Early diagnosis of children with Type 1 diabetes

Key points

- Early diagnosis of Type 1 diabetes is essential to allow treatment to start as soon as possible.
- The classic symptoms of Type 1 diabetes in children and young people are frequent urination/bedwetting in a previously dry child, excessive thirst, excessive tiredness and weight loss.
- If the early symptoms are missed then diabetic ketoacidosis (DKA) will develop. If untreated it leads to unconsciousness and death. DKA requires hospital admission and not only is it life-threatening it is costly to the NHS.
- Diabetes UK are campaigning to increase awareness amongst non-specialist healthcare professionals and the general public of the symptoms of diabetes to reduce the number of children diagnosed in DKA: [www.diabetes.org.uk/The4Ts](http://www.diabetes.org.uk/The4Ts).

Introduction

There are around 31,500 children with diabetes in the UK who have Type 1 (1). The incidence of Type 1 diabetes is increasing in children and young people by approximately 4% per year in the UK (2).

Concerningly, the latest National Paediatric Diabetes Audit (NPDA) report shows that 16% percentage of all children are not diagnosed with Type 1 diabetes until they are in DKA (3). This figure increases to 24% in the under 5s (3).

Children can develop DKA within 24-48 hours of first presentation with the symptoms of Type 1 diabetes, with the under 2’s most at risk (4). DKA is a serious condition and occurs when a lack of insulin causes high blood glucose and blood ketone levels which leads to vomiting and high blood acidity causing severe dehydration. If untreated it leads to unconsciousness and death. DKA requires hospital admission and not only is it life-threatening, its occurrence is extremely traumatic for a child and their family.

Making sure that parents, carers and non-specialist healthcare professionals recognise the classic symptoms of Type 1 diabetes is crucial.
Current situation

The classic symptoms of Type 1 diabetes are frequent urination/bedwetting in a previously dry child, excessive thirst, excessive tiredness and weight loss.

Children and young people will not necessarily display all symptoms at the same time, and symptoms may vary depending on the age of the child. For example:

- Bedwetting in a previously “dry” child is the earliest symptom of diabetes occurring in 89% of children over the age of four (7,8);
- Weight loss occurs in 50% of children aged 10-14 years but only in 5% of those under the age of two (7);
- Lethargy occurs in 10 - 20% of children of all ages (7);
- Constipation occurs in around 10% of children under the age of five and is secondary to chronic dehydration (7);
- While oral and vulval thrush has been reported, recurrent infections are uncommon as a presentation, occurring in only 2% (4).

Reasons why the early symptoms of Type 1 diabetes are missed may include:

- parents may fail to report symptoms such as excessive thirst or bedwetting;
- in children under the age of 2 these symptoms may not be immediately obvious, and the child may appear to be unwell with less specific symptoms (4);
- in young children early symptoms can often be non-specific, e.g. headache, constipation, vulval thrush, abdominal pain, vomiting;
- in older children and adolescents, while the classic symptoms of frequent urination and excessive thirst are usually present, they can be misinterpreted by parents and schools, and may be ignored by young people themselves;
- if a child presents with one symptom of Type 1 diabetes, non-specialist healthcare professionals may fail to ask about other related symptoms;
- non-specialist healthcare professionals may fail to carry out capillary blood glucose level testing on a child presenting with symptoms of Type 1 diabetes;
- If a child has already developed DKA by the time they seek medical attention, the symptoms (which can include vomiting, deep sighing respiration, reduced conscious level and abdominal pain) can be misdiagnosed as an acute abdomen, possible gastroenteritis, acute asthma or pneumonia (4).

Every year in the UK, ten children die from DKA, making it the leading cause of mortality and morbidity in children with Type 1 diabetes. The majority of these deaths are due to cerebral oedema (swelling of the brain - a potential complication of DKA) (9).

Other forms of diabetes
Type 1 diabetes is by far the most common form of diabetes in children and young people, accounting for 96% of all cases. Other forms of diabetes occur rarely in children
and young people. It is estimated that around 2% have Type 2 diabetes and 2% have MODY, other rare forms of diabetes or their diagnosis is not defined (1).

**Any child found to have high blood glucose levels by non-specialist staff should be assumed to have Type 1 and be seen by the specialist paediatric diabetes team the same day.** Specialist paediatric diabetes teams may consider other forms of diabetes if appropriate.

