

# Home management: Evaluation of a service for children with type 1 diabetes

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## Article points

1. The benefits of home management of children with a chronic condition are well documented.
2. Home management reduces readmission rates.
3. Within a small team, a diabetes link nurse's input is invaluable.
4. Home management can sustain consistently good metabolic control.
5. Existing practices need to be reviewed against current National Institute for Health and Clinical Excellence guidelines.

## Key words

- Type 1 diabetes
- Home management
- Paediatric diabetes nurse specialist

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Many paediatric diabetes teams not yet practicing homecare at diagnosis are looking at the practicalities of offering this service as it has been identified as one of the key priorities for implementation in the National Institute for Health and Clinical Excellence guidelines for type 1 diabetes in children and young people (2004). This article looks at the service which has been developed over the last 14 years in a general hospital with a small paediatric diabetes team and the lessons that have been learnt.

Reducing hospital stays in all areas of paediatric care is increasing in popularity. Children undergoing surgery and those with chronic illnesses spend far shorter periods in hospital and many are now receiving care in their own homes. Diabetes home care was the forerunner of this with a number of earlier articles discussing the benefits in the 1970s and 1980s (Laron et al, 1979; Rayner, 1984).

## Support for home management

After years of debate on whether children newly diagnosed with diabetes should receive their care in hospital or at home, the evidence is pointing to home care. The National Service Framework (NSF) for diabetes suggests that, where competent and skilled support is available, children can be managed at home (Department of Health [DoH], 2001) and the National Institute for Health and Clinical Excellence (NICE), in its guidelines for children and young people with type 1 diabetes, states that home management should be offered

(NICE, 2004). This recommendation has been graded A, indicating a high level of evidence.

The following are recurring points found in articles discussing the advantages of avoiding hospital admission (McEvelly, 1991, 1996; Swift et al, 1993).

- The family's distress is alleviated.
- The family's independence is promoted.
- The child's normal day-to-day routine is maintained.
- Consistent advice is available from the diabetes team, rather than multiple staff members in the ward setting.
- It is easier to personalise education to fit in with the family's circumstances.
- Families are more at ease in their own home.
- Minimum contact with the ward avoids hospital dependence, therefore reducing readmissions.

The emotional impact of a diagnosis of type 1 diabetes, on all the family, can be overwhelming. Although home management increases parental responsibility it would appear that the many benefits of home

management quoted in articles on the subject outweighs this (Lowe and Davis, 1997; Matthams, 2003).

### Experience of setting up the service

In 1992 a paediatric consultant, new to the author's hospital, was keen to start home management. Thereafter, funding was secured from the hospital for the creation of a paediatric diabetes specialist nurse (PDSN) post to support the service. Prior to this the average stay in the paediatric unit post-diagnosis was 7.2 days. A bargaining tool used then, and which is still applicable today when seeking funding, is the reduction of inpatient days, which offsets the cost of extra nurse hours required.

In its infancy the diabetes team consisted of a paediatric consultant with a special interest in diabetes, a PDSN for 15.5 hours per week and a paediatric dietitian. Some large paediatric centres are able to offer complete home care and avoid hospital attendance completely (McEvelly, 1991). In district general hospitals which have a small diabetes team, such as the author's, this is generally not feasible but home management post-diagnosis is. The amount of commitment needed from all team members should not be underestimated. In addition to the time spent with the family in the home, travelling time puts further pressures on the workload of the PDSN.

As the author's team felt they were unable to avoid attendance completely, children were seen in the paediatric ward for assessment and confirmation of diagnosis before being allowed home for their education to be continued by the PDSN. Guidelines, formulated by the consultant and commented upon by the author, are made available for the medical and nursing staff to assure consistency of care. Children who present with diabetic ketoacidosis are admitted for stabilisation and discharged as early as possible – the average inpatient stay for these children is 1.2 overnight stays.

An explanation of the home management

service is verbally given to the children and their families, and arrangements for the PDSN to visit, at the time of the first injection, are made. In the absence of the PDSN the paediatric consultant would be involved in the initial education, or the family can return to the ward for support with injections and blood glucose testing.

The initial home visit provides the opportunity to assess the home situation and the family dynamics, which helps to appropriately plan the continuing education.

The teaching given is recorded on a checklist which is signed by the nurse and family as each topic is covered. The number and frequency of visits vary depending on the family's competence and needs. We have found that the average number of visits during the first two weeks is 5.8.

Adjustments to insulin doses are discussed by telephone according to need. Children and their families are given the PDSN's and the consultant's home telephone numbers and the telephone number for the children's ward in order to provide 24-hour support.

At this time those children diagnosed by their GP and referred to the ward arrived with an understanding that they would be admitted to the ward for a number of days. Most families responded with relief when they found out that this was not the case. This can have the effect of lessening the impact of diagnosis. Lowe and Lyne (1999) suggest that this can facilitate the process of adjustment.

