

# The importance of self-care: How the “Getting Sorted” programme helps young people manage their diabetes

Nicky Kime, Liz Webster, Sheonagh Clarke

**This article looks at a diabetes education programme called “Getting Sorted” that was developed with the help of young people with diabetes. Its aim is to provide an effective way of training young people to be skilled in the self-management of their condition. The course is based on workshops where a “peer expert” gives advice to other young people with type 1 diabetes, as well as using fun activities and discussions of issues that affect a young person’s ability to implement effective self-management. A 2-year trial of the programme has seen it have some successes, which are detailed here along with plans for the programme in the future. The importance of establishing good self-care in young people with type 1 diabetes is stressed throughout, as this can help prevent long-term complications of the disease and improve general well-being.**

It is widely accepted that type 1 diabetes in young people represents a major public health concern. In the UK, 26 500 young people have the condition (Diabetes UK, 2012) and, worryingly, this group has one of the worst records for diabetic control in Western Europe (Burns et al, 2008). The latest evidence from the National Diabetes Paediatric Audit Report (NHS Information Centre, 2011) shows that more than 85% of children and young people with diabetes did not achieve the NICE target of  $HbA_{1c} < 58$  mmol/mol (<7.5%).

For long-term conditions, such as type 1 diabetes, self-care is central to optimising health and well-being, because the condition quickly worsens with lapses in lifestyle and dietary routine. Any harm that results from these short-term lapses can result in emergencies that have a long-term impact and which can incur additional, but essentially avoidable, healthcare costs (Patterson et al, 2009). Therefore, it is important that young people develop self-care skills and learn to optimise their blood sugar levels, keeping to  $HbA_{1c}$  20–58 mmol/mol (4–7.5%) to avoid hypoglycaemia and potential

complications.

Adolescence is the most important time for influencing future health outcomes and self-care skills developed during this period form the basis of effective long-term care throughout a person’s life. Potential solutions to combat the increasing trend of poor glycaemic control in young people with type 1 diabetes need to focus on teaching young people the best way to look after themselves in their everyday lives. One way of doing this is through self-care programmes that cater for young people with type 1 diabetes and focus specifically on their needs. The programmes that deliver the most impressive self-care outcomes are those that attend to the expressed needs of young people and use a holistic model to address the medical, psychological and social needs of the individual. Importantly, such programmes do not assume that all young people with type 1 diabetes are a homogeneous group with the same requirements. Rather, the content of these programmes is tailored to match each individual’s needs and adapted as necessary for such variables as age, cultural influences and literacy levels. This is

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## Article points

1. Young people with type 1 diabetes need to be educated in self-management in order to prevent long-term complications of the disease.
2. An education programme designed with young people in mind called “Getting Sorted” has had a successful trial.
3. An effective self-management programme for young people with type 1 diabetes would provide the NHS with considerable cost savings.
4. Plans to develop the programme include family education elements and a family starter pack.

## Key words

- Education programme
- Peer group support
- Self-care
- Type 1 diabetes

## Authors

Nicky Kime is Senior Research Fellow at Leeds Metropolitan University; Liz Webster is Principal Lecturer and Director of “Getting Sorted”, Leeds Metropolitan University; and Sheonagh Clarke is Business & Enterprise Officer at “Getting Sorted”, Leeds Metropolitan University.

subsequently translated into care that is appropriate to the young person’s lifestyle as well as their family (Crowley et al, 2011).

### The “Getting Sorted” self-management programme

One self-care programme that has been designed specifically for young people with type 1 diabetes is the “Getting Sorted” programme (Kime et al, 2012). “Getting Sorted” is based on the adult Expert Patient Programme (EPP), and young people with type 1 diabetes have been involved at every stage of programme design and development, from inception through to service provision. In 2007, initial research was conducted to find out exactly what young people with type 1 diabetes wanted an EPP to address and which format would most effectively meet their unique health needs. The research led to the development of a series of five workshops that mainly address the psychosocial aspects of diabetes.

The workshops began in 2007, with the initial series being conducted over a period of 3 years. Participants, aged 12–17 years, from five Primary Care Trusts (PCTs) in Yorkshire and the Humber, were invited to participate in the workshops by a letter, initially, which was given to them by their paediatric diabetes specialist nurse (PDSN).

