

Children and young people with diabetes: A practical guide for primary care

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Learning objectives

After reading this article, the participant should be able to:

- Identify and refer a child or young person with type 1 or type 2 diabetes presenting in primary care.
- 2. Outline the dietary recommendations for children and young people with type 1 or type 2 diabetes.
- Discuss insulin treatment for children and young people with type 1 diabetes including during puberty.
- 4. Describe optimal management of diabetes at school and during adolescence.

Key words

- Children and young people
- Insulin
- Puberty
- School

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Diabetes is not uncommon in childhood, affecting 1 in 450 children, with the majority (97%) having type 1 diabetes (Royal College of Paediatrics and Child Health, 2009). The incidence of both type 1 and type 2 diabetes is increasing, but it is likely that a large UK general practice will see only one newly diagnosed child every 2 years. Treatment of this complicated condition can be challenging for children, their families and healthcare professionals, and treatment priorities and strategies will need to adapt as the child grows. This article reviews some of the common clinical issues in managing diabetes in children and young people. Illustrative case examples are presented in *Boxes 1* and 2.

ost children and young people (CYP) with type 1 diabetes present with the classic symptoms of polyuria, polydipsia, lethargy and weight loss. However, healthcare professionals do not always consider diabetes in the context of childhood, and many parents may suspect diabetes but delay seeking medical help because they do not want to believe this could happen to their child (Lowes et al, 2005). This is problematic, particularly considering the subsequent outcome of diabetic ketoacidosis, and potential death, if diabetes is untreated.

There are particular difficulties in diagnosing young children, particularly those under 2 years of age. Parents may have concerns that the child is fretful, restless or irritable, but questioning will reveal a story of increased or constant milk feeding and heavy, soaking nappies. Older children may present with secondary nocturnal enuresis. Ketoacidosis will cause Kussmaul breathing, leading to a diagnosis of

chest infection, or abdominal pain that may be mistaken for an acute surgical emergency. Urine testing for glucose and ketones is easy in most children (if they have diabetes, they will be polyuric). If the urine test is positive and/or a random capillary blood glucose is >11.1 mmol/L, urgent discussion with the local paediatrician should take place (Alberti et al, 2004).

A number of other forms of diabetes are increasingly being diagnosed. *Table 1* highlights the differential diagnosis of glucose intolerance in childhood and the likely clinical presentation (Porter and Barrett, 2004). Secondary diabetes related to cystic fibrosis or high-dose steroid replacement is well recognised. Genetic forms of diabetes such as maturity-onset diabetes of the young (MODY) can present in childhood: correct diagnosis is important as management may be affected. A useful resource is the website www.diabetesgenes.org (accessed 22.01.14), which contains information on genetic forms of diabetes and a MODY risk calculator.

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Table 1. Presentation, investigation to identify type of diabetes, and treatment.*			
Type of diabetes	Presentation	Investigation	Treatment
Type 1	Polyuria/polydipsiaLoss of weightUsually lean	 Random blood glucose >11.1 mmol/L Ketonuria GAD/IA2 antibody postive 	• Insulin
Type 2	 Obese Ethnic minority background Strong family history of type 2 diabetes Acanthosis nigricans Other features of metabolic syndrome (such as polycystic ovary syndrome, high blood pressure, abnormal lipids) May be incidental finding 	 Random blood glucose >11.1 mmol/L May have ketonuria GAD/IA2 antibody negative 	 Metformin as first-line treatment Insulin may be necessary if diagnostic uncertainty, blood glucose concentration very high or in the presence of ketones
MODY	 Polyuria/polydipsia Loss of weight Family history of early-onset type 2 diabetes in close relatives (<25 years of age) Usually lean 	 Random blood glucose >11.1 mmol/L May have ketonuria GAD/IA2 antibody negative 	 Further investigations to be discussed with the local paediatric diabetes team Insulin may be necessary if diagnostic uncertainty or blood glucose concentration very high Some forms of MODY respond to sulphonylurea treatment Seek further advice
Disease-specific associated diabetes	 Cystic fibrosis Chemotherapy Genetic syndromes, such as Bardet-Biedl, Prader-Willi and Down's syndrome 	Further investigations to be discussed with local paediatric diabetes team	

GAD=glutamic acid decarboxylase; IA2=insulin antibody; MODY=maturity-onset diabetes of the young. *Adapted from Porter and Barrett (2004).

Of great concern is the increasing incidence of type 2 diabetes in childhood, especially in areas with high proportions of ethnic minorities. However, the numbers are still relatively small, and the UK does not seem to have the high prevalence seen in North America or Japan (D'Adamo and Caprio, 2011). The clinical presentation of CYP with type 2 diabetes can be similar to that of CYP with type 1 diabetes, and cases with ketosis have been described, although this is often mild (Fagot-Campagna et al, 2000; see also *Table 1*).

The majority of children with type 2 diabetes in the UK are from south Asian backgrounds and have a strong family history of type 2 diabetes (Haines et al, 2007). Making a confident diagnosis of type 2 over type 1 diabetes can be a challenge, even for an experienced paediatrician. The most pragmatic approach in case of any doubt is to give insulin therapy (Rosenbloom et al, 2011). This is likely to be necessary where blood glucose levels are in double figures or significant ketonaemia is present, even in an individual with type 2 diabetes. Once the child is safely on treatment and stabilised, the precise

diagnosis can then be reviewed regularly in the relative safety of the diabetes clinic. A good overview on management of type 2 diabetes in childhood is provided in the *Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence* (Rosenbloom et al, 2011).

