

Diabetes in children and young people: Optimising management throughout the care pathway

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Article points

1. The number of children and young people (CYP) with diabetes in the UK is growing and, in order to ensure the avoidance of complications, diabetes management should be optimised as soon as possible.
2. Structured education, for both the inpatient staff and CYP and their families, is essential, with an emphasis on shared goals. CYP and their families should be educated and supported in injection technique and should be aware of complications, such as hypoglycaemic episodes and diabetic ketoacidosis.
3. There should be a multidisciplinary approach to care, with involvement from a psychologist in order to identify any emotional problems and to help with the transition from paediatric to adult services.

Key words

- Diabetes management
- Inpatient care
- Paediatric diabetes

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The number of children and young people (CYP) with diabetes is growing, particularly in the under fives. Optimising diabetes management as early as possible is essential and this requires the highest standard of inpatient care. The implementation of the *Paediatric diabetes best practice tariff* in England means that in-depth clinical assessment of both psychosocial and physical health by the multidisciplinary team will now be possible. This, in turn, will enable paediatric diabetes nurse specialists to ensure earlier implementation of evidence-based practice from diagnosis. This article will discuss aspects of diabetes management, including key practical skills and two case studies of children with type 1 diabetes. Both case studies reflect on the challenges faced within the ward environment, the role of inpatient staff, along with insight into the perspective of CYP and their families.

The quality of inpatient diabetes management is a concern in many countries worldwide (Moghissi et al, 2011; Edge et al, 2012; Royal College of Paediatrics and Child Health [RCPCH], 2012; American Diabetes Association, 2013), so publication of the first audit of children's inpatient-specific care standards (Edge et al, 2013) is timely. Leaflets developed by the Healthcare Quality Improvement Partnership and Diabetes UK (2012) and the Diabetes UK campaign "*What are the type 1 essentials for children and young people?*" (Diabetes UK, 2013) aim to raise awareness of what care to expect in hospital and the importance of the specialist diabetes team during these episodes of care, as well as advocating people with diabetes to self-manage their condition.

Education for inpatient staff

The education of inpatient staff is essential to ensure consistency of information at diagnosis. The specialist team should enable staff to develop these skills by providing invitations to attend workshops and study days, as well as asking

staff to observe clinics and pump starts and to be involved in peer review (NHS Diabetes [now part of NHS Improving Quality], 2012a). Inpatient staff should be invited to attend team meetings at least annually. This can provide opportunities to make team goals explicit and ensure consistent high-quality care throughout the care pathway.

According to the audit by Edge et al (2013), out of all the audit standards, education for inpatient staff was least likely to be achieved, despite featuring in 89% of paediatric diabetes specialist nurse (PDSN) job descriptions. The reasons for this are likely to be multifaceted but inspirational leadership, coupled with the concentration of staff expertise on one ward (as is the case with conditions such as cystic fibrosis and childhood cancers) has been suggested as key to a successful ward environment (Edge et al, 2013). Following on from the launch of the national core curriculum (SWEET and NHS Diabetes, 2012), a "basic awareness" e-learning module is currently being piloted. This has the potential to add more value, providing accessible and affordable learning

Box 1. Children's diabetes inpatient experience: One-minute questionnaire.

Please answer the three questions using the scale (1 being poor, 10 being excellent) and a brief comment (both negative and positive) below; it only takes a minute!

1. How well did ward staff introduce themselves and explain clearly what would be happening?
1 2 3 4 5 6 7 8 9 10 (please circle)
What are you most likely to tell your friends and family about this?
2. How well did ward staff explain and demonstrate key areas, such as blood glucose monitoring, insulin injection technique and rotation, carbohydrate recognition and counting, hypoglycaemia signs and symptoms and treatment?
1 2 3 4 5 6 7 8 9 10 (please circle)
What are you most likely to tell your friends and family about this?
3. Overall, do you feel you were listened to and given the right amount of clear information before discharge home?
1 2 3 4 5 6 7 8 9 10 (please circle)
What are you most likely to tell your friends and family about this?

opportunities for the multidisciplinary team (MDT).