Specialist paediatric diabetes teams should consider Type 2 diabetes if:*

- diabetes is diagnosed over the age of 10;
- the child is of Black or South Asian origin;
- there is a strong family history of Type 2 diabetes;
- BMI is above the 85th percentile for age and sex;
- Pancreatic islet autoantibodies (GAD, ICA) are absent (10).

Specialist paediatric diabetes teams should consider the possibility of other forms of diabetes if the following characteristics are present:

1) **Neonatal Diabetes:**
Diabetes diagnosed below 6 months of age. People diagnosed before the age of 6 months should be referred for free genetic testing whatever their current age. In neonatal diabetes, often neither parent is affected.

2) **MODY (Maturity Onset Diabetes of the Young)**
Characterised by 3 key features:

i) a young age of onset (at least one family member diagnosed below 25 years of age)

ii) autosomal dominant inheritance (the diabetes is passed down from an affected parent to their child)

iii) non-insulin dependent diabetes (or if insulin treated, a measurable c-peptide >3 five years post diagnosis)

In both Neonatal Diabetes and MODY pancreatic antibodies (GAD, IA2, ZnT8 and ICA) will be negative – indicating a non-autoimmune cause of diabetes.

There are specific features of other types of monogenic diabetes and further details of these and neonatal diabetes and MODY can be found on [www.diabetesgenes.org](http://www.diabetesgenes.org)

* If there is any doubt at all about the type of diabetes the child should be presumed to have Type 1 diabetes and insulin therapy should be commenced.

**Diabetes UK calls to action**
Diabetes UK supports the need for increased awareness of the symptoms of Type 1 diabetes amongst parents, carers, healthcare professionals and the general population in order to reduce the number of children who are not diagnosed until they are in DKA.

In 2012, Diabetes UK launched the 4Ts campaign. This aims to increase the awareness of the early signs and symptoms amongst parents, carers and anyone who looks after children, and to improve recognition, early diagnosis rates and appropriate referral of children and young people with Type 1 diabetes by healthcare professionals. For further information see: www.diabetes.org.uk/The4Ts

**Diabetes UK recommends:**

- all GP’s, primary healthcare professionals, health visitors school nurses and other non-specialist healthcare professionals should be educated in the symptoms and management of Type 1 diabetes.
- parents of children with any of the symptoms of Type 1 diabetes should see a doctor straight away for immediate capillary blood glucose testing. Urine glucose testing should only be performed if a child can void immediately, and will always require confirmation by a capillary blood glucose test.
- a capillary blood test should be taken immediately for any child presenting with any symptom of Type 1 diabetes. Waiting for a fasting blood glucose level is not appropriate and the HbA1c test should not be used to diagnose Type 1 diabetes in children.
- particular caution should be taken for children under 2, as they may not display classic symptoms of Type 1 diabetes.
- all primary health care staff must have access to a blood glucose monitor and be educated in it’s use.
- any child suspected to have Type 1 diabetes should be seen on the same day by a specialist paediatric diabetes team for confirmation of the diagnosis and management.
- Specialist paediatric diabetes teams should be aware of the rarer forms of diabetes (such as monogenic diabetes), and to refer children with signs of these rarer forms for specialist testing and management.
- Specialist services for paediatric diabetes which meet national standards should be commissioned.

**Data collection**

- the number of children diagnosed in DKA is included in the National Paediatric Diabetes Audit dataset in England and Wales. The equivalent data should be made available annually in Scotland and Northern Ireland.
## Conclusion

Children and young people with diabetes must be diagnosed as soon as possible to allow appropriate treatment to start.

To help achieve this, and reduce the rate of diagnosis in DKA, Diabetes UK recommends that every opportunity should be taken to raise awareness of the symptoms of Type 1 diabetes amongst parents, carers, school staff, and the general population.

All non-specialist healthcare professionals should be educated in the recognition, diagnosis of and referral pathway for Type 1 diabetes in children and young people.

Specialist paediatric diabetes teams should be aware of the rarer forms of diabetes and refer children with signs of these rarer forms for specialist testing and management.

## Further information

- Type 1 aware mini-video: http://www.jdrf.org.uk/type1aware
- Rarer forms of diabetes http://www.diabetesgenes.org/

## References

3. NPDA