Cases of delayed or missed diagnosis of diabetes are regularly observed (Ali et al, 2011). About 30% of children with new-onset diabetes have had at least one related medical visit before being diagnosed (Bui et al, 2010). At best, children can still be relatively well at presentation; at worst, they can die before they reach hospital. Where there is any concern about the possibility of diabetes in a child or young person, it is essential to discuss the individual with a senior paediatrician as soon as possible.

Nutrition and weight management for overweight children with diabetes

Most children with type 1 diabetes do not have a significant weight problem. However, the inability to deliver insulin in a physiological manner means that most will be over-insulinised (Holl et al, 1998; 2003), except perhaps those on

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Box 1. Case report.

Narrative

CG is a 4-year-old girl who has recently been diagnosed with type 1 diabetes. She is brought to the practice as she has had diarrhoea and vomiting for 24 hours. She is now refusing to eat or drink and her mother is worried.

Discussion

The management of any child or young person with an intercurrent illness requires more frequent blood glucose monitoring, ketone testing (usually blood ketone testing) and regular contact with a healthcare professional. Families who are more confident with diabetes management are likely to need less support than those with a very recent diagnosis. The biggest concern is the development of diabetic ketoacidosis, as the physiological stress response triggered by illness can lead to insulin resistance and hyperglycaemia, even in the absence of any carbohydrate intake. Polyuria will occur and poor oral fluid intake will rapidly lead to significant dehydration. However, gastroenteritis often does not provoke a systemic response, and significant hypoglycaemia can occur, even in young children without diabetes. This child will need a clinical assessment and immediate discussion with the diabetes healthcare team. The new Best Practice Tariff should provide all children and young people and their families with 24-hour access to their diabetes team.

insulin pump therapy, and thus will be heavier than their counterparts without diabetes.

There have been a number of changes to the nutritional management of people with type 1 diabetes over the years. The emphasis is on healthy eating. A healthy diet, as recommended by the International Society for Pediatric and Adolescent Diabetes (Smart et al, 2011), is composed of: 50–55% carbohydrate, of which sucrose can be up to 10% of total daily energy intake; 30–35% fat, with <10% coming from saturated or trans-fatty acid sources; and 10–15% protein. Salt intake should be <6 g per day.

These dietary recommendations apply across the paediatric age range, but a flexible approach will be necessary for younger children, particularly toddlers. Frequent small meals, or "grazing", are typical of young children, and it will be easier to adapt the insulin regimen to fit the child rather than ask the parents to make drastic changes to the diet of their young children, who already provide a number of challenges.

Studies have examined the diet of different age groups of CYP (Smart et al, 2011). There are methodological problems with examining dietary patterns in a group of people who have been given a lot of information on how to eat. Food diaries, often used as a gold standard for assessment, are also an effective deterrent to "normal" eating. However, clinical experience does suggest that

people with diabetes are no different from the general population in terms of what may be called dietary "indiscretions". Ideally these would be infrequent, and although blood glucose levels can be controlled by carbohydrate counting and adjusting insulin dosage, the extra calories can lead to significant weight gain, which can be difficult to lose.

It is likely that most people with type 2 diabetes will be either overweight or obese; however, it is beyond the scope of this article to describe in detail the approaches to weight management for childhood obesity. A number of studies have been performed in CYP, varying from lifestyle adjustments to weight loss medication such as orlistat and sibutramine, and have been the subject of a Cochrane review (Oude Luttikhuis et al, 2009). NICE (2006) guidance is also available. Sibutramine is no longer available in the UK and orlistat is an over-the-counter preparation but has an indication only in adults. The majority of these studies had small sample sizes, and were of short duration, with many showing little effect on weight change (Oude Luttikhuis et al, 2009).

There do not appear to have been any studies that have specifically assessed weight management strategies in CYP with type 2 diabetes, but there is no reason to suspect that generic weight management approaches would not be appropriate. Children and their families will need to be motivated and engaged for any weight loss strategy to be effective. Data suggest that this can be very difficult. Studies also show that families struggle to recognise that their child may have a significant weight problem (Etelson et al, 2003; Eckstein et al, 2006). This may be because many parents compare their child's physique with that of other children in the playground; however, with 20% of children entering primary school overweight or obese in the UK, such playground comparisons may provide false reassurance to parents (Etelson et al, 2003; Eckstein et al, 2006).

Worryingly, it has been shown that even adolescents with type 2 diabetes and their parents underestimate the severity of the weight problem (Skinner et al, 2008). In one study, the mean BMI of 104 adolescents with diabetes was

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36.4 kg/m²; 87% were classed as overweight by North American guidelines (Barlow and Dietz, 1998). Yet 40% of parents whose child had a BMI >95th percentile felt that their child's weight was "about right", and 55% of adolescents with a BMI >95th percentile were unconcerned by their weight.

There was consistency in weight estimation between adolescents and their parents. Parents and adolescents who underestimated their weight problems had poorer dietary and physical activity behaviours than those who were more aware of the weight issues (Skinner et al, 2008). Adequate explanation of the importance of weight management for people with type 2 diabetes is therefore paramount.

Management of children with type 1 diabetes

Management of CYP with diabetes will depend on a number of factors, including age, weight, developmental stage, cognitive ability and family support.

