

# The “SKIP” course: A programme for children and young people with diabetes

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Group education for children and young people with type 1 diabetes requires a specific approach to meet the needs of these individuals as well as the needs of their parents and carers. The “SKIP” course incorporates the *National Service Framework for Diabetes* recommendations (Department of Health, 2001) and NICE (2004) guidelines to reinforce the essential aspects of management and self-care of type 1 diabetes. The course is offered to all individuals newly diagnosed with diabetes and their families over three sessions, and covers the management of insulin injections, blood glucose monitoring, dietary restrictions, hypoglycaemia, illness and the day-to-day events that must be taken into consideration by those with diabetes. The aim of the course is to develop the knowledge and skills required for better self-care in order to improve glycaemic control and reduce the risk of long-term complications.

Paediatric Diabetes Specialist Nurses (PDSNs) have previously provided education for individuals in managing their diabetes self-care with advice and support in a traditional manner – with home visits, telephone contacts and clinic appointments. However, many telephone contacts and home visits are reactive in crisis management and problem solving associated with anxiety and stress, as in many instances children and young people with diabetes and their parents or carers have insufficient knowledge and understanding in dealing with unexpected situations such as illness.

The increasing prevalence of type 1 diabetes in the young (Diabetes UK, 2010a) has impacted on the workload of PDSNs. Also,

PDSNs need to be trained in the use of more sophisticated equipment for monitoring, assessing and managing diabetes, such as insulin pumps and continuous glucose monitoring systems, as well as taking time to show individuals with diabetes how to use the technology. These factors have impacted on education opportunities, as PDSNs report a decrease in the number of community visits taking place as a result of time constraints between clinic appointments.

Children and young people, as well as their parents or carers, have to adjust to the diagnosis of type 1 diabetes, with the daily discipline required to manage the condition including blood glucose monitoring, insulin injections, timing and type of food in the diet,

## Article points

1. People with serious and chronic medical conditions require knowledge and information in order to help them make “informed choices” about their self-management.
2. The “SKIP” course is delivered over three group sessions and aims to build on the education that all children and young people with diabetes and their parents or carers receive from the diabetes team on diagnosis.
3. The “SKIP” course should improve glycaemic control in order to help individuals reduce the risk of adverse effects and long-term complications.

## Key words

- Children and young people
- Education
- Improved self-management
- “SKIP” course

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### Page points

1. Recommendations from the *National Service Framework for Diabetes* (Department of Health, 2003) and NICE (2003; 2004) guidelines advise the use of structured education programme models to empower individuals and teach them how to manage self-care of their diabetes.
2. Key criteria of such a programme demand an evidence-based, structured curriculum that is flexible, quality assured, dynamic and auditable.
3. An education questionnaire designed by the PDSN team to assess knowledge and understanding of parents in the self-care of their child's diabetes was administered 6 months after diagnosis; this information led to the development of a structured education programme for children and young people with diabetes and their families – the “SKIP” course.

exercise and activity. This can be difficult, but is essential to minimise the risk of acute complications, such as severe hypoglycaemia or ketoacidosis, as well as the risk of long-term complications, such as nephropathy, neuropathy, retinopathy and cardiovascular disease. In addition to these difficulties, individuals who develop type 1 diabetes in childhood can have their life expectancy reduced by 20 years or more (Diabetes UK, 2010b).

### Background

The onset of a severe, life-changing condition that may impact with varying degrees on the physical and psychological well-being of a child or young person is acknowledged by the NICE recommendations that children diagnosed with type 1 diabetes should be offered psychological support (NICE, 2004).

Diabetes is a priority area for the NHS as demonstrated by the publication of the *National Service Framework for Diabetes* (Department of Health [DH], 2003) and reinforced by NICE guidelines, which require patients to be assisted to achieve an  $HbA_{1c} < 58 \text{ mmol/mol}$  ( $< 7.5\%$ ) as an indicator of good glycaemic control (NICE, 2004). This emphasis on achieving target levels has led to the development of education projects and, in particular, group education modules.

