

# Sharing the news: caring for young people with diabetes

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## Introduction

**A regular training workshop on working with children and young people with diabetes has been organised by the paediatric diabetes clinical nurse specialist at University College and Middlesex Hospitals, London (UCLH), for the last 3 years. Paediatric nurses and medical staff from three trusts (and the community nursing team) are invited to attend. A combination of didactic, practical and interactive sessions are presented by the endocrinologists, the clinical nurse specialist, dietitian and clinical psychologist. This article presents a summary of the content of the workshop, the evaluation of participants' feedback and the subsequent impact on practice.**

**D**iabetes is a serious lifelong disease which is associated with an increased risk of cardiovascular, renal and eye complications. Diabetes and its complications account for 9% of hospital costs and over £2 billion of national UK health expenditure (Department of Health, 2001).

The incidence of type 1 diabetes in people under 15 years of age in the UK is around 16 per 100 000 per year. This increased annually by: 6.3% for children aged 0–4 years; 3.1% for children aged 5–9 years; and 2.4% for those aged 10–14 years between 1989–94 (EURODIAB ACE Study Group, 2000). The rise is of particular concern in children under 5 years in age, because this group requires longer follow-up and will be exposed to the risk of developing complications for a longer period of time.

## Background

For young people under the age of 20 years with diabetes, the most common cause of death is diabetic ketoacidosis (DKA). The figures for the occurrence of DKA in the UK are low but show little indication of decline. Ongoing education for young people with diabetes and their families within a supportive environment are essential for the maintenance of good blood glucose control. Partnership is the key towards achieving this goal, as has also been demonstrated in the monitoring

of other chronic illnesses such as asthma (Gibson et al, 1998).

The London Centre for Paediatric Endocrinology and Diabetes provides outpatient services as well as access for acutely ill people with diabetes to a general paediatric ward (through accident and emergency). Currently, the centre has a caseload of 119 young people with type 1 diabetes aged between 18 months and 19 years. In addition to regular multidisciplinary clinic visits, planned inpatient admissions are offered when there is consensus that admission would be helpful to the young person and their family (Christie and Fredman, 2001). Adolescents are admitted to the adolescent medical unit which is designed to address the special needs of adolescent health and development (British Paediatric Association, 1985). Consultations are offered to external diabetes clinical teams and families who wish to discuss case management. At present, the centre has a team which includes consultant endocrinologists, a clinical nurse specialist, a dietitian, clinical psychologists, and links with podiatry, renal medicine, ophthalmology and neurology.

The core multidisciplinary team uses a systemic approach to address the medical and psychosocial challenges presented by diabetes. The team take a collaborative approach based on narrative and solution-focused therapies. This

## ARTICLE POINTS

**1** There is a need for appropriate training for diabetes team members who are faced with caring for young people with diabetes within the hospital ward environment.

**2** A one day workshop was started for trained members of the nursing and medical staff from three local hospitals. Local community nursing teams were also invited to attend.

**3** All members of the multidisciplinary diabetes team give a series of interactive presentations covering medical, nursing, dietary, psychological aspects of living with the day to day challenges of diabetes.

**4** The workshop is now being recommended to colleagues from hospitals and services not directly linked to UCLH.

## KEY WORDS

- Education
- Workshop
- Child and young person
- Change in practice

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**PAGE POINTS**

**1** Nurses frequently say that they feel uncomfortable with their degree of knowledge when faced with difficult situations.

**2** We identified the need for appropriate training for team members who are faced with caring for young people with diabetes within the hospital ward environment.

**3** Presentations by the medical consultants focus on: how insulin works; current protocols for management of DKA; phenotypes of diabetes; and diabetes and adolescence.

**4** The clinical nurse specialist presents practical information on daily management of diabetes with opportunities to try out a range of insulin delivery techniques and injection devices.

**5** A four stage admission plan for young people newly referred to the team has been developed by the diabetes team at UCLH.

approach encourages an externalisation of diabetes and its associated problems, and demedicalises diabetes in an effort to empower young people and their families.