Insulin requirement

As in most areas of paediatrics, doses of medication, in this case insulin, are initially based on body weight. Doses prescribed at diagnosis are informed "estimates" of likely need. Most centres are likely to start doses at the lower end of the estimated range to avoid provoking hypoglycaemia soon after diagnosis. Most CYP will be quite insulin resistant for the first few weeks (approximately 4–8 weeks) after diagnosis, owing to the preceding persistent hyperglycaemia causing glucose toxicity just before diagnosis, and doses may need to be increased quite rapidly in the early stages. It is suggested that the total daily insulin requirement will vary from 0.7 to 1.0 unit/kg/day for prepubertal children (Bangstad et al, 2011).

For young people going through puberty, insulin requirement may be as high as 1.5–2.0 units/kg/day during the rapid growth phase – usually mid-to-late puberty (Bangstad et al, 2011). The increase in insulin requirement during the pubertal growth spurt is thought to be due to increases in growth hormone released during puberty resulting in insulin resistance (Dunger, 1992).

In addition, the insulin deficiency of type 1 diabetes leads to abnormalities in the growth

hormone/insulin-like growth factor-1 (IGF-1) feedback mechanism and pubertal children oversecrete growth hormone, making puberty a time of marked insulin resistance for children with the condition (Dunger, 1992).

Total daily doses of insulin are likely to be very high during puberty as young people also significantly increase their calorie intake to fuel normal growth (a 60 kg boy could need up to 120 units/day), causing anxiety for these individuals and their carers. Despite these large doses of insulin, even adolescents who are very engaged with their diabetes management can struggle to achieve tight glycaemic control.

The 20th anniversary of the DCCT (Diabetes Control and Complications Trial) is approaching, but the findings are still relevant and highlight the difficulties for adolescents. A total of 195 adolescents aged between 13 and 17 years participated in the trial (DCCT Research Group, 1994). Although the beneficial effect of improved glycaemic control was still evident, adolescents found it more difficult to achieve lower HbA, levels than their adult counterparts (64 ± 1.4 mmol/mol [8.06 ± 0.13%] versus 54 ± 0.03 mmol/mol [7.12 ± 0.03%], respectively; P<0.001), yet they had a greater tendency to develop severe hypoglycaemia (85.7 events per 100 person-years versus 56.9 events per 100 person-years in the adult cohort; DCCT Research Group, 1994).

Insulin injections

Young children with diabetes are likely to need shorter needles than adolescents and adults. However, this will need to be assessed for each individual – some teenagers can be very slim and the author has often used short (4 mm) needles in this group at diagnosis where there has been significant weight loss. All children are advised to rotate injection sites both throughout the day and from day to day to avoid the development of lipohypertrophy, although in my clinical experience there are a small number of people who appear to be particularly prone to this complication, even with good site rotation.

Insulin regimen

Few studies have examined the optimum diabetes regimen for children at different ages

- 1. For young people with type 1 diabetes, insulin requirement may be as high as 1.5–2.0 units/kg/day during the pubertal growth spurt.
- 2. This increase in insulin requirement is thought to be due to increases in growth hormone released during puberty resulting in insulin resistance.
- 3. In addition, the insulin deficiency of type 1 diabetes leads to abnormalities in the growth hormone/insulin-like growth factor-1 feedback mechanism and pubertal children over-secrete growth hormone, making puberty a time of marked insulin resistance for children with the condition

Page points

- Many clinical teams recommend intensive insulin regimens, either multiple daily injections or insulin pump therapy, for all children and young people with diabetes.
- 2. This will involve carbohydrate counting and dose adjustment of mealtime rapid-acting insulin.
- 3. These are likely to be the best regimens for very young children (under 5 years), who may eat unpredictably with respect to both timing and quantity of food.
- Rapid-acting insulin can be given after food for these children, so the dose can be tailored to the amount of food actually eaten rather than the amount of food offered.

in a structured experimental fashion (Spinks et al, 2007). As a result, the choice of regimen and insulin type is likely to be a negotiation between child, family and their healthcare team (Bangstad et al, 2011).

Many clinical teams are recommending intensive insulin regimens, either multiple daily injections (MDI) or insulin pump therapy, for all CYP with diabetes (Gosden et al, 2010). This will involve carbohydrate counting and dose adjustment of mealtime rapid-acting insulin. These are likely to be the best regimens for very young children (under 5 years), who may eat unpredictably with respect to both timing and quantity of food. Rapid-acting insulin can be given after food for these children, so the dose can be tailored to the amount of food actually eaten rather than the amount of food offered.

MDI are a good way of managing food refusal in any age of child without having to worry about the risk of hypoglycaemia. This is also a very good regimen for adolescents, who will have much less structure to their lives and will want to go out and socialise with friends at varying times. However, these regimens do involve a high treatment burden and require a great deal of individual and family engagement to work well – during adolescence it can be very difficult to achieve this degree of adherence to treatment. Many outpatient consultations with adolescents will involve negotiations about how to fit diabetes around the life of someone who would prefer to believe it was not there.

Some families will struggle with these regimens. Carbohydrate counting and insulin dose adjustment based on ambient glucose, food and physical activity are likely to require a reasonable level of understanding, and can be extremely challenging for families with special educational needs (either in the child or supporting family) or problems with literacy or numeracy. Support is available, often from the specialist nurse within the local diabetes team, but some families are still left with little confidence. In the end, people with diabetes have to make decisions about their diabetes management almost continuously, and no diabetes care team can provide this level of input.