There are a number of successful group projects that are well-established, but these are mainly for adults with diabetes; group projects for children and young people with diabetes are more difficult to facilitate because of the wide age range (pre-school to young adult) and the need to include the parents in the education offered. The “KICK-OFF” course (Price et al, 2012), which empowers young people in the management of their insulin and food intake, has shown improvements in individuals' quality of life and satisfaction with treatment and has been adopted by other centres; however, in the study sample there were no improvements in  $HbA_{1c}$ .

In Germany, the development of separate education programmes for children aged 6–12 years, adolescents and parents (Lange

et al, 2007) has been delivered as part of the diabetes management service with certification and reimbursement by health insurance. Here in the UK, 10% of the NHS budget is spent on provision of diabetes care (BBC News, 2012). Investment in more education programmes could possibly reduce expenditure arising from complications in the long term. However, evidence of a reduction in long-term complications requires statistical analysis that examines clinical data over a long follow-up period including  $HbA_{1c}$  control and whether those with fewer problems have achieved this through identifiable education programmes. Earlier improvements in quality-of-life outcomes as a result of empowerment in self-management of a chronic condition are generally more readily demonstrated or expressed by individuals.

### Programme development

Recommendations from the *National Service Framework for Diabetes* (DH, 2003) and NICE guidelines (NICE, 2003; 2004) advise the use of structured education programme models to empower individuals and teach them how to manage self-care of their diabetes. Key criteria of such a programme demand an evidence-based, structured curriculum that is flexible, quality assured, dynamic and auditable. Children, young people and their families should have an opportunity to become “expert patients”, developing effective self-management skills (DH, 2005).

An education questionnaire (*Box 1*) designed by the PDSN team to assess knowledge and understanding of parents in the self-care of their child's diabetes was administered 6 months after diagnosis. Responses in free text highlighted gaps in the parents' knowledge in aspects of diabetes management. This information led to the development of a structured knowledge and information programme – the “SKIP” course. This structured education programme was designed to provide knowledge and information to build on the one-to-one care plan and education that all parents and young people receive from the diabetes team on diagnosis before discharge

**Box 1. Patient education diabetes questionnaire.**

**1. Definition of diabetes**

- How do you tell a friend what diabetes is?

**2. Insulin**

- What is the name and type of your insulin?
- How do you store it?

**3. Injection technique**

- How do you prepare for your insulin injection?
- How and where do you give your injection?

**4. Sharps disposal**

- What do you do with your used lancets and needles?

**5. Blood testing**

- How do you prepare for the blood test?
- How do you keep a record of your blood tests?
- What is your target range for blood tests?

**6. Hypoglycaemia**

- What happens in a “hypo?”
- How do you treat this?
- How can you prevent a “hypo?”

**7. Diet**

- What foods do you include in meals and snacks for a healthy diet?

**8. Hyperglycaemia**

- When would you consider the blood glucose was too high?
- What happens when the blood glucose is too high?
- What can cause this?

**9. Sickness**

- Who do you contact for sickness advice?

**10. Ketoacidosis**

- When do you check for ketones?
- What do you do if ketones are present?

from hospital, in a practical, interactive and collaborative way and delivered in a group setting. The emphasis throughout the programme focuses on ways to achieve good glycaemic control in order to help individuals reduce the risk of adverse effects and long-term complications.

Parents were involved in the initial planning of the programme by opportunistic discussion on the usefulness of such a course; however, the decision to focus on essential self-management skills was determined by the clinical experience of the PDSNs in working closely with the families.

The challenge of providing a structured education programme that meets the needs of young people with a wide age range and their parents, while accommodating the varying levels of knowledge and understanding of the individuals in the group, reflects NICE guidance:

*“[...] the method of delivering education and content will depend on the individual and should be appropriate for the child’s or young person’s age, maturity, culture, wishes and existing knowledge within the family” (NICE, 2003).*

In order to assess how the programme would be received by the families and young people and to determine the content, presentation and delivery of future programmes, the “SKIP” course was initially trialled as two separate courses (Box 2). All children and young people who were newly diagnosed with diabetes (aged 14 months to 15 years), their parents or carers and siblings were considered for invitation. However, in cases where attending the sessions would have posed known problems for the family, and as this was a trial, an invitation was not offered.

