Improving diabetes care for young people

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- Challenges facing children and young people with diabetes
- How diabetes services should support this group of patients

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f children and young people aged over 12 years, 85% have blood-glucose levels higher than recommended targets, but only 6% have all recommended care processes recorded (National Paediatric Diabetes Audit Project Board, Royal College of Paediatrics and Child Health, 2012). The National Paediatric Diabetes Audit data highlights that access to quality care varies, so young people have a higher risk of developing complications in later life.

A Diabetes UK guide, Type 1 Essentials for Children and Young People, defines what care should be available to children, young people and their families. It reflects the impact diabetes has on children and young people’s lives. Its key elements are below.

1. Ongoing clinical care from a specialist, multidisciplinary paediatric diabetes team. Team members should have appropriate training in: clinical care; educational dietetic, lifestyle issues; mental health problems and foot care (National Institute for Health and Clinical Excellence, 2004). The team should include a consultant or specialty doctor, paediatric nurse with training in children’s diabetes, paediatric dietitian with experience and/or training in diabetes, and access to children’s psychology services.

2. Regular monitoring of diabetes control and screening for potential complications. Monitoring systems include:

   - HbA1C monitoring available in all clinics for all ages;
   - Screening for thyroid disease at diagnosis, then yearly for all ages; and
   - Screening for coeliac disease at diagnosis. From the age of 12 years:
   - Annual blood and urine tests to check renal function;
   - Annual digital retinal photography to check for retina damage;
   - Annual blood-pressure screening;
   - Examination of the feet and annual foot-care reviews.

3. Access to a full range of treatments to optimise diabetes management, such as:

   - Intensive insulin treatment with carbohydrate counting and access to the most appropriate insulin;
   - Continuous subcutaneous insulin infusions;
   - Continuous blood-glucose monitoring;
   - Smart meters, ketone meters and testing strips.

4. Support to self-manage diabetes. This should include:

   - Age-appropriate, structured education and lifestyle advice;
   - 24-hour access to specialist help and advice, and a key contact;
   - Consistent, high-quality information in appropriate formats;
   - The chance to see a dietitian regularly.

5. Access to emotional and psychological care. A psychologist with experience in diabetes and caring for children, young people and their families should be available. With the paediatric diabetes team they should offer regular screening of emotional and psychological status and ongoing intervention if required.

6. Care from specialist diabetes team when children and young people are admitted to hospital. Children and young people should have access to a diabetes specialist team and be allowed to self-manage their regimen, if this is deemed appropriate.

7. A smooth transition to adult/young adults diabetes services. Paediatric and adult services should collaborate to ensure the correct preparation for transition at the right time for the patient; for example, this might mean allowing him/her to be seen in clinic without their parents.

8. Real involvement in care. Children and young people should be involved in key decisions about their management and care. This could be through personalised care planning, copies of clinic letters to confirm what was agreed, and involving them in service design. They should also have the chance to complete a Patient Reported Experience Measure survey, which is part of the National Paediatric Diabetes Audit (tinyurl.com/NPDA-site).

9. Full support to manage diabetes at school. Patients should be able to take part in all aspects of school life, including extracurricular activities. Education and health services should collaborate to ensure patients reach their potential in school; this should include developing individual care plans, which are regularly updated and available to all involved in their care.

10. To be treated with respect and not experience discrimination. Patients should be treated as individuals and have the same opportunities as everyone else, including participating in activities, joining groups and gaining a job. NT

*Health professionals can access the guide at www.diabetes.org.uk

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References

- National Institute for Health and Clinical Excellence (2004) Type 1 Diabetes: Diagnosis and Management of Type 1 Diabetes in Children, Young People and Adults. tinyurl.com/DiabetesChildren