Data suggest that families will benefit from much more intensive support, but this can

prove difficult where diabetes teams are stretched already; alternative means of support do need to be developed (Brink et al, 2002). In the meantime, a conventional insulin regimen of twice-daily mixed insulin or an MDI regimen with long-acting background insulin and predetermined, fixed doses of rapid-acting insulin with meals, rather than carbohydrate-counted adjusted doses, may be a suitable compromise for these families.

Insulin pump therapy

Insulin pump therapy has been approved by NICE for use in childhood (NICE, 2008). The NICE guideline states that a child under 12 years of age will qualify for insulin pump therapy if an MDI regimen is considered impractical or inappropriate, which could include all children under 12 years of age. Children over the age of 12 would need to fulfil adult criteria (NICE, 2008). In areas where insulin pump provision has been unproblematic, some services are starting children on insulin pumps at diagnosis, but there are many centres where this is not possible for a number of reasons.

Data suggest that there is some benefit to be gained from insulin pump therapy in childhood, mainly with respect to avoidance of hypoglycaemia (Pickup and Sutton, 2008). Also, emerging data suggest that a combination of an insulin pump and continuous glucose monitoring (CGM; worn continuously) can improve glycaemic control. The STAR 3 (Sensor-Augmented Pump Therapy for A_{1c} Reduction) study examined the use of sensor-augmented insulin pump therapy. The results suggest that this can lead to improvements in HbA_{1c} levels in both children and adults, without an increased risk of hypoglycaemia (Bergenstal et al, 2010). CGM may be particularly useful in hypoglycaemia avoidance. A study of people with good glycaemic control (HbA_{1c} level <53 mmol/mol [<7.0%]) showed that control could be improved even in these individuals and without hypoglycaemia (Juvenile Diabetes Research Foundation [JDRF] CGM Study Group, 2009).

In contrast, a study examining continuous rather than focused use of glucose sensors showed a benefit in adults over 25 years of age, but not in CYP. This may have been related to a lower

rate of continuous use of the glucose sensor in younger people: CGM use for 6 days or more per week was 83% in those over 25 years of age, 30% in those aged 15–24 years and 50% in those aged 8–14 years (JDRF CGM Study Group et al, 2008).

Some studies have examined the benefits of self-monitoring of blood glucose (SMBG). Findings suggest that four or more blood glucose tests per day is associated with a 13 mmol/mol (1.2%) reduction in HbA_{1c} (Levine et al, 2001). In these studies it is difficult to ascertain whether it is the people who are most engaged with their diabetes who benefit the most from frequent blood glucose monitoring: doing six blood tests a day just to document them in a glucose diary is likely to be of limited therapeutic value. However, CYP taking MDI regimens will be asked to perform four blood tests per day, whereas CYP using pump therapy will be asked to perform a minimum of four to six tests per day.

Hypoglycaemia

Recurrent hypoglycaemia can be a significant barrier to achieving tight glycaemic control in adults and children with type 1 diabetes. Fear of hypoglycaemia is well described and clinical experience suggests that some CYP keep blood glucose levels high to avoid episodes of hypoglycaemia. Yet no strong link between fear of hypoglycaemia and sub-optimal diabetes control has been demonstrated (Gonder-Frederick et al, 2011).

Of importance are recent changes to the regulations concerning diabetes, driving and hypoglycaemia. These will be relevant to young people with diabetes, many of whom will ask their GP to provide a "medical" reference. The regulations now state that people on insulin must have awareness of hypoglycaemia and must not have had an episode of severe hypoglycaemia in the last 12 months (Driver and Vehicle Licensing Agency, 2013). While few data have been published in this area, impaired awareness of hypoglycaemia has been described in up to 29% of CYP with diabetes (Ly et al, 2009). Detailed discussions about the regulations for driving with diabetes need to be had with young people who are planning to learn to drive.

Management of diabetes at school

The management of any child with a chronic condition in school can be challenging; dealing with blood tests and injections can prove even more so. With an increasing emphasis on intensive insulin regimens, schools are being asked to do more for children with diabetes, especially primary school children who are unable to do their own injections or, at the very least, need some adult supervision.

Although schools have a duty of care towards children with all sorts of medical needs, there is no legislation in the UK – or in many other countries globally – that specifies the supportive role of school staff (Diabetes UK, 2008). Studies of parents and children have shown that negative experiences are not uncommon in school. A number of children use the school toilets to do injections and blood glucose testing, and there are concerns that school staff lack even a basic understanding of diabetes; consequently children rely on peers and not teaching staff for help (Newbould et al, 2007; Amillategui et al, 2009).

Data from Spain suggest that 44% of parents have had to rearrange their work schedules to support their children at school (Amillategui et al, 2007) and UK data show that if children were unable to administer their own insulin, 70% of schools expected a parent to come and give the injection (Diabetes UK, 2009). However, the difficulties for schools and teaching staff should not be underestimated, and expectations of a high level of knowledge and understanding of diverse medical conditions, from epilepsy through congenital heart disease to diabetes, are significant.

Adolescence

Adolescence is the period of transition from childhood to adulthood. It is a time of great change in biological, social and psychological terms. The impact of puberty on diabetes and the associated increased insulin requirement has already been discussed. If SMBG is performed regularly yet readings are often high because of the insulin resistance of puberty, this will be demoralising for adolescents. If high doses of insulin are given to overcome insulin resistance, frequent hypoglycaemia may ensue, which can be very embarrassing for adolescents, or could lead to

- Recurrent hypoglycaemia can be a significant barrier to achieving tight glycaemic control in adults and children with type 1 diabetes.
- 2. Clinical experience suggests that some children and young people keep blood glucose levels high to avoid hypoglycaemic episodes, yet no strong link between fear of hypoglycaemia and sub-optimal diabetes control has been demonstrated.
- 3. Recent changes to the regulations concerning diabetes, driving and hypoglycaemia specify that people on insulin must have awareness of hypoglycaemia and must not have had an episode of severe hypoglycaemia in the last 12 months.
- 4. Since impaired awareness of hypoglycaemia has been described in up to 29% of children and young people with diabetes, detailed discussions about the regulations for driving with diabetes need to be had with young people who are planning to learn to drive.