Insulin safety is a national problem (Lamont et al, 2010) and although not currently mandatory, the "Safer use of insulin" e-learning module developed by NHS Diabetes has demonstrated a significant reduction in errors since its launch (James, 2013). Half of all centres in the children's inpatient audit recorded insulin-related prescription errors during admissions (Edge et al, 2013). This emphasises that insulin safety training must be a key recommendation.

In Leeds, reflection on the level of support provided by the children and young people (CYP) diabetes team to inpatient staff locally led to the development of diabetes-specific documentation and prescription charts relating to diabetic ketoacidosis (DKA), insulin pump therapy and multiple daily insulin. These documents cover multiple basal changes, correction doses, carbohydrate ratios and methods of calculation to ensure robust systems that minimise risk. They are available through the CYP diabetes module at the University of York.

In order to monitor the inpatient experience, the team in Leeds have devised a short questionnaire, which was based on the "Friends and family test" (NHS England, 2012) but adapted for CYP with diabetes. This one-minute questionnaire (*Box 1*) is used to ensure families have a voice and local

services can promptly respond to any concerns and improve standards of inpatient care.

Structured education for CYP and families

The *Paediatric diabetes best practice tariff* (Randell, 2012) states:

"Each provider unit can provide evidence that each patient has received a structured education programme, tailored to the child or young person's and family's needs, both at the time of initial diagnosis and on-going updates"

A structured age-differentiated curriculum, which meets Department of Health (DH) and Diabetes UK criteria (2005), has been developed locally in Leeds to support comprehensive and consistent education from diagnosis by the MDT and inpatient staff. Development of this curriculum may also reduce the number of missed opportunities for demonstrating and supporting practical diabetes skills.

According to Peyrot et al (2005), teams who shared the same goals as CYP and parents were shown to have the most significant impact on HbA_{1c} and, therefore, were better able to reduce impact of complications. The importance of age-appropriate education from diagnosis has been emphasised in national guidance (NICE, 2004a)

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1. Insulin safety is a national problem and although not currently mandatory, the "Safer use of insulin" e-learning module developed by NHS Diabetes has demonstrated a significant reduction in errors since its launch.
2. The local children's diabetes team in Leeds developed a "one-minute questionnaire" to ensure that children and young people with diabetes and their family can voice their concerns.
3. Research has showed that teams who shared the same goals as children and young people and their parents were shown to have the most significant impact on HbA_{1c} and, therefore, were better able to reduce impact of complications.

“The diagnosis of diabetes is a significant and life-changing event and families have been known to refer to the loss of their ‘healthy child.’”

Box 2. Seven transition stages model (Hopson et al, 1992).

- **Shock:** Awareness of emotions appears blocked.
- **Denial:** Importance of the change is minimised.
- **Self doubt and depression:** Experience of uncertainty and doubts related to how to control the new situation.
- **Acceptance of the new reality:** Acceptance of the new reality starts with detachment from the old patterns.
- **Analysis of the possibilities for resolution:** Individuals start to take a more active role through trying new coping strategies.
- **Looking for meaning:** The need for understanding how the individual's future will be affected is developed.
- **Integration:** The new experience is fully incorporated and integrated in the individual's life.

and is supported by research (Lange et al, 2007; Sassman et al, 2012) but, unfortunately, this is often seen as an “optional extra” in the UK (Juvenile Diabetes Research Foundation, 2013).

New diagnosis of diabetes

The diagnosis of diabetes is a significant and life-changing event and families have been known to refer to the loss of their “healthy child”. This psychosocial transition requires people to learn new ways of coping, understanding and behaviours. Hopson et al (1992) identified the “Seven transition stages model” (Box 2), which discusses the range of emotions and feelings experienced during this time. *Case study 1* describes some of the challenges parents or carers face when their child is newly diagnosed and gives examples of how these problems are overcome.

