



# Getting sorted

With the Government calling for young people to have access to the Expert Patient Programme, poor HbA1c levels and increasing rates of Type 1 among the under-15s, it was time to get things sorted. **Dr Nicky Kime** reports on the structured education programme for the young, by the young

**Y**oung people in England have one of the highest incidences of Type 1 diabetes and one of the worst records for diabetic control in Western Europe. Less than 20 per cent of them achieve recommended HbA1c levels. Also, Type 1 diabetes is increasing most rapidly amongst the under-15s. Clearly, there is a need for an approach to long-term care designed specifically for young people with Type 1. The Yorkshire and Humberside Strategic Health Authority (SHA), in its 'Healthy Ambition's policy document, has recognised the Getting Sorted programme as offering just such an approach.

Getting Sorted, a self-care programme for young people aged 12–17 with a long-term condition such as Type 1 diabetes, is located in the Carnegie Faculty of Sport and Education at Leeds Metropolitan University. Young people have been involved at every stage of programme design and development, from inception

through to service provision, and continue to have a key role in delivering and evaluating the programme. Young facilitators with Type 1 diabetes deliver workshops that aim to develop the knowledge, skills and confidence that allow young people to take effective control of their lives and manage their diabetes, rather than relying on adults. The project's success lies in enabling them to express their views and relate their experiences of living with Type 1 diabetes.

## Getting going

Getting Sorted is based on the adult Expert Patient Programme (EPP), which uses a model of lay-led self-management support. The Department of Health (DH) established the EPP in 2002 following the Government's commitment to help people with a long-term condition maintain their health and improve their quality of life in *A New Approach to Chronic Disease Management in the*

*21st Century*. In 2004, the *National Service Framework for Children and Young People* recommended that the EPP be made accessible to young people. The Government endorsed this when *Supporting People with Long Term Conditions* clearly stated the need to make sure that children and young people were able to access the EPP.

Liz Webster, Director of Getting Sorted, recognised that the adult EPP model would need to be adapted to meet the unique needs of young people with Type 1. In 2007, rather than arbitrarily designing and imposing a framework, she carried out some research among young people in Bradford living with Type 1, with the aim of finding out exactly what major problems or issues they would like to see an EPP programme address, and what format would most effectively meet their unique health needs.

A total of 74 young people with Type 1, aged 12–17, were identified as potential participants, out of a total population of 137 with the condition in 15 secondary schools across Bradford and Airedale. From this sample, 41 decided to take part. With the assistance of the clinical nurse specialist at the Bradford Diabetes Outpatients Clinic, three young adults aged 18–22 with Type 1 diabetes were recruited to receive the training necessary to facilitate the programme. They are able to relay their experience and provide advice in relation to clinical aspects of diabetes. It was also felt that young people would relate to, and be more responsive to, a young adult with Type 1 rather than healthcare professionals.

The first step was to gather baseline data from the young participants, which could then be used to help design and deliver self-care workshops. This was achieved through small discussion groups, which the young people preferred to call 'talking groups'. The talking groups were chosen as the method of data collection since they gave the young people the freedom to explore and elaborate on their own views and experiences. The three facilitators ran the groups with support from school nurses and the principal researcher. With permission from the participants and their parents, the sessions were recorded. Three key questions were asked:

1. What problems or difficulties have you faced living with Type 1 diabetes?
2. What topics should the self-care workshops include to help support you to manage these problems and difficulties?
3. How, when and where should the workshops be delivered?

## Getting to work

From the research a framework emerged that recognised young people as the experts. It consisted of a series of workshops, each with clear aims and objectives, focusing on a key issue identified in the talking group sessions, and incorporating individual and group tasks, and physical activities. This formed

**Caption t/c**

the basis of the programme, the foundation for its future development.

The young people themselves came up with 'Getting Sorted', a title that captures how important it is to 'feel sorted' in relation to their diabetes. The majority did not feel sorted. In fact, they felt as if their lives and their diabetes were beyond their power to manage.

In the last two years a programme has emerged that comprises five themed workshops held over 20 weeks:

- Getting to know each other: to ensure young people feel safe and comfortable in a group setting so they can begin to work together.
- Getting sorted: to help young people feel more in control of their diabetes, become more independent and be more responsible for their diabetes. The focus is on the relationship they have with their diabetes, as well as their parents, family and friends.
- Communication and relationships with others: to help young people improve their relationships with their peers, family and professionals, including telling and asking others more about their diabetes.
- Feeling good or sorted: to help enhance young people's self-esteem and work towards a positive body image, focusing on feedback from the previous three workshops and looking to the future; it includes practical advice on managing diabetes.
- Young people and facilitators' evaluation: to allow young people to reflect on their journey through the workshops and capture the benefits of taking part, including the ways in which they have had an impact on how they manage their condition.

The workshops address the psychosocial aspects of diabetes and incorporate a balance of physical activities, discussions and more focused exercises