The evening time schedule was chosen in order to minimise parking difficulties, conflict with after-school activities or disruption of mealtime for the families. Parents were asked to confirm acceptance of the invitation by letter or telephone, and follow-up calls were made if confirmation was not received.

*“The SKIP course was designed to provide knowledge and information to build on the one-to-one care plan and education that all parents and young people receive from the diabetes team on diagnosis before discharge from hospital. The emphasis throughout the programme focuses on ways to achieve good glycaemic control in order to help individuals reduce the risk of adverse effects and long-term complications.”*

*“PDSNs and dietitians delivered the ‘SKIP’ course in a group setting to the parents and children. Each of three sessions was structured to ensure consistency in subject matter, level of information, timing and presentation. Anatomical models, food maps, role play and written information were all used to reinforce the diabetes education.”*

Each session could accommodate up to eight families.

Each family was provided with a course programme at the start, which outlined the programme and curriculum to be followed. Certificates and small gifts were given to all the children and young people on completion of the course to reward and thank them for their participation and contribution to the sessions.

**Box 2. The number of children and young people, and their families, attending the trial of the “SKIP” course.**

**Course A**

- Three sessions from 6.15pm to 7.45pm, held over a 3-month period
- Patients invited = 5
- Patients attended = 5
- Parents and siblings also attended

**Course B**

- Three sessions from 6.15pm to 7.45pm, held weekly over a 3-week period
- Patients invited = 9
- Patients attended = 4
- Parents and siblings also attended

**Box 3. The subjects covered in the “SKIP” course over three sessions.**

**Session 1**

- Pathophysiology of diabetes
- Insulin action and storage
- Injection technique
- Sharps disposal
- Blood glucose monitoring and recording

**Session 2**

- Hypoglycaemia – causes, prevention, recognition and treatment
- Food – eating with enjoyment
- Exercise

**Session 3**

- Hyperglycaemia
- Managing illness

**Course structure and curriculum**

Three sessions, each lasting 1.5 hours, were delivered as a rolling programme (Box 3). The three sessions were designed to cover the essential knowledge and information relating to diabetes management that parents require following their child’s diagnosis, in a practical and collaborative way.

PDSNs and dietitians delivered the programme in a group setting to the parents and children. Each session was structured to ensure consistency in subject matter, level of information, timing and presentation. The programme was interactive, with an emphasis on the use of visual aids. Anatomical models, food maps, role play and written information including quizzes and games to illustrate clinical scenarios were all used to reinforce the diabetes education.

The last session included activities that enabled the children and young people to demonstrate how their knowledge and understanding had increased during the course. Participants in the “object in a box” game randomly selected an object from a number of items used in managing diabetes, and confidently gave feedback to the group (Box 4).

**Box 4. “Object in a box”: A game to reinforce information.**

- Game used at the last session to reiterate and reinforce information
- Parents and young people participate in the activity
- Items such as ketone test strips, glucose gel, diabetes identity card, piece of fruit and a mobile phone (with telephone number of hospital or PDSN for emergency advice) are hidden in a box
- The young people volunteer to pick out the objects in turn
- The first person to name the object and describe how it is used in the management of diabetes wins a point

### Evaluation

The course was evaluated by the participants and peer reviewed by the PDSNs and dietitians in the team. The young people and parents gave written comments in an anonymous feedback form. PDSNs and dietitians gave their reflections and views at a team meeting, which led to changes being made. The most significant feedback received from participants included:

- Fathers who had missed out on initial education at diagnosis because of work commitments were pleased to have an "out of hours" opportunity for education.
- Participants welcomed meeting people and sharing experiences.
- Participants felt that reinforcing knowledge and information given at diagnosis was empowering.
- More time was wanted for questions or to discuss worries or concerns relating to diabetes, even if they were not directly related to the programme content.
- Children and young people telling their "stories" of their experiences and anxieties relating to time spent in hospital on diagnosis were considered a valuable contribution to the course.

As no extra time or funding was made available for delivering future courses, this required a willingness and commitment in sharing the work and organising diaries to ensure staff would be available. Courses will be held over a 3-month period, with three courses planned a year to allow for school holidays and staff time commitments. All PDSNs and dietitians agreed the need to be punctual in starting the sessions on time, rather than waiting for "latecomers", as this did not give a positive message to those who were waiting. To promote an equitable service, all parents of children and young people newly diagnosed with diabetes would be invited to attend the course.

