

# NICE guidance on the care of children and young people with type 1 diabetes

Jo Dalton, Jane Houghton

## Introduction

The National Institute for Clinical Excellence guideline on the care of type 1 diabetes in children, young people and adults was published in July 2004. The guideline is in two parts: one for children and young people and the other for adults. As members of the guideline development group, the authors of this article were closely involved in drawing up the guideline for children and young people. They describe the development of the guideline, its aims and content, and how it will ensure that consistent and quality care is provided to all children and young people with type 1 diabetes.

In July 2004 the National Institute for Clinical Excellence (NICE) published its guideline for the diagnosis and management of type 1 diabetes in children, young people and adults (NICE, 2004a). It follows on from the National Service Framework (NSF) for diabetes (Department of Health [DoH], 2001; 2003) and is part of a series of technology appraisals and guidelines that NICE have produced for diabetes care (Table 1).

The guideline is in two parts. One is aimed at the care of children (age <11

years) and young people (age 11–17 years) and the other at adults, but they are linked through the recommendations for transitional care (summarised in Figure 1). The children and young people's section should be used in conjunction with the NSF for children (DoH, 2004). Several versions of the guideline are available, including full guidance, quick reference guide, and information for the public (Table 2).

This article gives an overview of the development of the paediatric guideline and its contents. We were members of the

## ARTICLE POINTS

**1** The NICE guideline on the care of children, young people and adults with type 1 diabetes was published in July 2004.

**2** The guideline is in two sections: one for children and young people and the other for adults.

**3** The guideline focuses on the care, management and ongoing needs of children and young people and their families across England and Wales.

**4** Several versions of the guideline are available, including the full guideline, quick reference guide, and information for the public.

**5** Implementation of the guideline should ensure that all children and young people with type 1 diabetes receive the same high-quality care.

## KEY WORDS

- Type 1 diabetes
- Children
- Young people
- Diabetes care
- NICE Guideline

Jo Dalton is a Specialist Practitioner, Paediatric Diabetes, Westmorland General Hospital, Morecambe Bay Hospitals NHS Trust, and Jane Houghton is a Nurse Consultant, Paediatric Ambulatory Care, Royal Preston Hospital, Lancashire Teaching Hospitals NHS Trust

Table 1. NICE documents relating to diabetes

Technology appraisals	
<b>Published</b>	Type 1 diabetes – long-acting insulin analogues (No. 53) Type 1 diabetes – insulin-pump therapy (No. 57) Type 1 and 2 diabetes – patient education models (No. 60) Type 2 diabetes – glitazones (review) (No. 63)
<b>In development</b>	Diabetic foot ulcers – new treatments Type 1 and 2 diabetes – inhaled insulins
Guidelines	
<b>Published</b>	Type 2 diabetes – retinopathy Type 2 diabetes – renal disease Type 2 diabetes – blood glucose Type 2 diabetes – management of blood pressure and blood lipids Type 2 diabetes – footcare Type 1 diabetes
<b>In development</b>	Diabetes in pregnancy Interventional procedures Pancreatic islet cell transplantation

**PAGE POINTS**

**1** The search for evidence revealed a lack of sufficient robust research into paediatric diabetes.

**2** Consequently, a separate grading scheme had to be used for the children's guideline.

**3** Some of the recommendations in the children's guideline have a good practice point (GPP) grading based on the views of the guideline development group.

**4** Nurses were actively involved in the guideline development as members of the guideline development group.

**5** Children and young people's views were also taken into account; a consultation day was held to look at service provision from their unique point of view.

**Transition to adult care**

- Agree protocols for transfer from paediatric to adult services
- Organise age-banded clinics and joint clinics with adult services
- Encourage attendance three or four times per year
- Allow time for young people to familiarise themselves with the practicalities of transition
- Timing depends on physical development, emotional maturity, stability of health, other life changes and local circumstances
- Offer advice on aspects of care that change with transfer to adult services (targets for short-term glycaemic control and screening for complications)

*Figure 1. NICE guidance on the transition to adult care, as summarised in the quick reference guide to the care of children and young people with type 1 diabetes (NICE, 2004b).*

guideline development group for this section of the guideline, and were therefore closely involved in its development.

**The children's guideline**

The children and young people's guideline focuses on the care, management and ongoing needs of this patient group and their families. The full children's guideline document is split into eight chapters, which cover the key areas:

- General guideline aims
- Recommendations for practice
- Diagnosis and initial management
- Ongoing management
- Complications and associated conditions
- Psychology and social issues
- Continuity of care
- Auditable standards.