Box 2. Case report.

Narrative

BB is 13 years old and has had type 1 diabetes for 4 years. Her glycaemic control has been suboptimal for some time with recurrent severe episodes of hypoglycaemia leading to seizures, usually overnight. She is a keen athlete and does a lot of training on a daily basis, but is now extremely concerned by these frightening episodes. The diabetes team feel that she would benefit from insulin pump therapy but the family are anxious and keen to discuss this option with healthcare professionals at the practice.

Discussion

Insulin pump therapy can be prescribed for young people over the age of 12 years if attempts to achieve target HbA_{1c} levels have resulted in disabling hypoglycaemia or the HbA_{1c} level remains >69 mmol/mol (8.5%) despite a "high level of care". Disabling hypoglycaemia includes episodes leading to significant fear. Nocturnal hypoglycaemia is common after physical activity as the body replaces depleted muscle glycogen. While there are no reliable data to suggest that pump therapy is best for sports enthusiasts, this form of treatment is likely to allow BB to be able to adjust her insulin replacement doses to match her levels of physical activity better, especially overnight. A pump would be a good choice, even on a trial basis, to enable this young person to pursue something she enjoys.

unacceptable weight gain (especially in girls). It is not surprising that adolescents find it hard to keep up with the management of their diabetes.

In addition, having a chronic condition such as diabetes at a time when fitting in with peers is of paramount importance is potentially very challenging. It is known that diabetes control deteriorates during this time: insulin doses may be omitted and clinic attendance can be erratic. A number of different approaches have been tried in an attempt to improve adolescent engagement with diabetes management, but there is no easy answer. Family support is crucial at this time and comprises "behaviours that foster, in an individual, feelings of comfort and belonging, and that he or she is basically accepted and approved of as a person by the parents and family" (Skinner et al, 2005).

Research shows a bell-shaped response to family support, with both those getting too little and those getting too much tending to do less well in terms of diabetes management (Gustafsson et al, 1987). Recurrent diabetic ketoacidosis is a significant risk, especially in girls, and those from lower socioeconomic backgrounds or with pre-existing psychosocial issues (Chapman et al, 1988).

Risk taking is part of what may be considered normal adolescent behaviour – testing out the boundaries as a phase of personal development. These risks will have a variable impact on health, but are likely to have a greater impact in those with an underlying chronic condition and may also be more prevalent in these younger people. In the UK, data suggest that 11% of 13- to 14-year-olds have smoked cigarettes, with 4% smoking every day, 17% have been drunk at least once and 11% have tried some type of recreational drug (Office for Standards in Education, Children's Services and Skills, 2008).

A large study from a multicentre collaboration across Germany and Austria showed that the prevalence of smoking in CYP with diabetes increased from 0.1% in children under 11 years of age to 28.4% in those aged 15-20 years (Hofer et al, 2009). Smokers had poorer glycaemic control (HbA₁, 76 mmol/mol [9.1%] in smokers versus 64 mmol/mol [8.0%] in non-smokers; *P*<0.0001) and there were also negative effects on diastolic blood pressure and lipid profile. However, this may reflect a group of individuals struggling to engage with their diabetes management in general. The long-term risks of micro- and macrovascular disease in people with type 1 diabetes are well described, and so all adolescents should be informed of the dangers and offered smoking cessation support as and when available.

The UK has the highest rate of teenage pregnancies in Europe: five times the rate in the Netherlands and twice that in France (United Nations Statistics Division, 2010). Teenage pregnancies are associated with poorer health outcomes for both mother and child (Chen et al, 2007), but this may in part reflect the poorer socioeconomic status of the young women who become pregnant during adolescence. There do not appear to be any studies examining pregnancy rates and outcomes in adolescents with diabetes, although pregnancies do occur.

UK data from studies of adult women with diabetes are quite sobering. A study conducted by the Confidential Enquiry into Maternal and Child Health (CEMACH, 2007) found that only 41% of pregnancies were planned, 28% of women smoked (compared with 35% of the general maternity population) and only 27% took folic acid before pregnancy. The preterm delivery rate was 36%, with a caesarean section rate of 67%, compared with 7% and 22%, respectively, in the general population. Women

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- 2. Smokers had poorer glycaemic control (HbA_{1c}, 76 mmol/mol [9.1%] in smokers versus 64 mmol/mol [8.0%] in non-smokers; *P*<0.0001) and there were also negative effects on diastolic blood pressure and lipid profile.

with diabetes also had a five-fold increased risk of stillbirth, a three-fold increased risk of perinatal mortality and a two-fold increased risk of fetal congenital anomaly.

Information and support for young girls and women with diabetes is vital to prevent unplanned pregnancies. Yet the correct methods and timing of providing such information to young girls remain unclear, both for girls with diabetes and those in the general population (CEMACH, 2007). Adolescent girls will have a lot of exposure to healthcare – time that could be used for education with the cooperation and encouragement of parents or carers, especially about detrimental lifestyle behaviours and the need to take folic acid 5 mg/day if pregnancy is anticipated.

