

# Patient Education in the Management of Diabetes

a report by

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We now know that type 2 diabetes is preventable through a change in lifestyle (sometimes including medication). Late complications of type 1 and 2 diabetes can also be effectively avoided or delayed using active intervention and available therapies. Despite these facts, the percentage of people with diabetes following the therapy proposed by healthcare professionals (HCPs) is quite low. For example, 25–30% of people with type 1 diabetes admit to forgetting their insulin injections. Approaches such as an increased physical activity plan or the use of a nutrition plan have an even lower percentage of followers.

The evidence is clear: sometimes people know what to do, and even want to do it, but they simply do not do it. People with diabetes or any other chronic disease need to be involved in their own treatment. Basic knowledge is important, but the reinforcement of appropriate attitudes and a continuous process of motivation is fundamental in changing established habits and behaviour. We need to educate patients and give them the tools and skills to manage their disease, allowing them to become autonomous and 'empowered', although of course, continuous availability for long-term follow-ups is essential.

Currently, there are different kinds of insulin and different ways of administering it. We have several reduced-pain glucometers and nutritional and physical activity plans that are more adaptable to each individual's daily life. However, one step is still missing – therapeutic patient education (TPE). This concept, originally from Jean-Philippe Assal, can be defined as being a process "...designed therefore to train patients in the skills of self-managing or adapting treatment to their particular chronic disease ... to enable a patient (or a group of patients and their families) to manage the treatment of their condition and prevent avoidable complications, while maintaining or improving quality of life."<sup>1</sup>

TPE is patient-centred and based on a more horizontal relationship between the patient and the HCP than the classic care model. We now know that analysing the patient's symptoms, diagnosing a disease and prescribing adequate therapies is not sufficient. When the patient

and HCP meet during consultation, their interaction can facilitate or interfere with the patient's adherence to therapy.

## Therapeutic Patient Education

The initial training of almost all HCPs is given according to an acute perspective of disease and is based on signals and symptoms that lead to diagnosis. In this model, the HCP is responsible for diagnosis, treatment and outcome. The model is centred on the HCP, who says what to do and when and how to do it. All the patient has to do is follow the HCP's prescriptions and future benefits will overcome the impact of the changes in daily life. However, when we talk about chronic disease, this model simply does not work. We need a global understanding of the patient and his or her psychosocial dimension. We need to move from the classic physician-centred model to a patient-centred one, and TPE and patient empowerment can help.

This empowerment, according to Bob Anderson<sup>2</sup>, is based on three main principles:

- almost 100% of diabetes care is provided by the patient and not by HCPs;
- with their experience, the diabetes care team can provide education and psychological support, but they cannot control the disease; and
- the probability of someone beginning and maintaining major changes in lifestyle is reduced if these changes have no meaning for them and were not chosen by them.

In this model, knowledge is exchanged and power and responsibility are shared. "It implies a real, planned and organised competencies transfer from the educator to the patient, with the goal to progressively transform the disease's dependence into responsibility and partnership with the HCP's team."<sup>3</sup> It implies a re-definition of roles and responsibilities and the establishment of a relationship between the HCP and the patient that enhances collaboration and a team spirit. This model avoids mutual frustration (of the HCP who cannot convince the patient to follow his or her instructions and advice, and of patients with diabetes who have no control over their disease and feel compelled to pursue goals that they do not consider to be their own) and promotes efficient teamwork based on the experience and knowledge of both parties.

The method should be interactive and involve the patient in problem-solving and coping with daily life, taking into consideration his or her psychosocial and cultural needs. Empowering patients should not aim at leaving them to their fate. It is a continuous process between the patient and the HCPs. It is an individual process whereby each patient faces up to his or her disease in a different way. Therefore, TPE is a complex process with countless variables.



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### The Healthcare Provider

The HCP should be a partner in: the negotiation of achievable goals; motivating patients to change; supporting and reinforcing any changes that may have happened; assuring patients of an emergency network;

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listening to their fears, expectations and questions and doubts; taking their beliefs and perceptions into consideration; helping them to acquire the necessary knowledge to manage their own disease; and helping them to become autonomous.

The establishment of a relationship between the HCP and the patient may not be an easy task. It should be based on communication that informs the patient about what is happening through active listening and coherence of attitudes from the HCP. Empathy is the main goal, and comparison of ideas and their reformulation are the main tools. A strong relationship with the HCP may be fundamental in encouraging patients towards acceptance and better management of their chronic disease.

### The Patient

The patient presents variables – either innate or acquired – that may interfere with adherence to treatment. These variables include personality, beliefs, fears, prejudices, locus of control and lifestyle. In relation to diabetes, the patient has health beliefs, ideas and perceptions of the disease and its treatment. In the classic model, not all of these factors are taken into account. Obedient adherence to the indications of the HCP is all that is expected from the patient. However, evidence has demonstrated that far fewer than half of patients follow prescriptions. Basic knowledge has proved to be very important for the patient, but is not sufficient for changes in established habits and behaviour in daily life.

In the TPE model, patients have an active role and their psychosocial factors are extremely important. According to Anne Lacroix,<sup>4</sup> someone faced with having a chronic disease passes through four stages before active acceptance: shock and temporary disbelief; revolt; bargaining; and sadness and depression. These stages are marked by different kinds of emotions, fears and questions that should be taken into consideration by the HCP and integrated into treatment strategies. The patient is no longer the object of treatment but instead plays a part in the outcome. He or she becomes part of the team and part of the solution. Goals are agreed as a result of patient input and the HCP's biomedical objectives. A negotiation process takes place where both parties listen to each other. This therapeutic relationship is the central treatment factor in moving from non-adherence to active participation. The patient takes care of him or herself and will, step by step, become aware of the consequences of his or her actions in collaboration with the health team. Active participation does not necessarily equal adherence to treatment, but it is a good starting point.