Nursing staff on the wards are important members of the diabetes team. Whilst basic nursing education may include sessions on diabetes, it does not adequately prepare nursing staff for caring for children and young people with diabetes on the ward. Nurses frequently say that they feel uncomfortable with their degree of knowledge when faced with difficult situations. Young people can be seen as deliberately manipulative.

Formal courses are available but these are adult oriented with minimal paediatric input. In addition, they tend to concentrate heavily on type 2 diabetes. There is a paediatric module but this currently has a long waiting list and due to the intensive sessions over several weeks, it may be aimed more at new clinical nurse specialists than ward nurses.

We identified the need for appropriate training for team members who are faced with caring for young people with diabetes within the hospital ward environment. Individual teaching sessions on the ward were attempted. This method was rejected as it was difficult for staff to attend sessions if they were rostered to provide clinical care on the ward. Equally, a link nurse scheme was not felt to be useful as it can only work with named individuals who may not pass on information to other staff members. It was therefore decided to offer a one day workshop, open to any trained member of the nursing and medical staff from three local hospitals who are part of the recently established diabetes network. Local community nursing teams are also invited to attend.

The workshop was advertised by posters placed on all of the paediatric and adolescent wards. The workshop dates were given to ward sisters and highlighted as being available within individual appraisals.

**Workshop aims**

The aims of the workshop are to:

- Provide information relevant to ward staff.
- Increase confidence in all members of staff

working with young people with diabetes.

- Enable understanding of the role of team members in the provision of care.
- Enable links between theory and practice.
- Introduce new perspectives on living with chronic illness.

**Workshop content**

Members of the diabetes team give a series of talks and interactive presentations. The morning sessions focus on medical management. Presentations by the medical consultants focus on:

- How insulin works.
- Current protocols for management of DKA.
- Phenotypes of diabetes.
- Diabetes and the adolescent.

The clinical nurse specialist presents practical information on daily management of diabetes, with opportunities to try out a range of insulin delivery techniques and injection devices, (e.g. pens and insulin pumps). The following areas are covered:

- Blood glucose monitoring (how, when and why).
- Management of hypoglycaemia and hyperglycaemia.
- Issues of contention such as manipulation, alcohol and drugs.
- Practical management of diabetes and its impact on daily life.
- The rationale behind the four stage admission plan for young people newly referred to the team. This plan has been developed by the diabetes team at University College and Middlesex Hospitals, London:

**Stage 1:** Continuous insulin infusion at 0.05 units/kilo/hour with regular blood glucose monitoring.

**Stage 2:** Nurses administer injections and monitor blood glucose levels.

**Stage 3:** The young person injects supervised by the nurses.

**Stage 4:** The young person injects without supervision and is then given a graded discharge and follow-up.

Transfer from each stage occurs when the young person, their parents and the medical team agree that stable blood glucose levels have been achieved.

Dietetic information focuses on:

- The theoretical development of dietary advice, from lines in the 1920s, to exchanges, and to the current use of glycaemic index.

- Case studies that explore how recent guidelines and healthy eating underpin practice in the ward.

The clinical psychologist uses small groups to explore the most important issues for nursing staff dealing with children and young people with diabetes. The main themes are:

- How to deal with non-compliance and young people who manipulate their diabetes.

- The differences in psychological impact of diabetes for children and adolescents.

- How diabetes affects relationships between young people and their families.

- How diabetes affects relationships between young people and their friends.

Participants consider the normal developmental tasks and challenges facing children, adolescents, parents and medical staff. They are encouraged to make connections between the developmental tasks and the demands of a diabetes regimen, and link the theory and practice sessions presented earlier in the day.

Psychological approaches that are presented focus on systemic and solution-focused theories that we have found useful in supporting young people with diabetes. In these approaches the patient is acknowledged as the expert and is encouraged to identify what works for them, i.e. identifying what helped during periods when their diabetes was under control (George et al, 1990).

