believe in the new NICE guidance and targets, how can we sell this lifestyle to them?

In this article, I will outline the key changes to the original guidance that have been made in NG18 and, where necessary, highlight some of the issues that may concern clinicians, children and young people with type 1 diabetes and their families.

# HbA<sub>1</sub>, targets

The new guidance is the first to recommend a target  $HbA_{1c}$  near the normal level, stating that clinicians should:

"Explain to children and young people with type 1 diabetes who have an  $HbA_{1c}$  level above the ideal target of 48 mmol/mol (6.5%) and their family members or carers (as appropriate) that any reduction in  $HbA_{1c}$  level reduces the risk of long-term complications." (NICE, 2015a) **Citation:** Thornton H (2016) New NICE guidance: Changes in practice for multidisciplinary teams. Part 1: Type 1 diabetes in children and young people. *Journal* of Diabetes Nursing **20**: 21–5

### **Article points**

- 1. This article highlights the key changes to NICE guidance on the management of type 1 diabetes in children and young people.
- Targets for HbA<sub>tc</sub> and fasting blood glucose have been lowered, which may concern some children and their families.
- Other changes now provide comprehensive advice on insulin regimens, education and management of hypoglycaemia and diabetic ketoacidosis. They also highlight the need for access to psychological therapies in all multidisciplinary teams.

#### Key words

- Children and young people
- NICE guidelines
- Type 1 diabetes

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- HbA<sub>1c</sub> targets have been reduced to 48 mmol/mol (6.5%) in the new guidelines, despite vocal opposition from clinicians and patient groups.
- However, reassuringly, the guidelines also state that aiming for these targets should not result in hypoglycaemia or emotional distress, and the advice remains for diabetes services to document the proportion of young people who achieve an HbA<sub>1c</sub> of ≤53 mmol/mol (7.0%).
- Blood glucose targets have also changed, including a fasting and pre-meal target of 4–7 mmol/L, which does not mirror the guidelines for adults.
- 4. Continuous glucose monitoring is now recommended, but only for children with frequent severe hypoglycaemia or impaired hypoglycaemia awareness, very young children, those who undertake high levels of physical activity and those with comorbidities or treatments that may make glycaemic control more difficult.

This is the headline that drew the most comments from both families and clinicians. In the consultation period held between December 2014 and March 2015, the Families with Diabetes National Network responded with the following comments (available at: http://bit. ly/11RpT3U; page 13):

"It is felt that the lower target will be detrimental to the wellbeing, not only of the child, but of their carer(s). We cannot emphasise just how strongly it is felt in the wider diabetes community that such a decrease in the target would be unacceptable. It is felt that such a target could only be met with an increased frequency of lower range blood glucose levels, increasing likelihood of hypoglycaemia."

These comments appear to have been listened to, as the final guidance now states that children should not experience problematic hypoglycaemia or emotional distress in attempting to achieve this target and that individualised targets should be set. There is also the following caveat:

"Diabetes services should document the proportion of children and young people with type 1 diabetes in a service who achieve an HbA<sub>1c</sub> level of 53 mmol/mol (7%) or lower."

(NICE, 2015a)

This is of interest as neither the National Paediatric Diabetes Audit (NPDA) Project Board nor the Dataset Committee has yet revised the NPDA dataset to match the new NICE targets and it perhaps gives clinicians a suggested aim for an acceptable individualised target for some children.

# **Blood glucose monitoring**

So how does the NICE guideline propose we achieve these targets? First, the target blood glucose levels have been revised to the following: • Fasting and before meals: 4–7 mmol/L.

- ●After meals: 5–9 mmol/L.
- ●Before driving (for older adolescents): ≥5 mmol/L.

The guidance also recommends a minimum of five blood glucose tests per day. These recommendations are disappointing as I have observed that far more tests than this are performed per day by families who achieve good control. Furthermore, they do not mirror the adult guidance (NICE, 2015b), which recommends targets of 5–7 mmol/L fasting, 4–7 mmol/L before meals and 5–9 mmol/L at least 90 minutes after meals, with testing taking place four to 10 times per day and even more frequently if required (for example, when driving or doing exercise).

I am unsure how many parents will be happy with a target fasting level of 4 mmol/L and the possibility of their children having hypoglycaemia in the early hours or on waking, especially when trying to get them ready for school. Maybe the recommendation concerning the use of real-time continuous glucose monitoring (CGM) in children with frequent hypoglycaemia and unawareness of hypoglycaemia symptoms is meant to assist with this.

There is an additional new section on considering CGM for other special cases, such as pre-school children and infants; children and young people who undertake high levels of physical activities, such as sports at regional, national or international levels; young people with comorbidities such as eating disorders and those receiving corticosteroids, which could make blood glucose control difficult; and those who continue to have hyperglycaemia despite frequent insulin adjustments.