**Grading scheme**

NICE guidance is based on current research evidence for the particular subject area. However, during the process of drawing up the paediatric guideline, it was very apparent that there was insufficient robust research into paediatric diabetes. The data contained in the majority of diabetes research, not just from the UK, but also from the rest of the world, were adult based. As a result, a separate grading scheme was used for the children and young person's guideline. Some of the recommendations have a good practice point (GPP) grading based on the shared views and/or knowledge and experiences of the guideline development group.

Exclusions to the remit of the guidance

document included contraception advice for young people with type 1 diabetes, the management of pregnancy for this group and for those who develop diabetes during pregnancy. These groups were excluded because NICE is planning to develop another guideline on aspects of pregnancy and diabetes in the not too distant future.

Another group not covered by this or any other guideline are young people with type 2 diabetes. However, it was made clear that when NICE reviews its guideline on type 2 diabetes it will include a chapter on the care and management of young people who develop type 2 diabetes, as this group was excluded from the original guidance on type 2 diabetes.

**Development of the guideline**

Although nurses have not always been invited to be members of the NICE guideline development group for previous guidelines, they were fully involved in both the adult and paediatric groups for this one.

Children and young people themselves were included too, by way of a consultation day to look at service provision from their unique point of view. It was also good to see that children and young people with diabetes were seen as a separate group, with different issues and needs, and not as mini adults.

As well as being research based as far as possible, the guidelines had to be written within the scope of NICE guidelines. Thus, for example, NICE does not allow the guideline to be so specific as to state exactly who should be on a team, such as a paediatric nurse – only that the care should

be given by a multidisciplinary paediatric diabetes care team with the range of skills required to meet the needs of this challenging patient group and their families and carers. Hopefully this will be enough to encourage areas that do not presently have paediatric diabetes nurses to consider the need for them with greater importance than has sometimes been the case in the past.

Although none of the recommendations are new, they do reinforce previous guidance documents, with suggestions for auditing to assess whether these recommendations are being implemented.

**Key recommendations**

The following key recommendations (from the quick reference guide) are identified as priorities for implementation. They should be interpreted, where necessary, with reference to the full guideline.

**Management from diagnosis**

Children and young people with type 1 diabetes should be offered an ongoing

integrated package of care by a multidisciplinary paediatric diabetes care team. To optimise the effectiveness of care and reduce the risk of complications, the diabetes care team should include members with appropriate training in clinical, educational, dietetic, lifestyle, mental health and foot care aspects of diabetes for children and young people.

At the time of diagnosis, children and young people with type 1 diabetes should be offered home-based or inpatient management according to clinical need, family circumstances and wishes, and residential proximity to inpatient services. Home-based care with support from the local paediatric diabetes care team (including 24-hour telephone access to their diabetes care team for advice) is safe and as effective as inpatient initial management.

**Education**

Children and young people with type 1 diabetes and their families should be offered timely and ongoing opportunities to

**PAGE POINTS**

**1** Children and young people with type 1 diabetes should be offered an ongoing integrated package of care by a multidisciplinary paediatric diabetes care team.

**2** The diabetes care team should include members with appropriate training in clinical, educational, dietetic, lifestyle, mental health and foot care aspects of diabetes for children and young people.

**Table 2. Guidance on type 1 diabetes available on the NICE website ([www.nice.org.uk](http://www.nice.org.uk))**

**Type 1 diabetes: diagnosis and management of type 1 diabetes in children and young people**  
Full guideline (developed by the National Collaborating Centre for Women and Children’s Health)

**Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults**  
NICE Guideline

**Type 1 diabetes: diagnosis and management of type 1 diabetes in adults**  
Quick reference guide

**Type 1 diabetes: diagnosis and management of type 1 diabetes in children and young people**  
Quick reference guide

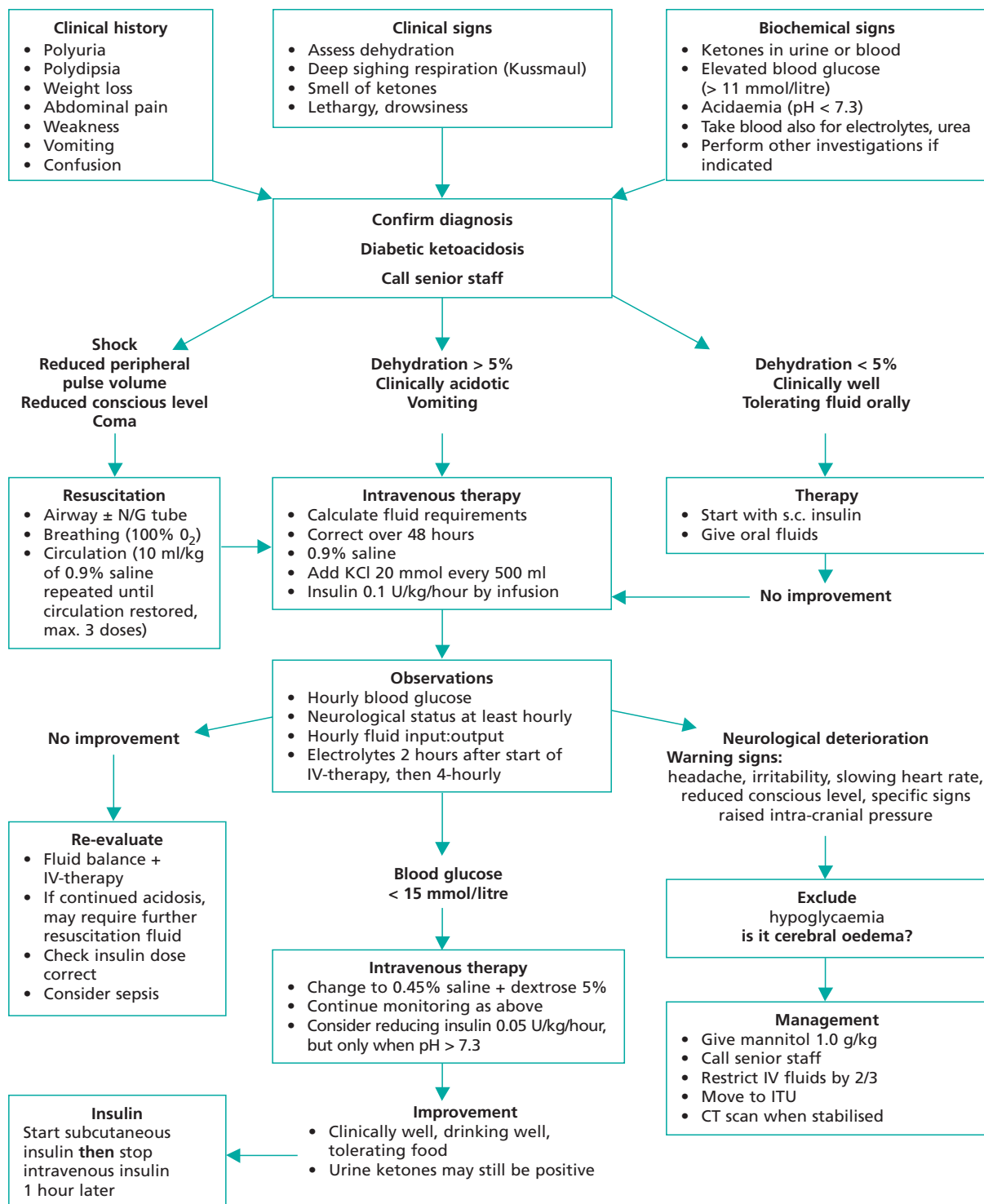
**Type 1 diabetes: diagnosis and management of type 1 diabetes in adults**  
Information for the public

**Type 1 diabetes: diagnosis and management of type 1 diabetes in children and young people**  
Information for the public

**Type 1 diabetes: diagnosis and management of type 1 diabetes in adults, children and young people**  
Evidence table

Printed copies of the quick reference guides and the information for the public are also available from the NHS response line by telephoning 0870 1555 455 and quoting reference number N0622 for children and young people’s quick reference guide, N0558 for adults’ quick reference guide, N0623 for the children and young people’s information for the public, and N0559 for the adult’s information for the public. The public information versions are also available in Welsh.

## Algorithm for the management of diabetic ketoacidosis\*



\*Adapted from *BSPED Recommended DKA guidelines. Guidelines for the management of diabetic ketoacidosis 2004* (British Society for Paediatric Endocrinology and Diabetes), copyright 2004, with permission from the British Society for Paediatric Endocrinology and Diabetes.

