

Doctor, who will be looking after my child's diabetes?

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The multidisciplinary diabetes team is the cornerstone of care

Type 1 diabetes is the third most common chronic disorder in childhood, after asthma and cerebral palsy. It is life threatening, life long, and invades the lives of children both day and night without respite. It is reported to reduce lifespan on average by 25%.¹ Its incidence is continuing to rise across the country and is presenting at an earlier age.^{2,3} The prevalence shows that in a district population of 250 000 there will be 75 young people with this condition.

The standards of paediatric diabetes services provided for these children have been questioned recently,⁴ and in the past have been shown to be inadequate,⁵ resulting in suboptimal metabolic control. There is indisputable evidence that the long term complications of diabetes are related to preceding levels of glycated haemoglobin (HbA_{1c}) with an exponential rise occurring with levels >8.5%.⁶ In many young people with diabetes there is poor compliance with insulin regimens,⁷ mortality is significantly increased,⁸ and the microvascular complications of retinopathy, nephropathy, and neuropathy are commonly reported by early adulthood.⁹

ADVISED SERVICE PROVISION

National guidelines for paediatric diabetes care were published in 1995, based on the St Vincent Declaration,¹⁰ which were endorsed by the Royal College of Paediatrics and Child Health. These are incorporated in the recently published Standards of the Diabetes National Service Framework (NSF).¹¹ They state that children and adolescents with diabetes should be managed by an appropriately resourced and trained paediatric multidisciplinary team consisting of a paediatrician with a special interest in diabetes, a paediatric diabetes specialist nurse, a paediatric dietitian with expertise in diabetes, a senior paediatric ward nurse with experience in diabetes, and easy access to services in psychology, psychiatry, podiatry, and ophthalmology.

In addition they should be seen in a designated children's diabetes clinic and where there are fewer than 70 children in a district they should be under the care of one specialist paediatrician. It has been recommended that the caseload of

a paediatric diabetes specialist nurse (PDSN) should not exceed 100 children.¹²

The cornerstone of this team is the PDSN who has the pivotal role of providing education (in its broadest sense) and holistic care to the child and family, both in hospital and in the community.

CURRENT PROVISION OF DIABETES SERVICES

Jefferson *et al*, in this edition of *Archives of Disease in Childhood*, report on the current provision of diabetes services for young people in the UK.¹³ The results showed improvements compared with previous surveys but are still suboptimal. Twenty two per cent of consultants looking after these children said they have no special interest, and therefore by implication, no specialist training in diabetes. Moreover, 26% care for fewer than 40 children and 9% of clinics are still not designated paediatric diabetes clinics; therefore their young people would be seen in general paediatric clinics without specialised diabetes staff support. These should be unacceptable practices today.

The fact that the provision of diabetes specialist nurses for children has increased should be applauded, but many are still not trained to treat children; they may also provide care for adults with diabetes or for other paediatric subspecialties, and thus reduce the possible whole time equivalent diabetes provision. It has been recommended that nurses responsible for the care of children with diabetes should have received not only paediatric nurse training, but also specialised diabetes training and experience of working in the community.¹¹

Sadly paediatric dietetic provision is still lacking in 35% of clinics and the provision of psychological support within clinics has been unchanged over the past four years; the latter remains grossly inadequate with 78% of clinics not having easy access to any source of counselling services.

It remains an inexcusable deficiency that 12% of clinics do not provide regular measurements of glycated haemoglobin, which is the only evidence based marker of long term vascular complications.⁶

Standardisation of methods between centres is also essential if meaningful audit is to be conducted.

REASONS FOR CONCERN

Why should paediatricians be concerned about these results and why should every district caring for young people with diabetes need an appropriately trained multidisciplinary team? Studies recently reported from large groups of paediatric clinics around the world¹⁴ and in Scotland¹⁵ have shown not only disappointing mean HbA_{1c} levels (8.6% and 9.1% respectively) but also large variation in levels of glycaemic control between centres. Poor HbA_{1c} concentrations relate directly to long term complications.¹³ The reasons for such variation seem to be due less to intensification of treatment or insulin regimens per se than to organisational details of care, such as time allocated to parents and children, a personal approach to management, and many psychological and cultural factors. Mortensen, in his Copenhagen clinic, significantly reduced HbA_{1c} values by 1% by intensified multidisciplinary support and education.¹⁶ This approach, along with other new initiatives,¹⁷ needs to be pursued with more commitment in the UK and with proper cost-benefit assessments. There is evidence that with major improvements in paediatric diabetes care associated with a decrease in HbA_{1c}, there should be a reduction in long term complications.¹⁸