### Instruments of Therapeutic Patient Education

Treatment efficiency depends on TPE and this education demands specialised long-term follow-up with interactive strategies. These strategies can be acquired only through the professional training of HCPs, including physicians, nurses, physiotherapists, dieticians and social workers.

### The Diabetes Education Study Group

The Diabetes Education Study Group (DESG) was founded in 1979 by Jean-Philippe Assal and became one of the 15 study groups of the European Association for the Study of Diabetes (EASD). Trying to gather all those involved in the TPE process, the DESG has changed its name and symbol several times, but only 'Diabetes Education Study Group' seemed to include all of the participants – doctors, patients, nurses, educators, to name a few – and all their intrinsic processes and relationships. The DESG's symbol also evolved into its present form, representing a triangle composed of three forces, again in an attempt to show all the interactivity between all of the TPE's variables: diabetes, physician and patient; diet, insulin and exercise and medical, educational and psychosocial.

The DESG stated its aims as being the development and evaluation of educational programmes with the final objective of increasing the quality of life of the diabetic patient by: promoting his/her independence; improving metabolic control; underlining the importance of prevention; and early recognition of the disease. Another of the DESG's main aims is to encourage relevant research. In order to raise awareness of the importance of TPE and the empowerment model in the management of chronic diseases, particularly diabetes, the DESG regularly produces educational material aimed at HCPs and patients. These cover different areas of TPE in diabetes such as foot care, blood glucose monitoring and weight loss. All of these materials, initially produced in English, are currently being translated into several languages and are available for download from the DESG's website ([www.desg.org](http://www.desg.org)). One of the most important documents produced was the *Basic Curriculum for Therapeutic Patient Education*.<sup>5</sup>

Furthermore, the DESG organises an annual workshop for members of the General Committee, promoting the sharing of knowledge and exchange of experience. Currently, the DESG has more than 1,000

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members. These are mainly physicians, nurses, dieticians and psychologists. Its General Committee has 56 members representing 32 countries throughout Europe and geographically related countries. In some of these countries, associations have close contact with the DESG and organise activities in the DESG's name, such as the French Diabète Education de Langue Française (DELFF), the Italian Gruppo

Italiano di Studio per l'Educazione sul Diabete (GISED), the Portuguese Associação Protectora dos Diabéticos de Portugal (APDP), the Catalan

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**Conclusion**

As a model for chronic diseases, diabetes mellitus has shown the inefficiency of current education models used by the majority of HCPs. The evolution from medicine focused on acute disease and based on

physical symptoms towards chronic diseases, such as diabetes, where most care is carried out by patients themselves, has created the need for a new model of care. The concept of TPE acknowledges the role of education as a 'therapeutic means' with the additional benefit of conventional therapeutic measures. With 'empowerment', patients have to take charge of their responsibilities, help to define therapeutic goals in an informed way and choose the appropriate strategies to achieve them.

In this new scenario, HCPs need to redefine their role in the therapeutic relationship to avoid the frustration of poor results in their daily clinical practice. This challenge is not new. If patients did not have to inject themselves, it would not have been necessary to create such a health structure. Despite our faith in technology, pharmacology and genetic manipulation, we should not forget the complexity of human nature. Medical care will always need to be focused on the on their cultural, social and family context. This is the challenge for all HCPs in the future: to be able to integrate new biomedical knowledge into the social sciences that aim to understand humans and their complexity. ■

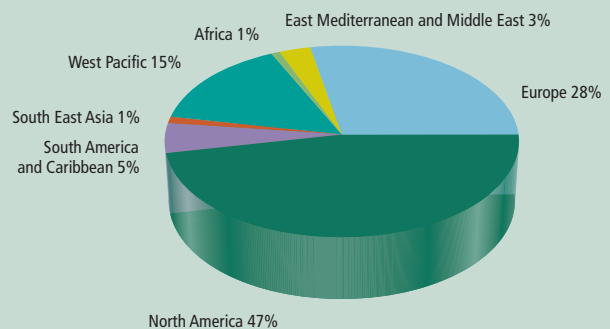
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**Spotlight – Diabetes**

- North America, Europe and Western Pacific Asia have the highest prevalence of diabetes, largely as a result of increasing obesity, which is responsible for 78% of diabetes cases.
- In Western Europe, 15% of heart attacks result from diabetes; in Central and Eastern Europe the figure is 9%.
- Sustained elevation of blood glucose causes most severe tissue damage to the kidneys, eyes, peripheral nerves and vascular tree.
- In The Netherlands, diabetes costs are 2.5% of the total healthcare budget. The financial burden of type 2 diabetes in the UK is 4.9% of the nation's healthcare budget.
- The annual global cost of diabetes is currently estimated to be at least US\$153 billion. By 2025, the International Diabetes Federation (IDF) predicts healthcare expenditure of between US\$213 billion and US\$396 billion – between 7 and 13% of the global healthcare expenditure. High prevalence countries such as Nauru could spend up to 40% of their budget managing the disease.
- The developed world will suffer a 140% increase in diabetes prevalence by 2025, compared with a 40% increase in the developing world.

Sources: International Diabetes Federation, World Health Organisation, Alliance for European Diabetes Research, European Association for the Study of Diabetes.

**Cost of Diabetes Worldwide by Region in 2003**



**Percentage Prevalence of Total Population**