Transition of care from paediatric to adult services is a recognised challenge for all groups of young people with chronic medical conditions (American Academy of Pediatrics et al, 2011). "Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from childcentred to adult-oriented health care systems" (Blum et al, 1993). The National Service Framework (NSF) for Children and Young People (DH, 2004) recommends that transition be seen as a guided, educational, therapeutic process, rather than merely an administrative event. Although the majority of models of transitional care consider joint working between adult and paediatric secondary care, many of these young people do not come to clinic at all. It is likely that the role of the primary care team could become paramount for these young people, and more work is needed in this area.

Diabetes review

In 2012–13, a mandatory Best Practice Tariff was introduced to provide an annual payment for the treatment of every child and young person under 19 years of age with diabetes (Randell, 2012). This is in recognition of the increasingly complex nature of paediatric diabetes care, involving a multidisciplinary team of specialised personnel. Funding will be given provided that a number of criteria are met. These include 3-monthly outpatient reviews, structured education, 24-hour

access to specialist diabetes advice and annual screening for complications as recommended by NICE (2004). Service commissioners will monitor compliance with the tariff criteria, which are likely to undergo further review in the near future. Readers should note that this is a hospital tariff rather than a GP one.

Also relevant are the GP requirements under the Quality and Outcomes Framework (QOF):

- DM001 the contractor establishes and maintains a register of all patients aged 17 or over with diabetes mellitus.
- DM010 the percentage of patients with diabetes, on the register, who have had influenza immunisation.

NICE (2004) guidance recommends that all children over 12 years of age have an "annual review" with screening for microvascular complications. Young people need to have their blood pressure checked, retinal screening, urine screening for microalbuminuria and a blood test for assessment of renal function. Children under 12 years of age will have annual blood tests to screen for autoimmune thyroiditis, which occurs in up to 10% of those with type 1 diabetes. Coeliac disease is also more prevalent in this patient group. It is recommended that this is tested for at diagnosis of diabetes, and future testing reconsidered if symptoms of coeliac disease develop (NICE, 2004).

Conclusion

Childhood diabetes is a complex medical condition that requires healthcare professionals to have a large number of clinical, educational and psychological skills for successful management. There is no doubt that joint working with children and their families is as rewarding as it can be challenging. This is an area where joint working with primary care is still underdeveloped but could lead to improved outcomes for children and their families.

Alberti G, Zimmet P, Shaw J et al (2004) Type 2 diabetes in the young: the evolving epidemic. The international diabetes federation consensus workshop. *Diabetes Care* **27**: 1798–811

Ali K, Harnden A, Edge JA (2011) Type 1 diabetes in children. *BMJ* **342**: d294

American Academy of Pediatrics et al (2011) Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* **128**: 182–200

- 1. In 2012–13, a mandatory Best Practice Tariff was introduced to provide an annual payment for the treatment of every child and young person under 19 years of age with diabetes.
- This is in recognition of the increasingly complex nature of paediatric diabetes care, involving a multidisciplinary team of specialised personnel.
- 3. Funding will be given provided that a number of criteria are met, including 3-monthly outpatient reviews, structured education, 24-hour access to specialist diabetes advice and annual screening for complications as recommended by NICE.
- Service commissioners will monitor compliance with the tariff criteria, which are likely to undergo further review in the near future.

"Childhood diabetes is a complex medical condition that requires healthcare professionals to have a large number of clinical, educational and psychological skills for successful management."