Since the two trial courses, four "SKIP" courses have been run, delivered by five PDSNs and three dietitians. In total, 43 children and young people with diabetes have been invited, and 20 have attended

with their parents and siblings; of these, two individuals and their families were unable to attend the last session of the course, and two children were of pre-school age, so their parents attended without them. Each session was attended by three to six families; in three families, only one parent attended.

### Anticipated outcomes of the "SKIP" course

Anticipated outcomes of the "SKIP" course include the following.

- Service development – providing an opportunity for patient choice in accessing further educational support and advice.
- Empowerment of children and young people with diabetes, and their families, in managing their diabetes care successfully.
- Enhanced clinical effectiveness by increasing the individual's knowledge and information, which will help to improve the individual's diabetes control and long-term outcomes and reduce the risk of severe complications.
- Collaborative development of educational material that can be extended for further modules.

### Summary

Those who work with individuals with diabetes seek to provide opportunities for advising and educating them on the management and self-care of their condition. However, many individuals are reluctant to attend either individual or group education sessions (Bleakly and McKee, 2010). It is therefore not surprising that 50% of those invited did not accept the invitation to attend the "SKIP" course. The reasons given for this were:

- Family commitments.
- Transport difficulties.
- Wrong time.
- Non-English speaking.
- Do not need to attend.

The author and her colleagues recognise that the offer of the "SKIP" course to children and young people with diabetes and their parents or carers requires an approach

### Page points

1. Since the two trial courses, four "SKIP" courses have been run, delivered by five PDSNs and three dietitians. In total, 43 children and young people with diabetes have been invited, and 20 have attended with their parents and siblings.
2. Anticipated outcomes of the "SKIP" course include: providing an opportunity for patient choice in accessing further educational support and advice; empowering children and young people with diabetes, and their families, in managing their diabetes care successfully; helping to improve the individuals' diabetes control and long-term outcomes; and the collaborative development of educational material that can be extended for further modules.

***"The diabetes team would like to offer children and young people with diabetes from an ethnic minority group a specialist education module delivered within the local community setting, supported by the use of an interpreter and community worker. This would enable the PDSNs and dietitians to meet the needs of this group and improve service delivery and outcomes."***

that will generate a more enthusiastic response. To achieve this, the course is now discussed on diagnosis as part of the information individuals are given on what the diabetes service offers within the author's centre, and it is emphasised that this is part of the package of care available to individuals with diabetes and their families.

In accordance with *Guidance on the Use of Patient-Education Models for Diabetes* (NICE, 2003), a formal assessment of individuals' knowledge in managing self-care of their diabetes will continue, with the education questionnaire given a year after diagnosis rather than after 6 months. A diabetes audit, which will take place in the latter part of 2012 as part of the clinical governance requisite relating to the clinical effectiveness of the NHS in the provision of patient care, will incorporate information from the "SKIP" course; comparisons between individuals who attend the course and those who do not attend will be reviewed and assessed.

In conclusion, people with serious and chronic medical conditions require knowledge and information in order to help them make "informed choices" about their self-management. The "SKIP" course has received positive feedback from both service users and members of the diabetes team, with an expectation that the benefits will improve service delivery and enhance the health and well-being of the individual with type 1 diabetes, in both the short- and long-term.

### Future initiatives

The paediatric diabetes population in Bristol has approximately 20 individuals who are Somali, representing 5% of the current caseload, and most have poor glycaemic control. Therefore, plans are being made to offer an enhanced programme in the form of a workshop for this ethnic minority group. The diabetes team have identified specific issues relating to the interaction with this group of people; as English is their second

language their literacy may be poor, and their cultural beliefs may affect diet and exercise. Education in diabetes management can be challenging for these individuals and their families, as well as for members of the diabetes team. The diabetes team would like to offer these individuals a specialist education module delivered within the local community setting, supported by the use of an interpreter and community worker, using specific and appropriate visual, aural and written aids and resources. This would enable the PDSNs and dietitians to meet the needs of this group of people more efficiently and appropriately and improve service delivery and outcomes. ■

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