NICE is currently completing a technology appraisal on integrated sensor-augmented pump therapy systems (Medtronic's MiniMed Paradigm Veo and Animas/Dexcom's combined Vibe and G4 Platinum system), the outcome of which is due January 2016. This may or may not help with funding but, unfortunately, it will close the Individual Funding Request (IFR) route. IFRs are considered where the individual or treatment is exceptional; that is, if the treatment can be described as exceptional by virtue of the rarity of the condition or the difference of the individual from the generality of similar patients. This will not be the case now CGM is being integrated into normal clinical practice. Teams will need to look at the "Application and Case for Introduction of New

Medical Device" service development request. This is for providers to apply to Commissioners for in-year funding of any new medical device or extended use of an existing device (for a new indication or patient group, for example) that will impact on Clinical Commissioning Group budgets. This includes cases in which the device is prescribed in hospital but generates additional Payment by Results (PbR) costs or is excluded from the PbR National Tariff, resulting in costs being passed on to Commissioners.

# **Insulin regimens**

It is now common practice to use intensive insulin regimens for all children and young people with diabetes and the guidance recommends multiple daily injections (basal-bolus regimens) from diagnosis or, if this is not suitable, to consider insulin pump therapy. Insulin should be administered before food, with dose adjustment at each meal. If a child or young person with type 1 diabetes does not have optimal blood glucose control, offer appropriate additional support, such as increased contact frequency with the diabetes team. If necessary, offer an alternative insulin regimen (multiple daily injections, insulin pump therapy or once-, twice- or three-times daily mixed insulin injections). This is of use to children who, despite our best efforts to encourage them, refuse to inject or administer boluses in school, and for whom it is probably safer to move on to insulin regimens administered under supervision at home.

It is somewhat disappointing that there are no new recommendations about the use of metformin in combination with insulin for children with a high BMI. This was, unfortunately, not addressed as part of the guideline review, so teams have no clear guidance to adopt. In contrast, the adult type 1 diabetes guidelines recommend the addition of metformin in people with a BMI  $\geq$ 25 kg/m<sup>2</sup> or  $\geq$ 23 kg/m<sup>2</sup> if from a South Asian background (NICE, 2015b).

# Education

The importance of age-appropriate education is emphasised, with a more

detailed list of suggested topics than in previous guidelines, including the need for education on level 3 carbohydrate counting (this is carbohydrate counting with adjustment of insulin dosage according to an insulin:carbohydrate ratio) from diagnosis. The dietary recommendations also emphasise healthy eating. Interestingly, a low-glycaemicindex (low-GI) diet is being actively promoted despite the fact that the adult guideline clearly states that adults with type 1 diabetes should not be advised to follow a low-GI diet for blood glucose control (NICE 2015b). This is because it was not in the scope of the latter review. Unfortunately, this could cause confusion for young adults in transition, especially those who are managed in a joint service.

Structured education is not emphasised, as in the adult guidelines, despite it being a Best Practice Tariff requirement (NHS England, 2013). Recommendations on exercise management have also been slightly amended to reflect current guidelines but are generally unchanged.

# Hyperglycaemia and hypoglycaemia management

More detailed advice is given in a new section on the management of hyperglycaemia, emphasising the monitoring of blood ketone levels rather than urinary ketones. Advice on correction dosing at each meal and management of illness is more detailed, with requirements to revise sick day rules annually with the young people and their families.

The section on management of hypoglycaemia has been expanded but does not go so far as to recommend restoring blood glucose levels to 5.6 mmol/L as per International Society for Pediatric and Adolescent Diabetes consensus guidelines (Ly et al, 2014), which has become our policy when rolling out the Individual Healthcare Plans for schools, as detailed in this Journal (Singleton, 2015).

# Screening for complications and associated conditions

The screening advice has been updated with

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- Children should be offered intensive insulin regimens from diagnosis, either with a basal-bolus regimen or an insulin pump. If necessary, alternative insulin regimens (multiple daily injections, insulin pump therapy or once-, twiceor thrice-daily mixed insulin injections) should be offered.
- Age-appropriate education is important, including level 3 carbohydrate counting. Structured education is not emphasised despite being a Best Practice Tariff requirement.
- Detailed advice is given on managing hyperglycaemia, including measurement of blood rather than urinary ketone levels, and hypoglycaemia.
- Recommendations on screening for microalbuminuria have been updated, and advice on screening for diabetic foot ulcers and coeliac disease is outlined in separate guidance.

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- 1. Annual hypertension and retinopathy screening should occur from the age of 12 years onwards, but all children should have routine eye testing every 2 years.
- New recommendations to provide psychological interventions when necessary emphasise the need for all multidisciplinary teams to have access to a psychologist.
- The new guidance has more comprehensive advice on managing diabetic ketoacidosis (DKA), including a a clear definition of severe DKA and a detailed care pathway.

screening the recommendations of only early-morning specimens of urine for microalbuminuria, in order to avoid false positives. An albumin:creatinine ratio (ACR) of  $\geq$ 30 mg/mmol should be investigated immediately, whereas an ACR of 3-30 mg/mmol should have two further abnormal results on repeat to initiate investigation.