Over 1000 young people attended the workshops, which were delivered by a trained coordinator and peer-facilitator. Both of these roles are part of the wider “Getting Sorted” team, which is based at Leeds Metropolitan University and works with children and young people with long-term conditions, primarily those with type 1 diabetes.

The key objective of the programme is to enable young people to increase their understanding and self-manage their diabetes in ways that suit them. This means that the programme is not

simply focused on the medical aspects of self-care, but incorporates discussions on a wide range of issues, according to the needs of individuals, their lifestyle and their diabetes. It includes topics such as communication, relationships, socialising, parental concerns, school, sporting activities and managing the clinic consultation. These discussions take place within the context of practical, fun activities, such as team-building exercises and games, where young people and peer-facilitators (who also have type 1 diabetes) share experiences and learn from each other.

The programme is based on the three self-care principles of self-efficacy, empowerment and engagement, which will help young people to develop new strategies and solutions to deal with the issues they may face, rather than having to rely on traditional healthcare approaches (*Box 1*).

### Regional Innovation Fund

In 2010, after the initial “Getting Sorted” programme had been deemed successful (based on a qualitative approach incorporating one-to-one interviews and discussions), the Strategic Health Authority in Yorkshire and the Humber commissioned the programme to run in seven sites across the region with an investment of £90 100 from the Regional Innovation Fund (RIF). Leeds Metropolitan University also contributed £42 000. The programme was conducted in Bassetlaw, Calderdale, Doncaster, Harrogate, Hull, Northallerton and Scarborough. The aim was to test the efficacy of the “Getting Sorted” self-management model against four key factors:

- Inpatient and outpatient activity.
- Long-term HbA<sub>1c</sub> levels.
- Cost savings to the NHS.
- The impact on young people’s lives.

The programme, which comprised five workshops, was conducted over 2 years starting in May 2010 and ending in July 2012 (Webster and Clarke, 2012). Forty-one young people aged 12–17 took part in the programme, and peer-facilitators with type 1 diabetes aged 18–22 were trained to deliver the workshops using a bespoke 2-day training course developed by young people and led by skilled “Getting Sorted” coordinators.

A mixed-method approach, incorporating quantitative and qualitative techniques of data collection measured the programme’s

#### Box 1. Fundamental principles of self-help.

- Self-efficacy: Young people should be encouraged to take responsibility for their lives and their condition.
- Empowerment: Young people should be enabled to develop the knowledge, skills, understanding and motivation in relation to their condition.
- Engagement: Young people should be fully engaged in the process of managing their condition in a proactive way.

objectives. Clear aims were established in each individual workshop, which served as a key point of comparison with the outcome data. The quantitative element of the evaluation provided data in relation to the following:

- The number of young people recruited and their attendance on the workshops.
- The number of facilitators trained.
- Inpatient and outpatient activity, both before and after the workshops.
- HbA<sub>1c</sub> results for young people before and after the workshops.

The qualitative element of the evaluation involved a formative evaluation framework, incorporating recorded written and verbal feedback, which is outlined later in this article.

### Findings from the evaluation

The aim was to measure the short-term impact of the programme over a specific 2-year period. Therefore, the following information explains the quantitative and qualitative outcomes from those 2 years.

#### Quantitative outcomes

- Forty-one young people attended the workshops and 14 facilitators were trained to deliver them.
- There was an average attendance rate of 70% across the workshops.
- Inpatient and outpatient activity was recorded for 34 of the young people. A reduction in inpatient and outpatient activity was seen in the 6 months after the workshops compared to the 12 months before.
- HbA<sub>1c</sub> results showed no improvement overall. However, collected data showed that 9 out of 41 young people who had a pre-workshops HbA<sub>1c</sub> between 86 and 108 mmol/mol (10.0 and 12.0%) improved to a post-workshops level between 69 and 91 mmol/mol (8.5 and 10.5%).

