

Diabetes UK: Type 1 essentials for children and young people

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The National Paediatric Diabetes Audit revealed that 85% of children and young people with diabetes have HbA_{1c} levels higher than the recommended targets, and that less than 6% of those over the age of 12 are getting all of the recommended diabetes care. In order to improve this situation, Diabetes UK developed a handy guide entitled *Type 1 essentials for children and young people*, outlining ten essential checks and care that all children and young people with type 1 diabetes can expect to receive. This article discusses the guide in detail, providing healthcare professionals with a practical tool to help parents and carers understand what good care and support involves.

The National Paediatric Diabetes Audit of 2012 revealed that 85% of children and young people with diabetes are not achieving the recommended HbA_{1c} levels of <58mmol/mol (<7.5%; Royal College of Paediatrics and Child Health [RCPCH], 2012), putting them at risk of both short- and long-term complications of diabetes, and potentially affecting their quality of life. The audit also found that checking for long-term complications may be inadequate, with fewer than 6% of children and young people over the age of 12 whose checks are recorded receiving all the recommended care. In addition, compared with the general population, young people with type 1 diabetes aged 15 to 34 have significantly higher mortality risk – young women are nine times more likely to die than the general population, and men in the same age group four times more likely (Health and Social Care Information Centre, 2012). It is of concern that while the percentage of children and young people achieving recommended HbA_{1c} levels is increasing, progress is unacceptably slow and falls far behind other European countries where there

have been substantial improvements in diabetes care in the past 10 to 20 years (RCPCH, 2012; Rosenbauer et al, 2012). Likewise, the percentage of children who have had all care processes recorded, though increasing, compares unfavourably with the percentages achieved for adults in England and Wales (RCPCH, 2012).

Diabetes UK aims to improve this situation through phase two of its five-year children and young person's campaign. This phase of the campaign, launched in March 2013 at the *Diabetes UK Professional Conference*, aims to significantly increase the number of children and young people with diabetes who achieve the recommended HbA_{1c} levels and who are recorded as having received all the support they are entitled to. A further aim is that all children with diabetes and their families have access to high-quality care, delivered by appropriately trained, multidisciplinary paediatric diabetes teams who can support them through all aspects of diabetes management. While some children undoubtedly receive this high-quality care, this is not the case for all.

Citation: Dowling L (2013) Diabetes UK: Type 1 essentials for children and young people. *Diabetes Care for Children & Young People* 2: 63–6

Article points

1. It has been found that the vast majority of children and young people with diabetes are failing to receive the recommended care.
2. *Type 1 essentials for children and young people* is a guide developed by Diabetes UK mainly to inform parents and carers of the essential checks and care that all children and young people with type 1 diabetes are entitled to.
3. Diabetes UK hopes that this practical tool would help to ensure that all children and young people with diabetes and their families have access to high-quality care.

Key words

- Diabetes UK
- Essentials
- Parents and carers
- Type 1 diabetes

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In order to achieve these aims, Diabetes UK produced *Type 1 essentials for children and young people*, outlining the ten essential checks and care that all children and young people with type 1 diabetes can expect to receive, including support available at school, in hospital and in wider society. Through this guide, Diabetes UK hopes to inform parents and carers of the basic elements of high-quality care every child with diabetes is entitled to. The guide would also help parliamentarians and commissioners to understand the needs of children and young people with type 1 diabetes and ensure that these needs are prioritised in the commissioning of healthcare services.

Consultation process

In developing this guide, Diabetes UK reviewed the *Children's charter for diabetes* (Diabetes UK, 2010), which was produced following consultation with children, parents and paediatric diabetes healthcare professionals. During the planning of the campaign, further consultation was undertaken with all the previous stakeholder groups to assess whether the issues were still current and aligned with the Best Practice Tariff (Randell, 2012); it was found that little had moved on despite the passage of a few years. As a result, ten statements were identified, representing what Diabetes UK believed must happen to ensure high-quality care for children with diabetes. This formed the basis of *Type 1 essentials for children and young people*,

which is reflective of the original statements in the *Children's charter for diabetes*.

Diabetes UK is urging paediatric diabetes teams to highlight to parents and carers the essential care, checks and help all children and young people with type 1 diabetes should be receiving, using this guide as a tool.

Type 1 essentials for children and young people, originally published by Diabetes UK (2013), is detailed below.

Type 1 essentials for children and young people: Is your child getting 10 out of 10?

Living with diabetes is a challenge for any child and their parents or carers. Their family will need help to cope with this challenge – at school, at play and on the journey to adult life.

This guide lists the ten things a parent or carer should expect from their child's diabetes care to make sure their treatment is on track and their condition is managed well. Healthcare professionals can use this guide to help a parent or carer to check whether their family is getting everything it should. If there is something here they are not getting, they can take this guide along to their next appointment with their diabetes healthcare team and discuss it with them.