Role of psychology from diagnosis

The importance of identifying psychosocial risk factors from the outset in CYP with diabetes is increasingly being recognised (Graue et al, 2004; Silverstein et al, 2005) and may help to provide tailored support that can protect against parental burnout (Haugstvedt et al, 2011; Lindström et al, 2011). Suggestions include identification of the most pressing needs in a family and finding the solution where possible. Furthermore, simply

allowing expression of negative thoughts and feelings can help people to work through these problems.

Fear of hypoglycaemia and not recognising an episode are particular worries for the parents of very young children. Barnard et al (2012) recommend greater attention be paid to questions that elicit increased understanding of thoughts, feelings and behaviours, and “fear of hypoglycaemia” scales such as those devised by Polonsky et al (2005) are encouraged in order to support this process and tailor treatment.

Structured behavioural group training for parents may also have a role and recent research from Sassmann et al (2012) has demonstrated this group training is effective in reducing parental stress and improving parental skills.

Therefore, encouraging CYP and their families to express thoughts and feelings must be a part of every contact and recognised as being as important as medication.

Injection technique and rotation

As with any clinical intervention, getting injection technique right from day one is essential. For the person with diabetes, learning the technique at such a vulnerable time has a high impact and is long lasting, and the skill can be used several times each day.

Recent research by Lo Presti et al (2012) has identified that CYP have minimal subcutaneous fat and consequently there is a strong case for the use of 4 mm pen needles (with a lifted skin fold in those under 6 years) in order to avoid intramuscular injections, which can result in unpredictable glucose levels. Lo Presti et al (2012) have identified the buttocks as the site with most subcutaneous fat and Hicks et al (2011) highlight that the buttocks have a long, slow absorption rate making this the ideal site for the first taught injection. Actively recommending the use of this site from the outset, rather than leaving this to parents to attempt to change at home, will further support best practice from diagnosis. However, it is important to note that the injection site used for the first injection will depend on the individual child and individual circumstances. For example, some children might prefer to be able to observe what is happening, or inject themselves. Informed decision-making based

on evidence-based information and individual assessment is key.

Hanas (2004) notes that the use of a local anaesthetic cream can be helpful for insulin pump changes and this idea has been adapted in our team and is used in children under 5 years, if there is a fear of needles. Other methods, such as the use of a ward play specialist in young children or cognitive behavioural approaches such as relaxation and guided imagery in older children, can add further value to this intervention. This is also helpful for finger prick tests and cannula insertion.

From diagnosis, families need to be advised of the importance of rotation between injection sites as well as between different sides of the body (Chowdhury and Escudier, 2003) as this decreases the risk of lipohypertrophy. In young children, easy-to-follow rotation techniques and devices, such as visualising a clock face or a key pad for older children, can encourage full use of one site before moving to the next.

Numeracy skills

In a study of diabetes healthcare professionals, Kerr and Varshneya (2012) highlighted that a significant number of people with diabetes face challenges with numeracy skills and this can impact on their ability to self-manage. Assessment of the numeracy skills of CYP and their families is essential from the outset so that they receive extra support if necessary. Using the individual's preferred formula to work out the carbohydrate:insulin ratio and correction doses and then ensuring consistency with calculating at every contact is essential to avoid confusion.

Alternatively, bolus decision support tools can be set up by the healthcare professional and then reviewed at each contact. In CYP, such tools can also support consistency in decision making between parents, carers and children as well as facilitating early identification of glycaemic excursions and a prompt review of settings, avoiding blame and supporting interdependence (Schilling et al, 2002).

DKA and insulin omission

Results from the audit of children's diabetes inpatient care (Edge et al, 2013) suggest that within one year, approximately 8.8% of children with diabetes are admitted to hospital with DKA.

Case study 1: Newly diagnosed child.

