Clinical services for children with diabetes

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Abstract
Diabetes mellitus is one of the most common long-term conditions in childhood. The management of children and young people is predominantly carried out by general paediatricians with a special interest in diabetes, together with paediatric diabetes specialist nurses and dietitians. Various guidelines and recommendations have been published with the aim of improving standards and quality of care; however, surveys conducted in the United Kingdom at periodic intervals have regularly shown deficiencies in the provision of care for these children and young people. With intensification of insulin regimens, education of the child and family is the cornerstone of management with a view to enabling self-care. Targets of each service should be to improve glycaemic control and thereby to prevent complications. Psychological support, social services, counselling, ophthalmology, and podiatry should be available. To ensure that care is of the highest standard, the team should have access to good clinic and hospital facilities and adequate manpower. Services should be commissioned accordingly to meet the demands of the local population. Regional networks form an important forum to discuss case load, sharing of resources, training for consistency in the region, and collection of outcome data with contribution to national audit.

Keywords delivery of health care; diabetes; dietician; education; regional networks; specialist nursing; type 1 diabetes

Introduction
Diabetes mellitus is one of the most common long-term conditions in childhood, and because much of the care and education of children and their families should be delivered at home, clinical services need to be flexible and locally based. In the UK, most children and adolescents with diabetes are managed in district general hospitals by general paediatricians with a special interest in diabetes, but the increase in the prevalence and the intensity of modern treatment regimens require that diabetes in children should no longer be considered a ‘general paediatric’ problem, but is a condition needing specialized care.

In recent years various guidelines and recommendations for the management of diabetes in children and young people have been produced, notably by the National Institute of Clinical Excellence in 2004 and the International Society of Pediatric and Adolescent Diabetes (ISPAD) in 2007–8. Despite these recommendations, services have been very variable across the UK, and surveys of children’s diabetes services have shown repeated deficiencies in many categories of care, and poor outcomes in terms of glycaemic control.

With this background of increasing incidence and complexity of management, we should aim to provide services which support children and their families in self-management, and this may need a rethink of traditional clinic-based management. It is important for the local diabetes services to have an understanding of the prevalence and characteristics of types of diabetes in that particular locality, as strategies for management need to be tailored to the particular population.

Guidelines and recommendations
In the UK there has been a considerable amount of work undertaken to produce guidelines and recommendations to manage diabetes in both adults and children. The Department of Health has published both the National Service Framework (NSF) for children (2004) and the NSF for Diabetes (2001). The main themes of the Children’s NSF are fair, high-quality, and integrated health and social care, with management as close to the child’s home environment as possible. The Diabetes NSF included several standards applicable to children as well as adults. In 2004 NICE produced a guideline for the management of T1DM for children, and ISPAD has produced at least 20 guidelines covering all aspects of care.

So, what are the features of a good service which should be provided by every centre looking after children and adolescents? A previous document produced by Diabetes UK (then the British Diabetic Association) in 1995 listed the recommended features of a service, all of which are still applicable (Table 1).

In addition to these ‘traditional’ recommendations, both NICE and ISPAD stress the importance of education of the child and family as a cornerstone in the management of diabetes, and many different group-, family- and individual-structured education programmes are currently being evaluated. Self-management is to be encouraged, with ongoing 24-hour support. Intensive insulin treatment regimens and pump therapy are recommended to obtain the best HbA1c level achievable for each individual child. The importance of maintaining glycaemic control (HbA1C less than 7.5%) and monitoring of complications is highlighted. Further recommendations include provision of adequate psychosocial support as a part of the ongoing care in the management of diabetes, and a smooth transition of care for adolescents with diabetes to the adult team. The collection of outcome data and contribution to national diabetes audits is also an essential element of a service.