### Service involvement

By 1995 we had observed a drastic reduction in readmission days for existing patients. Our mean readmission rate per year had been 56 days prior to 1995, by the end of 1995 this had fallen to 10. Over the last 10 years this has reduced further to a mean of 6.3 days per year for a total clinic cohort of around 140 children. This finding is not unique to this hospital (Kirk et al, 2003; Swift et al, 1993). This could be attributed to increased independence that home care fosters and

### Page points

1. Funding was secured from the hospital for the creation of a paediatric diabetes nurse specialist (PDSN) post to support the new home management service.
2. In its infancy the diabetes team consisted of a paediatric consultant with a special interest in diabetes, a PDSN and a paediatric dietitian.
3. An explanation of the home management service is given to the children and their families, and arrangements for the PDSN to visit, at the time of the first injection, are made.
4. The initial visit provides the opportunity to assess the home situation and the family dynamics, which helps to appropriately plan the continuing education.
5. Children and their families are given the PDSN's and the consultant's home telephone numbers and the telephone number for the children's ward in order to provide 24-hour support.

**Page points**

1. The development of the paediatric diabetes specialist nurse (PDSN) role and the reduction of children being admitted to the ward due to diabetes did have a detrimental effect on the service provision.
2. The ward staff who had previously been able to offer education and support in the absence of the PDSN became deskilled.
3. To address this knowledge gap and to maintain a high standard of care, regular diabetes education updates were arranged by the PDSN for the ward staff.
4. Due to the staff numbers this involved this had an impact on the PDSN workload and proved problematic for the ward staff to secure time away from the ward to attend.
5. In 2001, diabetes link nurse roles were developed with four nurses based in the paediatric unit being given further training to allow them to give competent and consistent advice and support to families when the PDSN is unavailable.

the familiarity of telephone contact with the team in the early stages making them seek advice earlier, thus avoiding hospital admission.

The development of the PDSN role and this reduction in the number of children being admitted to the ward due to diabetes did have a detrimental effect on the service provision. The ward staff who had previously been able to offer education and support in the absence of the PDSN became deskilled. Staff had inadequate knowledge and lacked the practical skills needed to competently deal with these families. Research by Findlow and McDowel (2002) found that the majority of registered nurses' knowledge of diabetes was deficient.

To address this knowledge gap and to maintain a high standard of care, regular diabetes education updates were arranged by the PDSN for the ward staff. Due to the staff numbers involved this had an impact on the PDSN workload and proved problematic for the ward staff to secure time away from the ward to attend.

In 2001, diabetes link nurse roles were developed with four nurses based in the paediatric unit being given further training to allow them to give competent and consistent advice and support to families when the PDSN is unavailable. The potential for link nurses to be an asset to the diabetes team is not well documented (McErlean, 2005) but in the author's experience, within a small team, their input is invaluable.

**Current service**

In January 2003 the PDSN hours were increased to 37.5 hours per week. Patient numbers have steadily increased so, in April 2003, one of the link nurses was released from the ward one day per week to allow him/her to work within the team. This has increased their knowledge and competency so enabling them to provide holiday cover for the PDSN and to be a source of information and support for the ward staff.

Both the consultant and PDSN take phone calls from families out of hours. This is not

formally recognised as part of their working hours. Larger teams may be able to operate an on-call service with staff rotation which they would be remunerated for.

Data have been submitted each year to the Diabetes UK National Paediatric Audit and now to the NHS Information Authority National Diabetes Audit. This has shown that our mean clinic HbA<sub>1c</sub> is consistently good with our centre remaining in the top eight as well as low admission rates due to hypo- and hyperglycaemic episodes. This would indicate that home management has a beneficial effect on overall metabolic control and is supported in the findings of other studies (Kirk et al, 2003).

**Considerations**

NICE states that existing practice should be reviewed against its guidelines (NICE, 2004). The review should consider the people and processes involved.

Before home management can be implemented the following are key areas to address.

- Is the present level of PDSN provision able to support the service?
- How is 24-hour telephone support to be offered?
- Who will provide cover if the PDSN is unavailable/on holiday?
- What are the training issues for ward staff?

It is only when these points are clarified and acted upon, and also consideration given to ensure that the recommendations laid out in the NSF for diabetes (DoH, 2001) and the NSF for children (DoH, 2004) are addressed, that the service can be offered and a decision taken as to what extent home management can be implemented.

After the first children have been managed at home it is then that time should be taken to retrospectively reflect on the experience and identify any gaps in service to ensure changes can be made to ensure best practice.

**Conclusion**

Management on diagnosis of type 1 diabetes in children varies widely across

the country. In light of NICE guideline recommendations, trusts that do not offer home management are looking into the possibilities of implementing it. The limitations of resources may mean that hospital attendance cannot be avoided completely, but immediate home care and education after diagnosis can then be offered, avoiding unnecessary admission and allowing the child and family to receive their care and education in the security and comfort of their own home.

The author's experiences over the last 14 years have proven that, even with a small but committed diabetes team, children can be managed at home successfully. Besides the well-documented benefits, the reduction of subsequent admissions for diabetes related problems when home management is established, both for the family and the NHS, should not be overlooked. ■

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