1. Care from a specialist team

The diabetes team should be able to give a parent or carer:

- Treatment.
- Advice about food choices.
- Advice about eating healthily and keeping active.
- Support and advice to help with feelings or worries.

The team should include:

- A consultant with experience in diabetes care for children.
- A children's nurse with experience in diabetes.
- A dietitian with experience in children's diabetes, who can offer advice on food choices.
- Someone who can help the child or young person with diabetes and their parents or carers get advice about feelings or worries.

2. Regular checks

All children should get:

- A blood test to measure their HbA_{1c} four times a year.



All children and young people with diabetes should receive regular checks to ensure their diabetes is well controlled.

- Regular checks of their weight, height and general health.
- Screening for other conditions that are linked to diabetes, including coeliac disease (when diabetes is diagnosed) and thyroid disease (when diabetes is diagnosed and then once a year).
- An opportunity to agree goals.
- An opportunity to talk about emotions or things they might be struggling with.
Children aged 12 years and over should also get:
- Blood and urine tests to check kidneys – once a year.
- Digital photo of retinas – once a year.
- Blood pressure check – once a year.
- Foot examination and foot care review – once a year.

3. The right treatments

Parents or carers should be told about all the available treatments, including newer therapies. They should get the treatments and care that are right for their child. These might include:

- Multiple daily injections, carbohydrate counting and the most appropriate insulin.
- Blood glucose and ketone meters, together with testing strips.
- Insulin pumps.
- Continuous blood glucose monitoring.

4. Support so they can do it themselves

As much as possible, the family should be able to manage the child's condition themselves. To help them do this, they should be able to get expert advice, education and information that are easy to understand. This should include:

- Consistent, high-quality information, in a format that suits the child or young person and their parents or carers.
- 24-hour access to help and advice.
- Education so the child can learn how to manage their condition.
- Advice on eating well and keeping active.
- A key contact in the healthcare team.
- The chance to regularly visit a dietitian, who can offer advice on food choices.

It is also worth pointing out to parents and carers that the child or young person with diabetes may be eligible for Disability Living Allowance (GOV.UK, 2013).



It is important to encourage and foster the independence the child or young person needs to successfully manage their diabetes.

5. Help with feelings or worries

Coping with diabetes can be difficult – for the child and for the rest of the family. It is normal to feel upset, angry, confused or worried. Make sure the parents or carers talk to their diabetes team about this.

As part of the diabetes care, the team should offer the child or young person with diabetes and their family the chance to talk to a psychologist who has experience in diabetes and how it affects children and their families. The child or young person and their family should be able to talk to the psychologist about particular issues if they need to, and have regular meetings to evaluate the psychological well-being of the child or young person with diabetes.

6. The right care when in hospital

If the child or young person is admitted to hospital for any reason, their parents or carers should have contact with a children's diabetes team. The family should also be allowed to carry

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on managing the child's diabetes if possible. This will help the hospital staff to look after the child in the right way.

7. A smooth transition to adult diabetes services

Moving from child to adult healthcare services is a big change. It can be a difficult time for teenagers, who are already dealing with other changes in their lives. But it is important that the move works well, so children keep on getting the care they need. The two diabetes services should work together to make sure the move goes as smoothly as possible for the child, at an age that is right for them, and in a way that suits them.

8. A say in care planning

The child or young person and their family should be involved in making decisions about the care they get, and have a say in how the child's diabetes is managed. For example, they should:

- Be able to work with their doctor or healthcare team to create a plan for how the child's diabetes will be treated and managed, talk through the plan, and ask any questions.
- Get copies of letters detailing what has been agreed to.
- Help design services that are right for them.

They should also be invited to fill in a national Patient Reported Experience Measure Survey, which collects information about the kind of care children with diabetes are getting.

9. Support at school

The child or young person with diabetes should have all the support they need to do well at school. They should be able to take part in all areas of school life, including classroom work, trips, sports and after-school clubs. The diabetes team should work with the school to make sure that happens. For example, they should:

- Agree a healthcare plan with the child or young person and their family.
- Identify who will ensure the child or young person gets the diabetes care they need at school.
- Keep plans up to date and ensure everyone knows what is happening.

10. Equal opportunities

The child or young person with diabetes should be given the same opportunities as everyone else, and not be treated differently simply because they have diabetes. They should be able to join in with sports, activities, clubs and groups. And they should be able to learn to drive and do most jobs.

Conclusion

With the high levels of variability in diabetes care for children and young people, immediate action is needed to address the situation. Although type 1 diabetes requires seemingly constant care and may change the family's life, given the appropriate support, the child or young person with diabetes can lead a full life and participate in the same activities as their peers. It is hoped that this guide will serve as a practical and effective tool to help achieve this. ■

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