All of these guidelines have huge implications for the organization of services, particularly with the emphasis on self-management and education. It is being suggested that the traditional clinic model of seeing a child every 3 months in a hospital outpatient setting may not be the best way to manage a long-term condition where the child and family themselves need to learn to be responsible and to make their own decisions on a day-to-day basis.
Recommendations from The principles of good practice for the care of young people with diabetes. London: British Diabetic Association, 1995

- Children should be seen in a designated children's diabetes clinic rather than in a general paediatric clinic
- Services should look after more than 40 patients
- The paediatricians looking after the children should have a special interest in diabetes
- The team should include a specialist paediatric diabetes nurse
- There should be one specialist paediatric diabetes nurse to each 70–100 patients
- The team should include a paediatric diabetes dietician
- Measurement of glycated haemoglobin should be done at each clinic visit
- Microalbuminuria screening should be carried out according to guidelines
- Retinopathy screening should be carried out according to guidelines
- There should be a joint or combined hand-over clinic to adult diabetes services

Table 1

Organization of local services

The system and personnel involved should be competent to diagnose and investigate appropriately, to provide ongoing treatment, and to educate and support; they should also have adequate knowledge and training to identify, prevent, and manage diabetic complications. This can be done only with a multidisciplinary team working in adequate facilities to provide standard high-quality efficient inpatient and outpatient care, as well as community care at home and at school.

Services in the past have been based on traditional divides between medical, nursing, and dietetic roles with, rarely, some psychological help. It is increasingly recognized that in a good team these roles will overlap, and it is perhaps more helpful to consider various competencies which should be shared across the team. Modern workforce planning reflects this view. However, this is only possible if there are adequate numbers of staff in each team, and it would be a mistake to settle for inadequate numbers of staff even though none of the Department of Health recommendations go so far as to recommend numbers of staff for a service.

There have been four national surveys in the UK to determine whether provision of services nationally matches up to the above recommendations. The third and fourth diabetes services surveys (1998 and 2005) showed some improvement, with a reduced number of centres each looking after larger numbers of children, and with more specialized consultants. However, continuing deficiencies were noted, particularly in a high patient/nurse caseload, poor access to psychological help, and too few dieticians, as well as a lack of good transition services in many areas. A further survey is currently under way.

The local child and young person’s diabetes team usually consists of one or more paediatric consultants with knowledge of managing and providing diabetic care, paediatric-trained diabetes specialist nurses, and specialist paediatric diabetes dieticians. The local diabetes services cannot exist in isolation; they need to be linked with regional diabetes networks, children’s services departments, and their partners in Children’s Trust arrangements (including education), primary care, and adult diabetes services to promote effective care.

Manpower (the who)

Diabetes specialist nurses: the paediatric diabetes specialist nurses play a major role in the effective management of children’s diabetes. They form an important link between the child, the family, and the medical services, and usually act as a first port of call for the initial concerns. It is now recommended by the Royal College of Nursing that one full-time paediatric diabetic specialist nurse is required in the care of 70 children. These nurses should be able to establish a holistic and developmental approach to diabetes care in patients from infancy to adolescence. They should be able use their clinical judgment and autonomous decision-making, enabling them to undertake a range of specialist clinical actions within the specific setting.

The responsibilities of the paediatric diabetes specialist nurse based in hospital or community and working as a member of the team are outlined in Table 2.

Doctors: each children’s diabetes service should have one or more consultant paediatric diabetologists/endocrinologists or general paediatricians with an interest and specific training in diabetes to lead the service and the team. The syllabus for such training in the UK is currently being revised by the RCPCH College Specialty Advisory Committee. In districts with fewer than 70 children under the age of 16 years with diabetes, all should be under the care of one designated consultant paediatrician. These numbers are likely to vary in different countries, and local needs should be adequately supported with appropriate numbers of doctors. It is important that the doctors ensure that their training is regularly updated and that they make themselves aware of significant developments in the management of diabetes. They should be aware of existing guidelines and recommendations, and they will plan the local implementation in practice. Although it could be argued that medical staff are superfluous in the management of the straightforward child with well-controlled diabetes, they are generally the team members with the best understanding and awareness of complications of diabetes and associated conditions. Once complications are suspected or identified, the child or young person may need further specialist medical input, and this will be coordinated by their consultant.

It could be argued that the main role of the consultant is in service development and planning. In particular this will involve the collection of national audit data, collation of an annual report detailing local service provision, planning pump provision, and the specification of services with the Commissioners of services, discussions with local authorities in the planning of provision for diabetes in schools, and organizing transition services together with the local adult diabetologist.