Advice on screening for foot care and coeliac disease (CD) is provided in the related NG19 and NG20 guidelines (NICE, 2015c; 2015d). The latter now recommends that, in the absence of CD symptoms, people with type 1 diabetes should be screened for CD at diabetes diagnosis only, which is of concern as, in clinical practice, I have observed several young people develop asymptomatic CD and move from negative to positive serology and be diagnosed by biopsy. The absence of annual screening could lead to missed diagnoses.

Annual hypertension screening should commence from the age of 12 years, which brings the guideline into line with the NPDA dataset (available at: http://bit.ly/1Z3wTcO). There is no change in the recommendation for annual retinopathy screening that commences at the same age. Routine eye testing is recommended for all ages every 2 years. Recommendations on dental check-ups are detailed in the related CG19 guidance (NICE, 2004).

Despite being part of the NPDA, lipid screening was not reviewed by the Guideline Development Group. This is a missed opportunity given results of the 2013–2014 NPDA, which showed that 83.9% of young people with type 1 diabetes had a total cholesterol level of  $\leq$ 5 mmol/L and 54.2% had a level of  $\leq$ 4.0 mmol/L (Royal College of Paediatrics and Child Health, 2015). Assuming an ideal total cholesterol level of  $\leq$ 4 mmol/L, these results reveal a group that is not being screened and could be missing out on lifestyle interventions that could be protective for their cardiovascular health.

### **Psychological and social issues**

Currently, the Best Practice Tariff advises that

every young person with diabetes should be assessed at least annually by their diabetes care team to see if they would benefit from referral to a clinical psychologist. Many of the previous statements have been updated in the new guideline, but the main change is the following recommendation:

"Consider a programme of behavioural intervention therapy or behavioural techniques for children and young people with type 1 diabetes in whom there are concerns about psychological wellbeing in order to improve: • Health-related quality of life – for example, counselling or cognitive behavioural therapy (CBT), including CBT focused on quality of life.

• Adherence to diabetes treatment – for example, motivational interviewing or multisystemic therapy.

• Blood glucose control in children and young people with high  $HbA_{1c}$  levels ( $HbA_{1c}$ above 69 mmol/mol [8.5%]) – for example, multisystemic therapy." (NICE, 2015a)

This strengthens the requirement for the team to have access to a clinical psychologist.

## Management of diabetic ketoacidosis

Advice on the management of diabetic ketoacidosis (DKA) is more comprehensive than in the previous guideline and has changes in recommendations on fluid management and insulin rate. It has more detailed guidance on the recognition and definition of DKA and a clear definition of severe DKA (a blood pH <7.1). Senior support is required to manage DKA, and this is now clearly stated. Actual weight should be recorded rather than estimated weight, and this is essential for accurate fluid and insulin calculations. Oral rehydration and subcutaneous insulin should only be administered when there is no nausea or vomiting, and when the young person is alert and not clinically dehydrated. Nursing staff need to be aware that oral fluids should not be given to children on intravenous (IV) fluids unless the child is fully alert, vomiting has stopped and the DKA is resolving.

Glucose should be added to the rehydration fluids once blood glucose levels fall below 14 mmol/L and should be increased in concentration if blood levels fall below 6 mmol/L. IV insulin should be maintained but additional glucose added to the bag. Long-acting analogue insulin should continue to be dosed subcutaneously during IV treatment.

The monitoring required is described in detail, along with the requirement for a face-to-face medical review at least every 4 hours and more frequently if the child is under 2 years of age. Inotropes are also mentioned, in that they may need to be discussed with a paediatric critical care specialist in the event of hypotensive shock.

To enable return to normal therapy once DKA is resolved, there is clearer guidance on how to restart subcutaneous insulin. For children on insulin injections, this should be given at least 30 minutes before stopping IV insulin, and for those on pumps a new infusion set should be sited and basal rates commenced at least 60 minutes before stopping IV insulin. This is because IV insulin only has a half-life of 2–5 minutes and the blood glucose level will rise rapidly if there is no insulin on board.

Once DKA has resolved, the guidelines recommend that further discussions occur with the children and their families to establish the cause and to reduce the risk of reoccurrence.

### **Concluding remarks**

The revised NICE guidance gives a clear, comprehensive guideline for the standard of care for children and young people with diabetes. It outlines what we should be doing in our daily clinical practice. The guidance is designed to enhance clinical care, with an aim to improve metabolic control and reduce both the acute and the chronic complications of diabetes. Diabetes care teams will need to report their compliance with this new guideline to their Trusts through their governance processes, and they will need to update their clinical guidelines, standard operating procedures and information leaflets. As a team, they all need to believe in the new guidance to ensure they have a clear, harmonised approach when discussing this new information with children and young people and their families. Unless we believe in the new targets, the standards will not be met.

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