A transtheoretical model of change is also used as a framework for thinking about how to help young people and their families (Rollnick, 2002; Prochaska and DiClemente, 1992). The model hypothesises a number of motivational stages which lie on a continuum of change. They are referred to as precontemplation, contemplation, determination, action and maintenance. Once change begins, the theory suggests that people start to re-discover skills and resources, which in turn help to maintain the changes made. Many adolescents with diabetes refuse to acknowl-

edge the distress associated with their diagnosis and/or their daily management, and adhere poorly with treatment regimens. If they believe that they do not have a problem (precontemplation) or acknowledge concern but are not ready to start changing their behaviour (contemplation) then only patience, information and acute medical support are offered. The team will help young people to recognise and acknowledge problems, and support their decision to move towards action and improved health outcomes as they become ready to do so.

Another feature of our approach is the use of externalising language to talk about diabetes and other problem areas such as stress (White and Epston, 1990). Young people, their families and the team are encouraged to view diabetes as something that exists outside the child. Diabetes is referred to as 'the diabetes' instead of 'his/her/your diabetes'. Families are asked to think about how they normally deal with uninvited or unwelcome guests that cannot be asked to leave (e.g. a mother-in-law). Younger children are encouraged to draw what the diabetes would look like if it was outside their body and to role play challenging situations with puppets. Workshop participants often ask for practical ideas for engaging and supporting young people during admissions on the ward for DKA. Examples of solution-focused questions are used to help establish individual goals and address concerns. Cognitive techniques are described which can be used to address specific diabetes management questions (difficulty self-injecting, poor eating patterns and behavioural difficulties) that are seen as challenges by the ward staff (Christie, 2000).

Visual metaphors are used to help young people and the ward team to visualise personal achievements and reinforce success. A mountain, for example, represents a journey that requires a support team, brief stops or detours and various challenges to progress. The young person can draw in where they are on the mountain to show their progress as they regain control and put diabetes in its place, as indicated in Figure 1.

## PAGE POINTS

**1** Psychological approaches that are presented focus on systemic and solution-based theory that we have found useful in supporting young people with diabetes.

**2** A transtheoretical model of change is also used as a framework for thinking about how to help young people and their families.

**3** Many adolescents with diabetes refuse to acknowledge the distress associated with their diagnosis or their daily management, and adhere poorly with treatment regimens.

**4** The child and young person, their families and the team are encouraged to view diabetes as something that exists outside the child.

**5** The clinical psychologist uses small groups to explore the most important issues for nursing staff dealing with children and young people with diabetes.

## PAGE POINTS

1 Participant evaluation has been consistently high and applications to attend the workshop increase every time the course is offered.

2 The workshop offers a combination of didactic, practical and interactive sessions that increase knowledge and provide a greater understanding of our approach to working with young people living with diabetes and their families.

3 The workshops are held on a regular basis and the content and presentation are regularly updated and reviewed using participant feedback.



Figure 1. Visual metaphors can be used to help young people with diabetes.

## Workshop evaluation

Seven workshops have been held since March, 1999. Written evaluation forms are completed by participants and summarised by the DSN. Participant evaluation has been consistently high and applications to attend the workshop increase every time the course is offered. Many participants have said that the workshop greatly exceeded their anticipated learning aims and objectives. At a practical level, both nurses and doctors have an opportunity to use the technical equipment that young people with diabetes have to use on a daily basis. This provides opportunities to see how easily injection devices can be used to avoid delivering insulin.

The feedback has emphasised that the workshop offers a real perspective on how to live with diabetes on a daily basis. The impact on practice has been verbally reported by participants in nurse supervision groups and our observation of changes in the way that concerns are discussed in ward rounds. Participants have described:

- A greater understanding of why young people might struggle at times to comply with treatment regimens.
- An increase in confidence when administering and advising less well trained members of staff in the delivery of specific care protocols.
- An increased ability in how to talk with children and young people and support diabetes related distress.
- New perspectives on living with diabetes on a daily basis.

## Conclusions

The workshop offers a combination of didactic, practical and interactive sessions that increase knowledge and provide a greater understanding of our approach to working with young people with diabetes and their families. The benefits are reduced levels of anxiety when young people with diabetes are admitted for inpatient management, and more effective medical and psychological management of emergency admissions for DKA. The workshops are held on a regular basis, and the content and presentation are regularly updated and reviewed using participant feedback. We hope to expand ideas and hold similar workshops for local schoolteachers and parents in the future. ■

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