Paediatric specialist diabetes dieticians: the dietician has an important role in educating the family about the importance of diet in the control of the child’s diabetes. The whole family may
Roles and responsibilities of the paediatric diabetes specialist nurse

- Provide individual specialist teaching for the child and the family, facilitating self-care skills and knowledge to undertake blood glucose testing and injections, and to deal with hypoglycaemic or hyperglycaemic episodes
- Provide age-appropriate teaching and ongoing education and support to the child and the family
- Act as a source of specialist advice for children and family at home, including basic dietary advice and the management of acute complications
- Should be able to offer basic psychological/psychosocial or counselling support to the child or young person and their families
- Provide adequate information about sick-day rules, lifestyle changes, travel needs and long-term complications
- Instigate insulin treatment and adjust doses according to protocols
- Undertake nurse-led clinics in hospital or community and formulate plans
- Implement and evaluate specialist diabetes care innovations across the catchment area and also contribute to policy, standards and development of the care
- Provide specialist education/training to other nurses and professionals
- Offer support for the educational services (i.e. school or college) where the child or young person is likely to spend his early formative years; organize treatment plans for the teaching staff to cope with the child/young person’s diabetic needs
- Maintain effective communication with children/young people and their families, and also other members of the multidisciplinary team
- Identify opportunities for clinical audit and research to improve standards of care

Adapted from the Royal College of Nursing document on specialist nursing services for children and young people with diabetes, 2006.

Table 2

need to make some changes to their overall diet when the diagnosis is made. It is important that they are educated to eat a healthy balanced diet to meet the needs of the child’s growth and to help with diabetes control.

The advent of the newer insulin regimens has helped in relaxing the strictly controlled diet previously advised in children with diabetes. Multiple-injection regimens, in which rapid-acting analogue insulin is given at every meal and snack, have become more common; these require a detailed understanding of carbohydrate counting in order to match insulin with food and to achieve the best control. The dietician will generally play the major role in teaching the child or young person and their family how to measure carbohydrate quantity and to adjust insulin to carbohydrate intake.

The dietician will also provide information and support when the institution of a gluten-free diet is required in those 5–10% of children who develop coeliac disease. The dietician is an essential and integral member of the team, and should be available in clinic for immediate advice, and must also be able to visit the families at home, where it is much easier to discuss the child’s diet and regular routine.

Psychology/psychosocial support: the diagnosis of diabetes in a child or young person causes a great deal of emotional stress and anxiety, with some mothers in particular demonstrating post-traumatic stress symptoms. The diagnosis also requires many lifestyle changes and intrusions, which some families find difficult to cope with.

Children with chronic disease are twice as likely as healthy children to have a psychological problem, and overall the prevalence of psychological problems in children with diabetes is 25–30% higher than in healthy children. Of all children with diabetes, girls rather than boys report anxiety and depressive symptoms in the year after diagnosis, and the risk of developing psychological problems is greater the older the child. Needle phobia and separation anxieties can be difficult to manage, and there are stages of life – particularly around the age of 8–10 and then later at puberty – where children and young people may show acting-out behaviour or anxiety and depression.

Although the paediatric diabetes team will be able to offer support and education for the child and family to deal with the diagnosis, some children and families are likely to need additional support beyond the expertise of the team. Hence it is important that the clinic has easy access to mental health professionals or specialist services in child psychology/psychiatry. It has been noted from the fourth national survey in the UK that only 22% of clinics had attendance of a psychologist or psychiatrist to the diabetic clinic; 87% of clinics could refer to a psychologist, and 90% to a psychiatrist, but the waiting times for these specialist services ranged from 1 week to 18 months, which is obviously unacceptable.

Local structures (the how)

Diagnosis: children and young people presenting with signs and/or symptoms suggestive of diabetes should be referred urgently on the same day by telephone to a specialist paediatric team experienced in the management of childhood diabetes, and then should also be seen on the same day. The diagnosis should be explained sensitively, and where competent and skilled community support is available and the child is well, the paediatric diabetes team may be able to manage the child or young person with newly presenting diabetes at home or during a very short admission.

