Caring for my diabetes: A diabetes education and self-management programme for service users with learning disabilities and Type 2 diabetes

Background and aims

Caring for my diabetes was designed and run by diabetes specialist dietitians (DSDs) and diabetes specialist nurses (DSNs) with the support of adult learning disability nurses (HPFT) in West Hertfordshire. It was piloted initially as a series of five of two hour sessions targeted at people with learning disabilities who also have Type 2 diabetes.

Until now, there has been little or no attempt to provide tailored information on diabetes to people with learning disabilities. The traditional approach has been to inform and advise patient, family and/or carers, for the patient.

The pilot was intended to determine:

- Whether it is possible to reach and engage people with learning disabilities in a systematic and structured way so as to help them understand and manage their condition
- How to give people with learning disabilities more autonomy in making choices with respect to health, diet, lifestyle and their condition
- To tailor information and advice so that people in the target group feel more confident in managing diabetes
- To provide the opportunity for medication and dietary and lifestyle measures to be addressed together to maximise positive outcomes

Methods

The programme was piloted initially in Watford and is intended to be rolled out in other localities in Herts Valleys in 2018. Nine patients – most of them accompanied by their carers and learning disability nurses– attended the programme.

Programme Structure

Referral process

- Initial referral – made by Learning disability nurse.

- If the patient is suitable and agrees, the patient is booked onto a group

Group sessions

- Group sessions between 4 and 10 people (with carers present as necessary)
- Week 1: induction - carers receive an explanation about the programme, what they can expect and how best to benefit from it
- Weeks 2-5: - patient and carers - explanations of diabetes, diet, healthy choices and exercise – which are specifically tailored for the target group
- Attendees are encouraged to ask questions, are prompted for their own experience and knowledge of the condition – the ideal is to make sessions friendly and interactive
- Handouts: weekly food and drink diary and diary of physical activity – patients are strongly encouraged to complete these and use them as the basis for discussion on their growing knowledge and confidence about the condition and the way they manage the condition week by week
- Attendee evaluation at the end of each session: *what did I learn? How helpful was the content? What do I need more help to understand?*

Programme Content

The programme covers the following topics via group discussion, group activities and practical demonstrations.

- What is diabetes?
- Carbohydrates and healthy choices
- Fats and healthy choices
- Physical activity
- Blood glucose monitoring
- The importance of check-ups

Feedback from attendees

Feedback from attendees was unanimously positive. The evaluation method we used at the end of each session (attendees place a tick by one of three faces – a smiley face, an expressionless one, and a sad one) was chosen because it is very simple. However, although it demonstrates that all attendees were happy with the

sessions, it provides no additional useful information on how confidence on understanding and managing the condition may have been improved as a result of the sessions.

The main problem to attendance was coordinating carer's times. Many of the service users are dependent on carers' help for travelling to the programme. Matching carers schedules to session times proved challenging and sometimes resulted in a service user missing a session.

Plans and recommendations

An additional session will be incorporated as part of the roll-out to other areas as it is felt that five sessions is insufficient to get across the emphasis on activity and so an active session was thought to be useful for the attendees including an exercise referral.

There needs to be better coordination of carer times with session times, so that no patient is forced to miss a session that he or she would like to attend.

It may be a good idea to benchmark ourselves against other similar programmes nationally and continually monitor them in the interests of continuously improving our provision.

We need to find and implement more comprehensive ways of evaluating individual sessions and the programme as a whole. The use of biomedical markers such as weight, BMI, HbA1c, BP and cholesterol pre course and after 6 month is planned

We may need to investigate the need for following up patients who have completed the programme to see whether they may need to attend refresher sessions.