

The role of Diabetes UK: education through information

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Introduction

Diabetes UK is the leading UK-based charity for people with diabetes. In addition to funding research and campaigning, Diabetes UK aims to help people with diabetes to live with the condition. Through the provision of information for people with diabetes and healthcare professionals alike, Diabetes UK is a key part in the life-long educational process that must be in place for successful diabetes management. Responding to research and the changing needs and numbers of people with diabetes – children, adolescents, adults and the elderly – are among its top priorities.

Living with diabetes is a life-long learning process for the individual. Information and education are key from the point of diagnosis, when everything is new, strange and often frightening, through the daily juggling act to maintain good control, to the challenges of complications. Fortunately this was recognised in the National Service Framework for diabetes, standard 3 (Department of Health, 2001) which states that:

'...people with diabetes need the knowledge, skills and motivation to assess their risks, to understand what they will gain from changing their behaviour or lifestyle and to act on that understanding by engaging in appropriate behaviours.'

Knowledge and skill for people with diabetes

How do people with diabetes gain that essential knowledge and skill? Most comes from their healthcare providers, especially their nurses, both through formal education initiatives and through personal consultation with the healthcare team. However, people also seek information from other sources:

- the internet (with its many potential pitfalls)
- friends and neighbours (who may fill in the blanks with their own interpretations)
- other people with diabetes (who can provide a tremendous amount of support)

- the media – magazines, newspapers and television
- Diabetes UK.

Diabetes UK

Our vision

Part of Diabetes UK's vision is to provide the highest quality of care and information for all and to achieve a universal understanding of diabetes and of Diabetes UK. For this reason we produce information for both healthcare professionals and people living with diabetes in many formats, including our regular magazines, *Balance* and *Diabetes Update*, and our website (www.diabetes.org.uk), which receives about 750 000 hits a month.

Education

It is not in the remit of Diabetes UK to provide education, although we do support research into educational initiatives such as DAFNE (Dose Adjustment For Normal Eating; DAFNE study group, 2002) and DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed; Department of Health, 2004). It is within our remit, however, to support those who provide education, whether through initiatives such as the Diabetes, Diagnosis and Discussion initiative, a peer support programme for people with diabetes that is being piloted by Diabetes UK, or by providing information to healthcare professionals to facilitate the educational process.

ARTICLE POINTS

1 Diabetes UK provides information for people with diabetes about their condition throughout their lives, from the moment of diagnosis.

2 Up-to-date information is also provided for healthcare professionals, enhancing their ability to help people with diabetes.

3 Careline is a successful Diabetes UK initiative – people can telephone a trained counsellor to enquire about any diabetes-related topic.

4 Diabetes UK recognises the need to work closely with other organisations.

5 Responding to the changing needs of people with diabetes is the key to success.

KEY WORDS

- Diabetes UK
- Information
- Education
- Responsive

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Figure 1. The recently-published Diabetes UK weight management pack contains a poster (left), a booklet aimed at practice nurses (top right) and a patient information leaflet (bottom right).

The weight management pack

An example of the facilitation of the educational process by providing information to healthcare professionals is the weight management pack that was recently published by Diabetes UK (see Figure 1). This pack consists of several documents that can be downloaded as PDFs from our website at www.diabetes.org.uk/catalogue/education.htm (accessed 17.02.05). The pack includes patient information in the form of a leaflet 'Weight creeping up on you? Diabetes and weight management'. It also includes a booklet called 'Weight management: managing diabetes in primary care', aimed at practice nurses, covering issues around weight loss, such as assessing and motivating patients as well as the treatment options available.

Information

Diabetes UK's information is seen as the gold standard by many healthcare professionals and we take its production very seriously. Although most information resources are initially produced internally by our healthcare professional staff, throughout the process we consult with a wide range of healthcare professionals (especially those from our Professional Advisory Committee) as well as people with diabetes.