Inpatient facilities: the local hospital should be able to provide safe inpatient care for the child or young person with diabetes. Children or young people should be admitted to age-appropriate paediatric or adolescent wards, and all of the hospital team should be competent to care for acute issues such as diabetic keto-acidosis and hypoglycaemic seizures. Small children are likely to be more ill with acute presentations, and will need to be cared for in a high-dependency unit. Intensive care facilities in the hospital or safe transfer to a regional intensive care unit should be available for those who need them.

When children are admitted for conditions other than their diabetes, staff on other wards should be supported to allow self-care
of the diabetes if the child is well. There should be provisions for children to continue with their school curriculum/work during their admission to hospital.

**Outpatient clinics:** the aim of diabetes management is to keep children out of hospital, even at diagnosis, and most care is provided in outpatient clinics with continuing support offered at home. The clinics should be designated paediatric diabetes clinics and can be nurse- or consultan-led. Junior doctors may be involved if they are spending at least 6 months in the service. Casual involvement of doctors unfamiliar with diabetes is not to be encouraged.

Children should be seen in clinic or at home approximately monthly for the first 6 months after diagnosis, and NICE recommends that children are then seen 3 or 4 times a year. The paediatric diabetes clinic should ideally be organized age-band clinics to allow children or young people to feel comfortable in the hospital environment. Larger units may band the clinics as toddler clinics, clinics for the 5–12-year-olds, adolescent clinics, and transition clinics for different phases of maturity and understanding before transferring the care on to an adult unit. In teenage and transition clinics the young person should be offered the opportunity to come in and see the doctor or nurse alone before the parents are invited in. Teenage clinics in particular need to educate about lifestyle issues such as alcohol, smoking, and sex and contraception. Information leaflets/books and audio/video equipment should be easily available if required.

NICE recommends that height and weight monitoring, calculation of body mass index, and examination of injection sites are carried out at every clinic visit. In addition, glycaemic control, intercurrent health infections, hypoglycaemic episodes, and adjustment of insulin doses or regimens are also covered. Glycated haemoglobin (HbA1C) measurements should be made at every clinic visit, preferably so that the result is available during the consultation. Every attempt should be carried out to maintain HbA1C levels at less than 7.5%, as per NICE recommendations.

**Annual review clinics** are an opportunity to undertake a complete clinical assessment to identify possible complications of diabetes and associated conditions. A physical examination of puberty stage and injection sites, and examination of the feet and abdomen to look for hepatomegaly (a sign of poor diabetes control) should be carried out. Blood testing for coeliac disease (at least every 3 years) and thyroid under- or over-activity (annually) should be carried out. NICE recommends retinal screening, urine for micro-albuminuria, and blood pressure for children over the age of 12 years. Some units will have the luxury of the services of play specialists to assist the child and family during their visit to the hospital and make it a less stressful experience, and they can be particularly helpful with the annual blood-taking.

**Transition clinics** – adolescence is a time of rapid physical, psychological and social change, which can make working with young people challenging. Transition can be described as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems. This is therefore more than a physical transfer to adult services, and should be well planned with the young person and coordinated with the adult services. Diabetes UK and NICE have outlined some care recommendations for this to take place, and the salient points are outlined in Table 3.

### Recommendations for transition of care

- Allow for young people to familiarize themselves with the practicalities of transition
- Agree protocols for transfer from paediatric to adult clinics
- Joint clinics by the paediatric and adult diabetes teams to be organized prior to transfer so that the young person can become familiar with the personnel of the adult diabetes services
- Age of transfer depends on the physical development, emotional maturity, stability of health, and other life changes of the young person, and should be based on individual needs
- All staff should have adequate training in adolescent health and should give importance to privacy and confidentiality
- A named key worker should be identified to coordinate the transition process
- Offer advice on aspects of care with transfer to adult services (e.g. short-term goals of achieving glycaemic control and screening for complications)
- Adequate consultation time for the adolescents and young people to discuss their issues in clinic; also information/leaflets and counselling services regarding various issues for this age group should be readily accessible

Adapted from Diabetes UK: care recommendations for transition of care to adult services.