- Amillategui B, Calle JR, Alvarez MA et al (2007) Identifying the special needs of children with type 1 diabetes in the school setting. An overview of parents' perceptions. *Diabet Med* **24**: 1073–9
- Amillategui B, Mora E, Calle JR, Giralt P (2009) Special needs of children with type 1 diabetes at primary school: perceptions from parents, children and teachers. *Pediatr Diabetes* **10**: 67–73
- Bangstad HJ, Danne T, Deeb L et al (2011) Insulin treatment. In: Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence. International Diabetes Federation, Brussels, Belgium: 60–65
- Barlow SE, Dietz WH (1998) Obesity evaluation and treatment: Expert Committee recommendations. The Maternal and Child Health Bureau, Health Resources and Services Administration and the Department of Health and Human Services. *Pediatrics* **102**: E29
- Bergenstal RM, Tamborlane WV, Ahmann A et al (2010) Effectiveness of sensor-augmented insulin-pump therapy in type 1 diabetes. N Engl J Med 363: 311–20
- Blum RW, Garell D, Hodgman CH et al (1993) Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health* **14**: 570–6
- Brink SJ, Miller M, Moltz KC (2002) Education and multidisciplinary team care concepts for pediatric and adolescent diabetes mellitus. J Pediatr Endocrinol Metab 15: 1113–30
- Bui H, To T, Stein R et al (2010) Is diabetic ketoacidosis at disease onset a result of missed diagnosis? *I Pediatr* **156**: 472–7
- Chapman J, Wright AD, Nattrass M, FitzGerald MG (1988) Recurrent diabetic ketoacidosis. *Diabet Med* **5**: 659–61
- Chen XK, Wen SW, Fleming N et al (2007) Teenage pregnancy and adverse birth outcomes: a large population based retrospective cohort study. *Int J Epidemiol* **36**: 368–73
- Confidential Enquiry into Maternal and Child Health (2007) *Diabetes in Pregnancy: Are We Providing the Best Care? Findings of a National Enquiry.* CEMACH, London
- D'Adamo E, Caprio S (2011) Type 2 diabetes in youth: epidemiology and pathophysiology. *Diabetes Care* **34** (Suppl 2): S161–S165
- DCCT Research Group (1994) Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial. *J Pediatr* **125**: 177–88
- Department of Health (2004) National Service Framework for Children, Young People and Maternity Services. DH, London
- Diabetes UK (2008) Making All Children Matter: Support for Children with Diabetes in School. Diabetes UK, London. Available at: http://bit.ly/e1N3bT (accessed 23.01.14)
- Diabetes UK (2009) Right From the Start: A Triangulated Analysis of Diabetes Management in Primary Schools in England, Northern Ireland and Scotland. Diabetes UK, London
- Driver and Vehicle Licensing Agency (2013) *DVLA's current medical guidelines for professionals conditions D to F.* DVLA, Swansea. Available at: http://bit.ly/LXLHcW (23.01.14)
- Dunger DB (1992) Diabetes in puberty. Arch Dis Child 67: 569–70
- Eckstein KC, Mikhail LM, Ariza AJ et al (2006) Parents' perceptions of their child's weight and health. *Pediatrics* **117**: 681–90
- Etelson D, Brand DA, Patrick PA, Shirali A (2003) Childhood obesity: do parents recognize this health risk? *Obes Res* **11**: 1362–8
- Fagot-Campagna A, Pettitt DJ, Engelgau MM et al (2000) Type 2 diabetes among North American children and adolescents: an epidemiologic review and a public health perspective. J Pediatr 136: 664–72
- Gonder-Frederick L, Nyer MA, Shepard JA et al (2011) Assessing fear of hypoglycaemia in children with type 1 diabetes and their parents. *Diabetes Manag (Lond)* **1**: 627–39
- Gosden C, Edge JA, Holt RI et al (2010) The fifth UK paediatric diabetes services survey: meeting guidelines and recommendations? *Arch Dis Child* **95**: 837–40
- Gustafsson PA, Cederblad M, Ludvigsson J, Lundin B (1987) Family interaction and metabolic balance in juvenile diabetes mellitus. A prospective study. *Diabetes Res Clin Pract* **4**: 7–14
- Haines L, Wan KC, Lynn R et al (2007) Rising incidence of type 2 diabetes in children in the UK. *Diabetes Care* **30**: 1097–101
- Hofer SE, Rosenbauer J, Grulich-Henn J et al (2009) Smoking and metabolic control in adolescents with type 1 diabetes. *J Pediatr* **154**: 20_3
- Holl RW, Grabert M, Sorgo W et al (1998) Contributions of age, gender and insulin administration to weight gain in subjects with IDDM. *Diabetologia* **41**: 542–7

- Holl RW, Swift PG, Mortensen HB et al (2003) Insulin injection regimens and metabolic control in an international survey of adolescents with type 1 diabetes over 3 years: results from the Hvidore study group. *Eur J Pediatr* **162**: 22–9
- Juvenile Diabetes Research Foundation Continuous Glucose Monitoring Study Group, Tamborlane WV, Beck RW et al (2008) Continuous glucose monitoring and intensive treatment of type 1 diabetes. N Engl J Med 359: 1464–76
- Juvenile Diabetes Research Foundation Continuous Glucose Monitoring Study Group (2009) The effect of continuous glucose monitoring in well-controlled type 1 diabetes. *Diabetes Care* **32**: 1378–83
- Levine BS, Anderson BJ, Butler DA et al (2001) Predictors of glycemic control and short-term adverse outcomes in youth with type 1 diabetes. J Pediatr 139: 197–203
- Lowes L, Gregory J, Lyne P (2005) Newly diagnosed childhood diabetes: a psychosocial transition for parents? J Adv Nurs 50: 253– 61
- Ly TT, Gallego PH, Davis EA, Jones TW (2009) Impaired awareness of hypoglycemia in a population-based sample of children and adolescents with type 1 diabetes. *Diabetes Care* **32**: 1802–6
- Newbould J, Francis SA, Smith F (2007) Young people's experiences of managing asthma and diabetes at school. *Arch Dis Child* **92**: 1077–81
- NICE (2004) Type 1 Diabetes: Diagnosis and Management of Type 1 Diabetes in Children, Young People and Adults. NICE, London. Available at: http://bit.ly/bDO1Gs (accessed 23.01.14)
- NICE (2006) Obesity: Guidance on the Prevention, Identification, Assessment and Management of Overweight and Obesity in Adults and Children. NICE, London. Available at: http://bit.ly/he00bt (accessed 23.01.14)
- NICE (2008) Continuous Subcutaneous Insulin Infusion for the Treatment of Diabetes Mellitus: Review of Technology Appraisal Guidance 57. NICE, London. Available at: http://bit.ly/d46xv1 (accessed 23.01.14)
- Office for Standards in Education, Children's Services and Skills (2008) TellUs3 National Report. OFSTED, Manchester
- Oude Luttikhuis H, Baur L, Jansen H et al (2009) Interventions for treating obesity in children. *Cochrane Database Syst Rev* (1): CD001872
- Pickup JC, Sutton AJ (2008) Severe hypoglycaemia and glycaemic control in type 1 diabetes: meta-analysis of multiple daily insulin injections compared with continuous subcutaneous insulin infusion. Diabet Med 25: 765–74
- Porter JR, Barrett TG (2004) Acquired non-type 1 diabetes in childhood: subtypes, diagnosis, and management. *Arch Dis Child* **89**: 1138–44
- Randell T (2012) Paediatric Diabetes Best Practice Tariff Criteria.

