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## **The importance of self-care: how the 'Getting Sorted' self-management programme is helping young people to manage their diabetes**

**Nicky Kime, Liz Webster and Sheonagh Clarke**

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 <58mmol/mol (7.5%) HbA<sub>1c</sub>. For long-term conditions, like type 1 diabetes, self-care is central to achieving recommended HbA<sub>1c</sub> levels and optimising health and well-being, because the condition quickly worsens with lapses in lifestyle 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, health care costs (Patterson et al, 2009). Therefore, it is important that young people develop self-care skills and learn to optimise their blood sugar levels, at values below 7.5%, and above 4%, to avoid hypoglycaemia and potential complications.

Given that adolescence is the most important time for influencing future health outcomes, and self-care skills and self-efficacy developed during this period form the basis of effective long-term care, 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 how best to look after themselves within the context of 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. Indeed, 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 that addresses 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 age, cultural influences, literacy, etc. This is subsequently translated into the care that the young person receives, which is appropriate to the lifestyle of the individual, 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), but what is different about this programme is that young people with type 1 diabetes have been involved at every stage of programme design and development, from inception through to service provision, to create a programme centred on their needs. Initial research was conducted with young people living with type 1 diabetes in 2007, the aim of which was to find out exactly what young people 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 5 workshops that mainly address the psychosocial aspects of 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 on communication, relationships, socialising, parental concerns, school, sporting activities, managing the clinic consultation, etc. These discussions take place within the context of practical, fun-based activities where young people and peer-educators (both with type 1 diabetes) share experiences and learn from each another.

The programme is based on the three self-care principles of self-efficacy, empowerment and engagement, which assist young people in developing new strategies and solutions to deal with the

issues they may face, rather than young people having to solely rely on traditional healthcare approaches to dealing with type 1 diabetes (see Box 1).

#### Box 1

The programme is guided by three fundamental self-care principles:

- 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.

#### Regional Innovation Fund (RIF)

Building on the initial success of the 'Getting Sorted' programme, in 2010 the Strategic Health Authority in Yorkshire and the Humber commissioned the programme to run in 7 sites across the region with an investment of £90,100 from the RIF. Leeds Metropolitan University contributed £42,000. The programme was conducted in Bassetlaw, Calderdale, Doncaster, Harrogate, Hull, Northallerton and Scarborough. The aim of the RIF was to test out 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 and the impact on young people's lives. The programme was conducted over a 2-year timeframe, starting in May 2010 and completing in July 2012 (Webster and Clarke, 2012). A total of 41 young people aged 12-17 took part. In addition, fourteen 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. The facilitators were coached by skilled 'Getting Sorted' co-ordinators who have extensive experience of working with young people.

A mixed-method approach, incorporating quantitative and qualitative techniques of data collection, measured the programme's objectives. An approach such as this, i.e. triangulation, promotes a greater understanding of the findings and increases validity. 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 and HbA<sub>1c</sub> results for young people before and after the workshops. In addition, the qualitative element of the evaluation provided a greater understanding of the 'how' and 'why' in relation to the programme's success, specifically in relation to the positive impact on young people's health and wellbeing.

#### Findings from the RIF

The aim of the RIF was not to measure the long-term impact of the programme, but rather the short-term impact over a specific 2-year period. Therefore, the following information explains the quantitative and qualitative outcomes from the 2-year programme.

#### Quantitative outcomes

- Forty one young people attended the workshops and 14 facilitators were trained to deliver the workshops.
- There was an average of 70% attendance rate across the workshops.
- Inpatient and outpatient activity was recorded from 34 young people. There was a reduction in inpatient and outpatient activity post-workshops.
- HbA<sub>1c</sub> results showed no improvement overall; however, young people's HbA<sub>1c</sub> results in the poorly managed group (those with a HbA<sub>1c</sub> of over 9.5%) did improve.

The hospital admissions data shows a significant drop in post-workshop admissions (59%). This suggests approximately 10 admissions were avoided for workshop attendees as a whole. A conservative estimate of £1072 per admission suggests a total saving of £10,720. Even though the HbA1c results post-workshops showed no significant improvement overall, the HbA1c levels improved for young people in the poorly managed group. This indicates that the workshops had a positive impact on the young people's health and wellbeing, which is consistent with the fact that there was a 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. A move from 9% to 8% HbA1c is more valuable in terms of a young person's ability to self-manage and the long-term prevention of diabetes complications, than a move from 8% to 7% HbA1c.

#### Qualitative outcomes

An evaluative framework incorporating various innovative 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 wellbeing of the young people. The findings in all 7 locations were consistent in that the same themes and issues arose in each of the workshops. Overall, 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 is 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:

- 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.

#### Box 2

What young people had to say:

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

#### Success of the 'Getting Sorted' programme

In terms of the quality and effectiveness of the 'Getting Sorted' programme over the 2-year period, quantitative measures indicate that the overall cost saving to the NHS was £10,720 from a small population of 41 young people. 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 knowledge and skills to self-manage (see Box 2).

### Challenges

There were a number of challenges encountered during the course of the 2-year RIF 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 Paediatric Diabetes Specialist Nurses (PDSNs), actively promoted the programme in clinic, recruitment onto 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 through peer information, 'sell' the programme. 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, indicates 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 young people cancel at short notice because of poor health. A further limitation that impacted on the findings was that permission to collect quantitative data was only approved in 6 out of the 7 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; HbA1c 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 HbA1c results across the whole sample was inconclusive.

### Improvements to the 'Getting Sorted' programme following the RIF

Lessons learned from the 2-year RIF programme have resulted in a number of improvements. These are explained below.

A new business model has been developed with commissioners and providers. This is a collaborative clustering model that offers 3 series' of workshops per year, which can be accessed by several Primary Care Trusts (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 over twice as many young people as on the RIF programme, in half the amount of time, as a result of improved recruitment techniques. The cost of the service is now comparable with *adult* diabetes provision and is equal to 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 wider family 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- workshops, in order to measure the quality of life of young people attending the workshops.

### Conclusions from the RIF

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 HbA1c levels, should have access to a structured education programme and psychosocial

support, which need to be integral aspects of their diabetes care. An intervention, such as the 'Getting Sorted' programme, 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 (see Box 3). In addition, it serves to increase the choice for young people and families living with diabetes and represents an extra service that young people did not have access to before. 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 HbA1c 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 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 along these lines and received commissioned work in the form of:

- Family support events and groups (funding secured through JDRF and DUK Wales);
- A family 'starter pack' to help families manage carb-counting. This includes practical support, with recipes and supermarket shopping. 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 (1) the newly diagnosed young person and their family, (2) school and (3) transition.

### Box 3

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

- 59% reduction in inpatient activity;
- NHS cost savings of approximately 11K;
- Improvement in HbA1c levels for 'poorly managed' young people;
- Positive impact on young people's lives.

As far as the future work of the 'Getting Sorted' programme is concerned, the focus needs to be on extending the collaborative clustering 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 as young people who attend the workshops train as facilitators for future workshops. In addition, a HbA1c monitoring programme, one that ties in with future series' of workshops, will enable the positive health outcomes of the programme to be realised.

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