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<td><strong>Other clinics</strong> – in certain instances, provided that services and resources are available, nurse-led clinics can be set up at schools/colleges in addition to clinics in the hospital. This can be considered when there are problems with transport/geographical needs, and also causes less disruption to the child’s or young person’s education.</td>
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**Other services:**

- the paediatric diabetic clinic should have easy access to chiropody services
- retinal screening services are now mandatory for all over 12 years old, and can be coordinated with the annual review clinic providing a one-stop service; referral to an ophthalmology team is undertaken if changes/complications are identified
- ideally, a 24-hour out-of-hours advice service for the child and family should be available, but resources are not always available for this; this could be provided regionally (see below)
- there should be access to teams of social workers to assist the child and the family with their social care needs
- laboratory services and support for various screening and monitoring investigations should be available
- the hospital team should constantly liaise with the primary care team, and it is imperative that effective communication is undertaken to ensure that management of the child’s or young person’s diabetes is consistent in all surroundings.

**Support at educational institutions:** children and young people spend a lot of time in their school or college environment, and their diabetes needs to be looked after in these surroundings. It is
important that the paediatric diabetes team offers sufficient information and training so that teachers and support staff have a good basic understanding of the child’s treatment and are able to carry out blood-glucose testing and deal with hypoglycaemia. Furthermore, now that younger children are more likely to be using multiple-injection therapy and pumps, the diabetes team will be training support staff, and occasionally teachers, to administer or supervise lunch-time insulin injections and blood-glucose testing according to individual medical management plans. Some areas in the country are finding it difficult to make a way through the bureaucracy, and it is essential the local authorities (for education) and PCTs (for health) work together to draw up local policies and guidance.

Organization of regional services through networks

The Department of Health recently brought together key stakeholders in a working group which produced the document ‘Making Every Young Person with Diabetes Matter’. This document proposed that children’s and young people’s diabetes services in the UK should be organized in a series of regional networks. The remit of these networks is to support strategic development, to quality-assure local services based on audit outcomes, and to help with aspects which might be run regionally, such as pump services or out-of-hours support. This is similar to the arrangement of regional networks for other conditions (e.g. neonatology and cancer).

A benchmark for care can be agreed across the region, and training can be instituted to ensure that high-quality care is consistent. Networks can be a forum for review of case load and outcome measures, and support appropriate commissioning for paediatric diabetic services. As pump therapy is becoming increasingly common, equitable training for pump teams could be organized regionally. The regional network should also be an educational forum to share good clinical practice, crisis limitation, and managed clinical care in collaboration with other children’s trust, primary care trusts and strategic health authorities. Data collection for audit will be a key responsibility of the network. However, the regional networks will only be effective if they are commissioned appropriately and have sufficient infrastructure, including a network manager and data manager.

Commissioning of services

Commissioning diabetes care should be a strategic process involving service users, carers, clinicians, and partner organizations. It should also take into account local needs and focus on health and social care of the whole community. As a minimum, the commissioning process might involve an assessment of local needs, design of a local specification to meet those needs, procurement of services to deliver the local specification, and proactive monitoring to improve the provision of care. In different localities, commissioning may be carried out at a number of levels and in a variety of arrangements. These include primary-care-trust commissioning, practice-based commissioning, and through children’s trust arrangements. In some areas it may be advantageous to combine children’s diabetes commissioning with general paediatric services, and in others it may be helpful to tie in with adult diabetes services. Both local and regional components of the service need to be commissioned to ensure that a comprehensive service is delivered. The report ‘Making Every Young Person with Diabetes Matter’ is designed to be used by commissioners to inform their decisions.

FURTHER READING


Practice points

- Families and children with diabetes need to be taught the skills to manage the condition themselves in their daily lives
- This requires specialist support from a multidisciplinary team trained in the management of diabetes in children and young people, including doctors, nurses and dieticians
- Psychological support is essential, and this should be an integral part of the service
- Transition to adult services is of paramount importance, so that continuity of care is achieved and long-term complications can be monitored
- Regional managed clinical networks will be useful for auditing processes and outcomes, training, ensuring consistency of care, and possibly research activities

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