We ensure that we use the most up-to-date research and care recommendations, and, when there is a lack of evidence, our strong links with healthcare professionals from all backgrounds and disciplines enable us to reach a consensus to help us shape our information. We also ensure that our information is tailored to the needs of the various groups of people with diabetes: the young, their families, the newly diagnosed no matter what their treatment, the visually impaired and those whose first language is not English, for example. It is also important that we translate complex research findings into accessible information and continue to develop new materials as new needs develop, an example being information for children with type 2 diabetes. We also try to update our information resources regularly and welcome any feedback to allow us to achieve this and to ensure that the information we provide is in the most appropriate format and meets the needs of our members. Comments can be sent to care.advisor@diabetes.org.uk.

The Diabetes UK Careline

The Diabetes UK Careline is a further source of information for people with diabetes and it receives around 50 000 enquiries a year. The Careline number is 0845 120 2960 and it is open Monday to Friday from 9am until 5pm (a translation service is available) with recorded information available 24 hours a day. As well as offering information to people on a wide range of subjects, Careline also offers support through talking with a trained counsellor (see Figure 2).

Calls to Careline allow Diabetes UK to identify gaps in currently available information, and to then fill them. We have found this to be particularly true around the subject of diet – by far the most requested topic of information. This can be as simple as producing quick question-and-answer style responses to topics that the media has generated interest about, to developing a more detailed information resource, such as the weight management pack, which deals with many of the issues that callers to Careline, both lay and

PAGE POINTS

1 The weight management pack includes patient information leaflets and a booklet aimed at practice nurses.

2 Diabetes UK consults with a wide range of healthcare professionals as well as people with diabetes.

3 The Diabetes UK Careline is a source of information for people with diabetes which receives around 50 000 enquiries a year. People who call can talk to a trained counsellor.

professional, have raised.

As most people get their information on diabetes from the media, the internet or the man next door, this often means that the information they receive is distorted or even dangerous. A particular issue is the myth around 'mild diabetes' or 'a touch of sugar', which many callers to Careline cite as their particular problem. Because diabetes has been couched in these terms, many people fail to realise the seriousness of their condition and think that they only have to avoid sugar in their diet (another popular misconception).

A public role

We also have a wider role in informing the general public about diabetes. We use every opportunity to ensure that the messages about diabetes presented to the public are correct and well-informed, as far as resources allow.

Dispelling myths and legends

Diabetes UK tries to challenge these myths when they appear in print. We have also tried to raise awareness of the seriousness of diabetes through campaigning work, and to get our messages to the widest audience possible by working with corporate partners. We use these means particularly with black and ethnic minority groups, who are at a high risk of diabetes, but often have misinformed views of the condition (Audit Commission, 2000).

Working with other organisations

Diabetes UK works closely with other organisations (such as the British Heart Foundation) and corporate partners (such as supermarkets) to ensure that the information that they produce on diabetes is accurate and complements our own messages. We also work closely with political bodies in the four nations to ensure that diabetes is prioritised and that the standards laid down in the various national framework documents are implemented.

Patient education

Although Diabetes UK has a strong history of providing high quality information, this is not the same thing as education. Patient



Figure 2. The Diabetes UK Careline is a further source of information for people with diabetes, receiving around 50 000 enquiries a year.

education should be a planned life-long process, starting from the point of diagnosis and remaining as an essential component of diabetes care, integrated into regular clinical diabetes care. Information is one part of the educational process, as it provides the facts that people need. However, it is education that enables people with diabetes to take the facts and use them properly to make decisions about how they will manage their diabetes.

An example of this has been the DAFNE process. Many people (myself included) 'know all the facts' before going on the course, but through the educational intervention, become able to use the facts more effectively to improve their diabetes management.

Conclusion

Diabetes UK is committed to helping healthcare professionals give people with diabetes the highest standards of diabetes education by providing them with the gold standard of information. As an organisation representing all people with diabetes, we want to grow to meet the needs of the increasing numbers of people affected, to ensure that information is readily available when it is needed. ■

More information about Diabetes UK can be found at: www.diabetes.org.uk

PAGE POINTS

1 Diabetes UK tries to raise awareness of the seriousness of diabetes through campaigning work, and to get its messages to the widest audience possible by working with corporate partners.

2 Diabetes UK works closely with organisations like the British Heart Foundation.

3 Patient education should be a planned life-long process, starting from the point of diagnosis and remaining as an essential component of diabetes care.

4 Education enables people with diabetes to take the facts and use them properly to make decisions about how they manage their diabetes.

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