Ben is a 3-year-old boy newly diagnosed with type 1 diabetes. He arrived in the emergency department with diabetic ketoacidosis (DKA) and was managed using the British Society for Paediatric Endocrinology and Diabetes (BSPED) DKA protocol (2009). He did not require intensive care but had repeated attempts at venepuncture, which were very distressing. The diabetes team introduced themselves within the first 24 hours, explained the diagnosis and then listened to the family's concerns and questions. The team recognised the importance of engaging in the newly diagnosed structured education programme over the next few days in hospital and this then continued at home.

Inpatient staff involved the family at every opportunity during Ben's stay and encouraged their involvement in carbohydrate counting, blood glucose testing and injection technique, in order to build knowledge, practical skills and confidence. The team explained the treatment options (NICE, 2004a; 2008) but also clearly communicated their preference for commencing insulin pump therapy (IPT) from diagnosis (within the first 8 weeks). They explained that this was particularly important in those under 5 years of age in order to be able to vary the basal insulin requirement and bolus very small amounts at least five times a day, using the required ratios for both food and corrections according to varying insulin sensitivity throughout the day. The family expressed a preference for starting IPT with immediate effect.

Ben's mother was very anxious about giving the first injection and inserting the pump infusion set. The specialist nurse used role play with a familiar soft toy to talk through the procedure in an age-appropriate way. Both Ben and his family were visibly relieved to see the small pen needle as they had imagined a much larger one. A good first experience also increased confidence in the parents.

In Leeds, building sufficient knowledge and skills for an efficient and effective 24-hour out-of-hours service on a designated ward has served to reduce feelings of vulnerability in our local service. The out-of-hours service includes agreed evidence-based pathways and an escalation policy that states when to contact the specialist team. Edge et al (2013) found when CYP with diabetes were admitted, only 26% of PDNS and 15% of consultants were contacted within 2 hours.

Insulin omission is a common reason for DKA in CYP with existing diabetes and, as there are usually important psychosocial reasons for this (Wolfsdorf et al, 2009), an in-depth MDT assessment during the admission is vital in uncovering the root cause. This should be followed up with a routine referral to the team psychologist.

Adolescent health and transition

As with other life stages, such as starting school, adolescence is a period of significant change and realignment. Transition from child to adult services should not simply be a transfer of care but requires

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1. Transition from child to adult services should not simply be a transfer of care but requires a focus on adolescent healthcare needs. In order to support this process, each unit must have a clear policy for transition to adult services.
2. Emotional health is certainly challenged during adolescence and even more so in the presence of diabetes. Depression and other emotional problems have a prevalence rate of 15–20% in people with diabetes and this has an impact on glycaemic control.
3. A parenting style which supports gradually increasing independence whilst maintaining clear boundaries regarding serious matters such as DKA is advocated but this may need to be renegotiated during adolescence.
4. Food plays a significant role in our lives and, for those with diabetes, the impact of this intense and focussed relationship can cause additional burden.

a focus on adolescent healthcare needs. In order to support this process, the *Paediatric diabetes best practice tariff* requires that each unit in England must have a clear policy for transition to adult services (Randell, 2012).

Policy documents such as the *Diabetes transition* document (NHS Diabetes, 2012b) and *Not just a phase* (RCPCH, 2010) highlight that it is very important to create the right culture and to get young people's full participation in services. Additional training in communicating with young people has also been recommended in *Quality criteria for young people friendly health services* (DH, 2011). This is particularly important as health behaviours set down in adolescence are carried through to adulthood (Viner and Barker, 2005); therefore, getting it right at this stage is pivotal to long-term health. In addition, the research carried out by Allen and Gregory (2009) helps in considering the range of models available for this transition, with in-depth reflection on their component parts.