Based on data 3–6 months pre- and post-workshops, hospital admissions show a significant drop post-workshop (59%) and suggest that over a period of 2 years approximately 10 admissions were avoided for workshop attendees as a whole. This was calculated based on the average number of hospital admissions per young person per year. A conservative estimate of £1072 per admission (representing the standard tariff at this time) suggests a total saving of £10 720, although this

does not take account of the cost of the programme. Even though the HbA<sub>1c</sub> results post-workshops showed no significant improvement overall, the HbA<sub>1c</sub> levels improved for young people among those whose diabetes control was considered sub-optimal and had an initial HbA<sub>1c</sub> >80 mmol/mol (>9.5%) before starting the course.

#### Qualitative outcomes

An evaluative framework incorporating various data collection tools, including talking groups (young people’s description of focus groups), individual interviews, role-play, monologues, socio-grams and body images, provided evidence of the positive impact on the health and well-being of the young people. The findings in all seven locations were consistent in that the same themes and issues arose in each of the workshops. Overall, the findings from the workshops illustrated that the young people believed that the workshops had a positive effect on one or more aspects of their diabetes and helped them to feel more in control of their condition. The workshops were viewed as being more relevant to the young people than some other programmes, since the focus was not on lecturing young people with type 1 diabetes. Young people were able to talk about their own experiences in an environment that they felt was non-judgemental, which meant they could be open and admit mistakes. In addition, they were able to obtain advice from the “real experts” (i.e. other young people who have the condition and have, therefore, lived through similar experiences). The following information summarises the positive impact of the workshops on the health and well-being of the young people, as illustrated by the qualitative and quantitative findings:

- Developed a positive attitude to their diabetes.
- Learned about diabetes from peers of a similar age.
- Increased their confidence to cope with their diabetes.
- Developed better control of their condition.
- Felt less alone.
- Felt more confident at clinic.

#### Discussion

In terms of the quality and effectiveness of the “Getting Sorted” programme over the two-year period, quantitative measures indicate that the

*“The young people believed that the workshops had a positive effect on one or more aspects of their diabetes and helped them to feel more in control of their condition.”*

**Box 2. What attendees said about the “Getting Sorted” programme.**

- “‘Getting Sorted’ is showing people like us we’re not alone and we can help each other” (Scarborough).
- “‘Getting Sorted’ has helped me to talk to others about my problems. Now I do talk to my friends about it more” (Northallerton).
- “‘Getting Sorted’ is an enjoyable way of getting your problems out” (Doncaster).
- “My confidence has really increased since I started coming to the workshops” (Northallerton).
- “I enjoyed the activities and I liked talking about our feelings towards people and diabetes-related issues” (Calderdale).

overall cost saving to the NHS was £10 720 just among a small population of 41 young people, although this does not take into account the cost of attending the programme. Besides the positive financial impact of the programme, qualitative data demonstrates that young people have developed greater confidence to take active control of their condition and have increased their knowledge and skills about self-management (*Box 2*).

The workshops had a positive impact on the young people’s health and well-being indicated by the drop in hospital admissions for this group. Such a reduction is important, not only in terms of cost savings for the NHS, but also in relation to the severe health consequences for this group if they continue to be poorly managed and to the long-term prevention of diabetes complications.

**Challenges and limitations**

There were a number of challenges encountered during the course of the 2-year RIF-funded programme. The biggest challenge was recruitment. Recruitment onto the workshops was most successful when the “Getting Sorted” team supported the recruitment process and worked in partnership with individual diabetes units. Where diabetes teams, in particular the PDSNs, actively promoted the programme in clinic, recruitment to the workshops was higher. One of the most effective recruitment tools was to work with the young people who attended the workshops and engage them in telling their stories, then “sell” the programme through peer information. Even so, over the duration of the workshops some young people were unable to attend due to illness, jobs and other commitments. Information recorded detailing the reasons why young people did not attend the

workshops indicated that, due to the nature of type 1 diabetes, young people plan to attend all the workshops, but the unpredictability of this long-term condition means that they may cancel at short notice because of poor health. A further limitation that had an impact on the findings was that permission to collect quantitative data was only approved in six out of the seven sites. In the seventh site, the resources were not in place to support data collection. In addition, there was a limited time for post-data collection; HbA<sub>1c</sub> data was collected between 1–4 months after the final workshop. Finally, the relatively small sample of young people attending the workshops meant that the evidence for an improvement in HbA<sub>1c</sub> results across the whole sample was inconclusive.

