

How can we establish home care for children with type 1 diabetes?



Helen Thornton

As this is my first editorial for the *Paediatric and Adolescent Diabetes Nursing Supplement* of the *Journal of Diabetes Nursing* I wish to introduce myself to you. But firstly I wish to thank Jane Houghton not only for volunteering me for this position but also for her hard work over the years, championing the needs of children and young people with diabetes in many high places and her perseverance which has ensured that the voices of paediatric diabetes nurse specialists (PDSN) are at last being heard.

I have worked as a PDSN since 1989 for St Helens and Knowsley Hospitals Trust, a District General Hospital 10 miles from Liverpool. I have actively promoted the needs of children and young people with diabetes throughout my career locally, nationally and internationally. I am a past committee member of the Royal College of Nursing Paediatric and Adolescent Diabetes Special Interest Group and continue to actively support their activities.

I was given strategic lead for the implementation of the *National Service Framework for Diabetes: Standards* (Department of Health, 2001) and the more recent National Institute for Health and Clinical Excellence (NICE) guidance (NICE, 2004) for all children and young people with type 1 diabetes in our area. This work has meant the development of new skills and a better understanding of the wider diabetes community that our children and young people are a part of, including primary care trusts and their commissioning processes. Our consultant paediatricians and paediatric dietetic colleagues have other commitments, with equally important patient groups, on a day-to-day basis; therefore, it is only the PDSNs whose time is wholly dedicated to children

and young people and their families. Yet, nationally, there is still a lack of paediatric and adolescent diabetes consultant nurses. We need more nurses to be given the opportunity to take a strategic lead.

Many of you are doing tremendous work with your cases but Dr Foster and Diabetes UK (Dr Foster and Diabetes UK, 2005) still demonstrated the following.

- Eighty-five percent of children with diabetes are not maintaining their blood glucose levels within the recommended range.
- Just 25 % of primary care trusts have prioritised the improvement of paediatric services within their local delivery plans.
- The average ratio of PDSNs to children was found to be one nurse to 103 children.
- In line with the findings in 2004, only half of primary care trusts have written transfer of young people with diabetes to adult services.
- Only 46 % of primary care trusts provide psychological support for children with diabetes.

Sharing good practice: Home-based care

Despite this, there are many examples of good practice out there which we need to share with each other. If you have anything you would like to publish I can assure you, from past experience, that you will be given plenty of support from the *Journal of Diabetes Nursing* team to enable you to see your practice in print.

When reading articles in a journal such as this, we can reflect on our current practice and gain ideas on how to implement key recommendations and targets. One of the NICE (2004) type 1 guideline's key recommendations states that:

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At the time of diagnosis, children and young people with type 1 diabetes should be offered home-based or inpatient management according to clinical need, family circumstances and wishes, and residential proximity to inpatient services. Home-based care with support from the local paediatric diabetes care team (including 24-hour telephone access to advice) is safe and as effective as inpatient initial management.

Many of you out there already provide such a service but often this has been developed on our good will as nurses to provide services to our children and families, working long hours and providing 24-hour helplines for which we have not been properly resourced nor recognised for. We have all witnessed colleagues at national conferences taking calls from children and families during a conference dinner. But we ourselves need to change our culture of belief that we are the only people able to do the job. This is particularly so as we expand our teams after working single-handedly for many years. With hospitals trust's vicarious liability insurance and increased litigations we need to ensure that we adequately resource for provision of any new services.

The following two articles on home-based care demonstrate how this has been implemented differently in different areas – one a tertiary unit serving a large population and the other a district general hospital. The Birmingham home care team provides a comprehensive review of the evidence base (see pages 22–7) to enable you to reflect on what has now become a key recommendation of how care should be delivered to children and young people with diabetes. They argue that, although total home-based care may be unfeasible in some areas for a variety of reasons, moving to some form of home care is applicable to many units. This is demonstrated by the team from Warrington (see pages 28–31) and their readmission rates demonstrate positive outcomes.

Reviewing these two very different

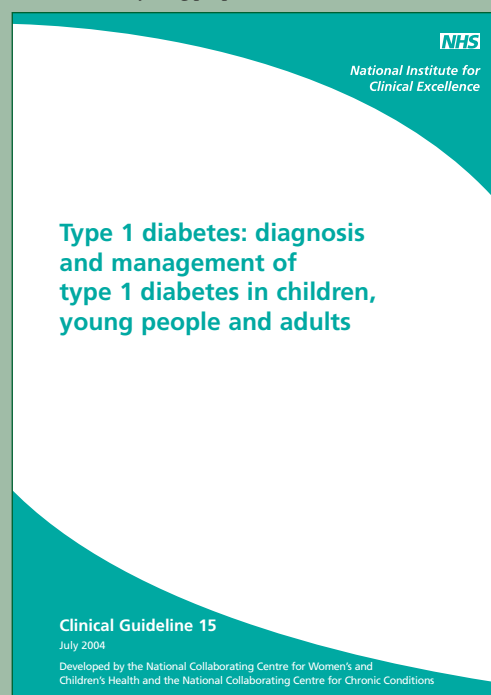
provisions may enable you and your team to consider your current position on beginning home-based management, develop your own model of care, and gain valuable resources and personnel for your local population.

Within your hospital/primary care trust there will be a clinical governance structure which reports on all published NICE guidance and measures what risks there are to the healthcare organisation if the guidance is not implemented. Mapping your current pathway of care for the individual with type 1 diabetes with key people in the organisations, ensuring user involvement and understanding the wider picture of where priorities lie can enable your voice to be heard and, more importantly, understood in higher places. Good luck – and if you are successful, please share with us all how you did it! ■

Department of Health (DoH; 2001) *National Service Framework for Diabetes: Standards*. DoH, London

Dr Foster, Diabetes UK (2005) *Your local care. Diabetes services in England*. Available at <http://www.drfooster.co.uk/websites/objectList.aspx?w=18> (accessed 17.01.2006)

National Institute for Health and Clinical Excellence (NICE; 2004) *Clinical Guideline 15. Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults*. NICE, London



The National Institute for Health and Clinical Excellence's Clinical Guideline on the diagnosis and management of type 1 diabetes in children, young people and adults.