 Available at: https://www.diabetes.org.uk/Documents/nhs-diabetes/paediatrics/BPT-information-parents-0312.pdf
- Rosenbloom AL, Silverstein JH, Amemiya S et al (2011) Type 2 diabetes. In: Clobal IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence. International Diabetes Federation, Brussels, Belgium: 21–30
- Royal College of Paediatrics and Child Health (2009) *Growing up with Diabetes: Children and Young People with Diabetes in England.* Research Report. RCPCH, London
- Skinner TC, Murphy H, Huws-Thomas M (2005) Diabetes in adolescents. In: Snoek FJ, Skinner TC (eds). *Psychology in Diabetes Care*. Wiley, Chichester
- Skinner AC, Weinberger M, Mulvaney S et al (2008) Accuracy of perceptions of overweight and relation to self-care behaviors among adolescents with type 2 diabetes and their parents. *Diabetes Care* 31: 227–9
- Smart C, Aslander-van Vliet E, Waldron S, Swift P (2011) Nutritional management. In: Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence. International Diabetes Federation, Brussels, Belgium: 66–69
- Spinks JJ, Edge JA, Matyka K, Malik S (2007) Type 1 diabetes mellitus management. In: Allgrove J, Swift PG, Greene S (eds). Evidence-based Paediatric and Adolescent Diabetes. Blackwell, Oxford
- United Nations Statistics Division (2010) Statistics and Indicators on Women and Men. Table 2c. Childbearing. United Nations Statistics Division, New York, NY, USA. Available at: http://bit.ly/gYNpsC (accessed 23.01.14)

Online CPD activity

Visit www.diabetesonthenet.com/cpd to record your answers and gain a certificate of participation

Participants should read the preceding article before answering the multiple choice questions below. There is ONE correct answer to each question. After submitting your answers online, you will be immediately notified of your score. A pass mark of 70% is required to obtain a certificate of successful participation; however, it is possible to take the test a maximum of three times. A short explanation of the correct answer is provided. Before accessing your certificate, you will be given the opportunity to evaluate the activity and reflect on the module, stating how you will use what you have learnt in practice. The new CPD centre keeps a record of your CPD activities and provides the option to add items to an action plan, which will help you to collate evidence for your annual appraisal.

- According to 2009 figures, approximately HOW MANY children in the UK have diabetes? Select ONE option only.
 - A. 1 in 100
 - B. 1 in 250
 - C. 1 in 500
 - D. 1 in 1000
 - E. 1 in 2500
- Which one of the following symptoms is NOT part of the Diabetes UK "4 Ts" awareness campaign? Select ONE option only.
 - A. Tantrums
 - B. Thinner
 - C. Thirsty
 - D. Tired
 - E. Toilet
- Approximately WHAT PERCENTAGE of children entering primary school in the UK are defined as overweight or obese? Select ONE option only.
 - A. 5%
 - B. 10%
 - C. 15%
 - D. 20%
 - E. 25%
- 4. A 15-year-old is obese. His BMI is just above the 95th centile.

According to Skinner et al (2008), WHAT approximate PERCENTAGE of parents would feel that this child's weight was "about right"? Select ONE option only.

- A. 40
- B. 50
- C. 60
- D. 70
- E. 80

- A 7-year-old girl has type 1 diabetes. She is frequently refusing her mid-day school meals.
 - Which ONE of the following insulin regimens is the most appropriate? Select ONE option only.
 - A. Once-daily insulin regimen
 - B. Twice-daily insulin regimen
 - C. Three-times-daily insulin regimen
 - D. Multiple daily injection regimen
- 6. A 17-year-old teenager has type 1 diabetes. Three months ago he had two episodes of hypoglycaemia, both requiring hospital admission. Since then he has had good control without hypos.

Which ONE of the following is the most appropriate advice to give about his planned driving lessons? Select ONE option only.

- A. Driving lessons are permitted with no medical restrictions
- B. Driving lessons are permitted provided he has a satisfactory blood glucose measurement before the start of every lesson
- C. Driving lessons are permitted after a further 3 months have elapsed without any hypos
- D. Driving lessons are permitted if continuous blood glucose monitoring and insulin pump therapy is initiated
- E. Driving lessons are not permitted for at least another 9 months
- According to Chapman et al (1988), which ONE, if any, of the following groups are at INCREASED risk of recurrent diabetic ketoacidosis?
 Select ONE option only.

- A. Boys
- B. Girls
- C. Primary school children
- D. Socio-economic class 1
- E. None of the above
- 8. According to recent data, impaired hypoglycaemic awareness has been described in up to HOW MANY children and young people with diabetes? Select ONE option only.
 - A. <5%
 - B. 15%
 - C. 30%D. 45%
 - E. >60%
- 9. A 7-year-old girl has been diagnosed with type 1 diabetes.

In addition to her diabetes and long-term cardiovascular risk monitoring, which ONE of the following annual blood tests is recommended, according to NICE guidance? Select ONE option only.

- A. Anti-gliadin antibodies
- B. CRP
- C. Growth hormone
- D. Rheumatoid factor
- E. Thyroid function
- 10.A 16-year-old teenager has recently been diagnosed with diabetes. She has a positive GAD/IA2 antibody test.

Which ONE of the following is her most LIKELY diagnosis? Select ONE option only.

- A. Gestational diabetes
- B. MODY
- C. Steroid-induced diabetes
- D. Type 1 diabetes
- E. Type 2 diabetes