WHAT SHOULD BE DONE

The multidisciplinary diabetes team is the cornerstone of care, and although the paediatrician with a special interest is seen as the leader of the team, it is essential that all those who care for these children with diabetes have received appropriate specialist training and participate in the continuing development of their teams. Equally it is of paramount importance that as new paediatric consultants are appointed, with responsibility for the care of children and young people with diabetes, they must have received appropriate specialist training. The CSAC for the British Society for Paediatric Diabetes and Endocrinology has advised on the framework for the training requirements for these paediatricians.¹⁹ Training should be comprehensive and include as a minimum:

- Twelve months or ideally 18 months or more "full time" experience of working in a paediatric diabetes multidisciplinary team gaining experience in:
 - the outpatient and community care of young people with diabetes within a multidisciplinary team
 - the management of the acute complications of ketoacidosis and hypoglycaemia

- methods of improving diabetes control
- the detection and management of the less common forms of diabetes, such as genetic disorders of insulin metabolism, type 2 diabetes, and diabetes in cystic fibrosis
- experience in the clinical care of adults with diabetes
- training in educational theory and psychology.

Continuing, lifelong professional training in the management of diabetes is also essential.

WHO IS RESPONSIBLE

With the forthcoming Implementation Strategy for the Diabetes NSF, Primary Care Trusts (PCTs) will be responsible for the commissioning of the pattern of delivery of paediatric diabetes care and therefore, they, together with the local paediatric diabetes team, must ensure the delivery of a first class and equitable multidisciplinary diabetes service. PCTs will be responsible for ensuring that the above services are available for all young people with diabetes and their families. In addition the Diabetes NSF suggests that there should be expert paediatric diabetologists giving support to the surrounding districts on a "hub and spoke" mechanism.¹¹

Diabetes UK advises families what care they should expect. Where that is substandard, families will need to work through the local PCT and Local Diabetes Services Advisory Group (LDSAG) or its new equivalent, to ensure an improvement in care.

TRANSITION TO ADULT SERVICES

Individual transition of care from paediatric to adult services has been highlighted in importance as Standard 6 in the Diabetes NSF.¹¹ There must be a planned transfer of care from the paediatric service to an adult service geared to the needs of these young adults. Jefferson *et al* report that 47% of centres, at present, have no young adult clinic into which to transfer young people.¹³ Improved liaison between adult and paediatric teams is essential.

CONCLUSIONS

In paediatric practice the numbers of affected children are relatively small compared to adults with diabetes. The majority are totally insulin dependent, and frequently social or family difficulties pose massive challenges which conflict with good clinical care. This results

in both serious short and later long term, diabetes complications, many of which are not witnessed by the paediatrician as they present after transfer to the adult service. The absence of visible vascular complications in the child or adolescent must not deflect paediatricians and their team or PCTs from recognising the vital need in all districts for the provision of specialist paediatric diabetes care.

This may cause conflicts of interest in small district hospitals where general paediatric and neonatal expertise may be deemed the prime concern. In order for the appropriate specialist experience in diabetes to be always available in all districts, at the time of the appointment of a new consultant who will take on the responsibility for paediatric diabetes care, the Appointments Committee must ensure that if the appointed candidate does not have the appropriate training, subsequent provision must be made for a planned and adequately resourced additional diabetes training programme. Alternatively, arrangements must be made for cooperative specialist care between two adjacent districts.

Properly organised, committed, and experienced paediatric multidisciplinary diabetes teams must be given the appropriate resources to work towards the major improvements in metabolic control, psychosocial function, and empowerment of young people and their families which are necessary to reduce the destructive long term complications of childhood diabetes. PCTs through their health professionals should, within the framework of the forthcoming Diabetes NSF, ensure that this care is available, so they can reassure all families that a first class equitable service will be provided.

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