**Improvements to “Getting Sorted”**

Lessons learnt from the 2-year RIF-funded programme have resulted in a number of improvements. A new business model has been developed with commissioners and providers. This is a collaborative cluster model that offers three series of workshops per year, which can be accessed by several PCTs/Clinical Commissioning Groups (CCGs). The advantage of this method is to reduce the cost for each PCT/CCG and increase the numbers of young people attending the workshops. In the West Yorkshire Cluster 2012/13, commissioned by NHS PCTs, “Getting Sorted” recruited more than twice as many young people as on the initial programme, in half the amount of time, as a result of improved recruitment techniques. The cost of the service per participant is now comparable with adult diabetes provision and approximates half the cost of one admission to hospital.

Closer collaboration with the diabetes teams has produced a PDSN group development committee. The purpose of this group is to enable PDSNs to keep up-to-date with the outcomes of the workshops and engage them in service re-design and delivery in the NHS.

A number of parent discussion groups have been held alongside the workshops in West Yorkshire. The aim of these was to listen to parents and establish what support mechanisms are required to assist the family of the person living with diabetes. These findings have been fed into the National

Parent Reference Group for wider dissemination. In addition, the “Getting Sorted” team have assisted in the facilitation of local family support groups.

A quality of life questionnaire “Disabkids Quality of Life Evaluation” has been introduced pre- and post- workshop, in order to measure the quality of life of young people attending the workshops in a more robust and quantifiable way.

### Conclusions

Currently, there is no recognised, accredited and structured diabetes self-management education programme in the UK. Similarly, the emotional and psychosocial support available for young people with type 1 diabetes is inconsistent. According to the diabetes tariff, all young people, regardless of their HbA<sub>1c</sub> levels, should have access to a structured education programme and psychosocial support as an integral part of their diabetes care. An intervention such as the “Getting Sorted” programme, which provides 25 hours of self-management education and psychosocial support, and has been shown to improve the health outcomes of young people with type 1 diabetes (*Box 3*). In addition, it serves to increase the choice for young people and families living with diabetes and represents an additional service for young people. However, “Getting Sorted” is only one strand of the all-round care that young people and their families should receive. No single aspect of care can work in isolation to positively influence young people’s ability to reduce HbA<sub>1c</sub> levels, which is why “Getting Sorted” is not meant to replace current medical care but is intended to complement and enhance the care that young people receive. Furthermore, young people’s diabetes care needs to be focused on the family as well as the individual. Knowledge generated through the “Getting Sorted” workshops indicates that self-management strategies have an impact on the entire family and, therefore, any approach should encompass the whole family. As a consequence, the “Getting Sorted” team has identified and developed other projects such as:

- Family support events and groups (funding secured through Juvenile Diabetes Research Fund and Diabetes UK Cymru).
- A family “starter pack” to help families manage carbohydrate counting. This includes practical support, with recipes and supermarket shopping.

#### Box 3. Areas of improvement at the end of the 2-year “Getting Sorted” programme.

The 2-year “Getting Sorted” programme has demonstrated an improvement in health and well-being outcomes for young people with type 1 diabetes. These outcomes are:

- A 59% reduction in inpatient activity
- NHS cost savings of approximately £11 000
- Improvement in HbA<sub>1c</sub> levels for young people who began the course with an HbA<sub>1c</sub> >86 mmol/mol
- Positive impact on young people’s lives.

For example, families are accompanied on their supermarket shop and are shown how to read food labels, which foods to avoid, how much of their diet needs to be carbohydrates, protein, etc.

- Three separate workshops focused on the newly diagnosed young person and their family, school and transition.

As far as the future work of the “Getting Sorted” programme is concerned, the focus needs to be on extending the collaborative cluster model across the region. Such an approach ensures the workshops are cost effective and efficient. Many different PCTs/CCGs, in similar geographical locations, can use the service to refer their young people. This model will ensure the programme becomes more sustainable. It is hoped that young people who attend the workshops will train as peer-facilitators for future workshops. In addition, an HbA<sub>1c</sub> monitoring programme, which will be used with future workshops, will enable the positive health outcomes of the programme to be fully realised. ■

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