Figure 2. Algorithm for the management of diabetic ketoacidosis. (NICE Guideline: quick reference guide – type 1 diabetes (children and young people) NICE, 2004b.) Reproduced by kind permission of NICE

access information about the development, management and effects of type 1 diabetes. The information provided should be accurate and consistent and should support informed decision-making.

**Monitoring glycaemic control**

Children and young people with type 1 diabetes and their families should be informed that the target for long-term glycaemic control is an HbA<sub>1c</sub> level of less than 7.5% without frequent disabling hypoglycaemia, and that their care package should be designed to attempt to achieve this.

**Diabetic ketoacidosis**

Children and young people with diabetic ketoacidosis should be treated according to the guidelines published by the British Society for Paediatric Endocrinology and Diabetes (BSPED). This guidance is given in the form of an algorithm in the quick reference guide (Figure 2).

**Psychosocial support**

Children and young people with type 1 diabetes and their families should be offered timely and ongoing access to mental health professionals because they may experience psychological disturbances (such as anxiety, depression, behavioural, and conduct disorders and family conflict) that can impact on the management of diabetes and wellbeing.

**Screening for complications and associated conditions**

Children and young people with type 1 diabetes should be offered screening for:

- coeliac disease at diagnosis and at least every three years thereafter until transfer to adult services
- thyroid disease at diagnosis and annually thereafter until transfer to adult services
- retinopathy annually from the age of 12 years
- microalbuminuria annually from the age of 12 years
- blood pressure annually from the age of 12 years.

**The future**

One interesting recommendation highlights the association between type 1 diabetes

and coeliac disease. However, this research has mostly been undertaken with children, not adults (which was a refreshing change). Further research is needed to establish whether adults need to be tested for coeliac disease, but until that time NICE can only recommend that children are tested at diagnosis and every three years until transfer to adult services.

Another really positive aspect of this paediatric guidance is the focus on the team approach to care, where all roles are equally respected and valued. The guideline development group took great care to adopt an inclusive, sharing approach to care in this guideline, rather than the traditional, medical clinician-led approach.

Paediatric diabetes teams cannot be forced to use the NICE guideline, but if they do not they may have to justify why they are not following them.

Being part of the guideline development group was a very positive and enjoyable experience, and we would recommend it to any nurse who is offered such an opportunity. Everyone involved in the development of this guideline in the NICE collaboration centres was willing to listen to each other's point of view.

It is hoped that this guideline will enable all children and young people with type 1 diabetes in England and Wales to receive the same high standards of care. ■

Department of Health (2001) *National Service Framework for Diabetes: Standards*. DoH, London ([www.publications.doh.gov.uk/nsf/diabetes/index.htm](http://www.publications.doh.gov.uk/nsf/diabetes/index.htm))

Department of Health (2003) *National Service Framework for Diabetes: Delivery Strategy*. DoH, London ([www.publications.doh.gov.uk/nsf/diabetes/index.htm](http://www.publications.doh.gov.uk/nsf/diabetes/index.htm))

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services (Children's NSF)* ([www.dh.gov.uk/nsf/children/index/htm](http://www.dh.gov.uk/nsf/children/index/htm))

NICE (2004a) *Type 1 Diabetes: Diagnosis and Management of Type 1 Diabetes in Children, Young People and Adults*. Clinical Guideline 15. NICE, London ([www.nice.org.uk/CG015NICEguideline](http://www.nice.org.uk/CG015NICEguideline), accessed 22/11/04)

NICE (2004b) *Quick Reference Guide. Type 1 Diabetes: Diagnosis and Management of Type 1 Diabetes in Children, Young People and Adults*. Clinical Guideline 15. NICE, London (<http://www.nice.org.uk/pdf/CG015childrenquickrefguide.pdf>, accessed 22/11/04)

**PAGE POINTS**

1 One recommendation highlights the association between type 1 diabetes and coeliac disease. This research has mostly been undertaken with children, not adults (which is a refreshing change).

2 Another really positive aspect of this paediatric guidance is the focus on the team approach to care, where all roles are equally respected and valued.

3 Paediatric diabetes teams cannot be forced to use the NICE guideline, but if they do not they may have to justify why they are not.

4 It is hoped that this guideline will enable all children and young people with type 1 diabetes in England and Wales to receive the same high standards of care.