Healthcare professionals who are involved in the transition from paediatric to adult services may be interested in the RCPCH Adolescent Health Programme (available at: www.rcpch.ac.uk/AHP). There is also a new learning module developed at the University of York, in collaboration with Leeds Teaching Hospitals Trust, which has just been launched in a response to the DH's plans to make this a national priority. *Transition: Closing the gap between child and adult services* can be accessed at: <http://bit.ly/1d7iEOs>. *Case study 2* demonstrates some of the issues that CYP with diabetes can face in adolescence.

Emotional health and coping

Emotional health is challenged during adolescence and even more so in the presence of diabetes. Depression and other emotional problems have a prevalence rate of 15–20% in people with diabetes (Barnard et al, 2012) and this has an impact on glycaemic control and can potentially lead to DKA. Reliable and validated tools such as "Problem Areas in Diabetes" (Polonsky et al, 2005) have been adapted for adolescents (Weissberg-Benchell and Antisidel-Lomaglio, 2011) and can provide insight into the presence of "diabetes burnout". A parenting style which supports gradually increasing independence whilst maintaining clear boundaries

Case study 2: Teenage girl with diabetes

Amy was diagnosed with type 1 diabetes at 6 years and is now almost 15 years old. She has been on multiple daily injection therapy for the last 8 years. Following several years of excellent control (HbA_{1c} <58 mmol/mol [7.5%]) and good family teamwork, Amy's HbA_{1c} has now been consistently above 69 mmol/mol (8.5%) for almost a year and had recently risen to 76 mmol/mol (9.1%).

Today Amy is unwell so her mother phones the out-of-hours service on the designated CYP diabetes ward and explains Amy seems to have a virus like her brother and has now started vomiting. Blood ketones are 3.1 mmol/L and blood glucose 22 mmol/L; therefore, the nurse advises to go to the emergency department promptly. Intravenous insulin is prescribed according to the BSPED (2009) DKA protocol. An in-depth clinical assessment is carried out immediately and continued over the next few days, including review of insulin doses (according to weight and age), injection sites and technique, carbohydrate counting, blood glucose monitoring and targets, and hypoglycaemia and hyperglycaemia management.

The next morning the specialist nurse listens to Amy and her family's story regarding events leading up to the admission. Amy is quiet and difficult to engage. She states whatever she does her blood glucose is always high. Amy's mother explains that Amy has been reluctant to test her blood glucose and take her insulin for a while now, often justifying that she is not hungry and will do it when she eats later. This has been causing conflict at home as Amy feels her mother is constantly nagging. Amy starts to open up and tells the specialist nurse that she does not see the point of going to clinic as it is boring and does not fit into her life. She says the doctor talks to her mother mostly and when he does speak to her it is as though she is a young child. Mum is very tearful and tells the nurse that she does not know what to do.

regarding serious matters such as DKA is advocated (Court et al, 2008) but this may need to be renegotiated during adolescence.

Eating disorders

Food plays a significant role in our lives and, for those with diabetes, the impact of this intense and focussed relationship can cause additional burden (Barnard et al, 2012; Hanson and Ross, 2013).

Emerging recognition for the disordered eating screening tool developed by Markovitz et al (2010), along with early treatment, will guide pathway development. Helpful components are likely to include regular effective communication with the MDT, a reduction in dietary restraints and family therapy (NICE, 2004b; Philpott, 2013). Knowledge of helpful specific resources such as the “Diabetes with eating disorders” website (www.dwed.org.uk) may aid conversations in consultations.

Follow up after discharge

Maintaining contact following discharge from hospital, whether newly diagnosed or with existing diabetes, is important and can provide timely support. This support should include practical advice, such as insulin dose adjustment, as well as proactive education and important emotional care.

Conclusion

Prospects are now ripe for improved health outcomes for CYP with diabetes. A comprehensive MDT, which includes a psychologist, can support in-depth assessment of emotional, as well as physical health from diagnosis. Investing in both accredited education and competency-based training opportunities is paramount to ensuring safe, evidence-based care. ■

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