MORE INFORMATION

The DAWN™ website provides a meeting point for DAWN™ stakeholders and features the latest news about DAWN™ initiatives and actions around the world. To find useful information about the study results, inspiring video testimonials, DAWN tools and publications, please visit dawnstudy.com.
DAWN™
Diabetes Attitudes Wishes & Needs
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• The DAWN™ International Advisory Board convened.

• 2001 2005 2008 2011

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• First global DAWN™ Nurse Dialogue Event in Israel with participation of 280 diabetes nurse specialists from 18 countries.
• Establishment of EDID: European Depression in Diabetes Research Consortium.
• 1st DAWN™ Award was given to Assistance to Young Diabetes (AYD) – an education and support project for Egyptian children.
• 2nd DAWN™ Summit in London. Participants from 33 countries and multiple partner organisations convened to develop the global DAWN™ Call to Action.
• 3rd International DAWN™ Summit in Florence as a partnership with the Therapeutic Patient Education (TPE) Congress setting the stage for the implementation of practical and research oriented initiatives. Participation of 900 delegates from 64 countries.
• At the summit, about 45 national best practices implementing the DAWN™ Call to Action were presented; either as plenum presentations or posters.
• Initiation of the DAWN™ Youth and DAWN™ MIND™ international studies.
• Release of the global type 2 diabetes guidelines including a section on psychosocial issues.
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• At the summit, about 45 national best practices implementing the DAWN™ Call to Action were presented; either as plenum presentations or posters.

MILESTONES FOR DAWN™ DURING THE LAST 10 YEARS

2001
• The DAWN™ study carried out covering 13 countries and qualitative focus groups undertaken in 8 countries.
• The DAWN™ International Advisory Board convened.

2002
• 1st DAWN™ Summit in London. Participants from 33 countries and multiple partner organisations convened to develop the global DAWN™ Call to Action.

2003
• First global DAWN™ Nurse Dialogue Event in Israel with participation of 280 diabetes nurse specialists from 18 countries.

2004
• Establishment of EDID: European Depression in Diabetes Research Consortium.

2005
• 1st DAWN™ Award was given to Assistance to Young Diabetes (AYD) – an education and support project for Egyptian children.

2006
• A special issue of Diabetes Voice on DAWN™ published by IDF and distributed to stakeholders in 160 member countries.
• DAWN™ results published in a large number of scientific journals including: Clinical Diabetes, Diabetologia, Diabetes Care and Diabetic Medicine.
• Development of the DAWN™ ‘Train the Trainer’ programme: The DAWN™ facilitators’ toolkit.
• Development of the DAWN™ ‘Train the Trainer’ programme: The DAWN™ facilitators’ toolkit.

2007
• Initiation of the DAWN™ Youth and DAWN™ MIND™ international studies.
• Release of the global type 2 diabetes guidelines including a section on psychosocial issues.
• A unique minority support programme in Scotland was highlighted with the 2nd DAWN™ Award supporting ethnic minorities failing to manage their diabetes.

2008
• 4th International DAWN™ Summit in Budapest as a partnership with the Therapeutic Patient Education (TPE) establishment of a global effort to monitor quality of life and perceptions of people with diabetes.
• More than 600 leading experts from 40 countries shared visions, successful projects and state-of-the-art patient research.
• 3rd DAWN™ Award was given to the Bharti Hospital, India for a project on coping skills strategies for youth.

2009
• Launch of the final DAWN™ Youth results and implementation of the five action goals for DAWN™ Youth.
• Media Roundtable in Rome on the DAWN™ Youth findings, with special focus on family relations and school support.
• Publication of the DAWN™ MIND™ study in Diabetes Care.
• National implementation of DAWN™ MIND™ Youth in the Netherlands.
• Release of the toolbox for national diabetes programmes with a dedicated section on psychosocial issues.

2010
• A good life with diabetes developed as the first international evidence-based, psychological self-help positive coping programme for people with diabetes.

2011
• Launch of the global DAWN™ You study, the world’s largest study of its kind, involving key stakeholders in diabetes management in 18 countries.
• DAWN™ MIND™ developed into a practical online tool to evaluate quality of life as part of routine diabetes care. Launched in Denmark involving eight diabetes centres.

• Launch of the global DAWN™ 2 study, the world’s largest study of its kind, involving key stakeholders in diabetes management in 18 countries.
• DAWN™ MIND™ developed into a practical online tool to evaluate quality of life as part of routine diabetes care. Launched in Denmark involving eight diabetes centres.
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INTRODUCTION

Approaching 300 million people in the world today have diabetes1, but despite the improving quality and availability of treatment, most of them are still not achieving optimum blood sugar control. Diabetes is a demanding disease that is largely managed on a day-to-day basis by patients themselves. This generates a lot of stress, embarrassment and even discrimination, making normal working lives difficult. Diabetes often leads to depression, with problems frequently spreading to other family members. In many cultures, the disease is still seen as so debilitating that people with diabetes have no hope of leading healthy, productive lives.

This book documents the efforts made all over the world under the DAWN programme in the first ten years of this century, to alleviate the emotional distress and suffering caused by diabetes. DAWN is the first initiative to collect large-scale evidence on the impact of diabetes on daily life, and how distress often limits the ability of people with diabetes to maintain effective self-management. Diabetes is a demanding disease that is largely managed on a day-to-day basis by patients themselves. This generates a lot of stress, embarrassment and even discrimination, making normal working lives difficult. Diabetes often leads to depression, with problems frequently spreading to other family members. In many cultures, the disease is still seen as so debilitating that people with diabetes have no hope of leading healthy, productive lives.

Now, in 2011, it is time to reflect on the decade that has passed and the many significant initiatives around the world that help to bring the DAWN Call to Action into practice. Despite the many challenges still faced by people with diabetes, positive developments in the area of patient-centred diabetes care, and especially self-management education and support, raise hope for significant developments in the decade to come.

The global DAWN 2 study will build on the wealth of insights, psychosocial studies, intervention programmes and awareness campaigns that have taken place in the wake of DAWN. The new global DAWN 2 study sets the stage for the next decade, which will construct a far more detailed picture of how patients can be supported at the centre of a network of care – both medical and psychosocial.

From its beginning in 2001, DAWN has developed through four International Summits and one DAWN Youth Summit especially for young people with diabetes. It has been guided in that journey by international diabetes experts, organisations and patient advocates, who have brought a wealth of experience in the many aspects of diabetes care.

The global DAWN 2 study will build on the wealth of insights, psychosocial studies, intervention programmes and awareness campaigns that have taken place in the wake of DAWN. The new global DAWN 2 study sets the stage for the next decade, which will construct a far more detailed picture of how patients can be supported at the centre of a network of care – both medical and psychosocial.

The International Charter

That is why the International Diabetes Federation (IDF) has developed its International Charter of Rights and Responsibilities for People with Diabetes1. People with diabetes should share the same human and social rights as people who do not have diabetes. The Charter is needed, to set a gold standard of principles on their fundamental rights. It aims:

- to optimise the health and quality of life of people with diabetes
- to enable the person with diabetes to have as normal a life as possible
- to reduce or eliminate barriers preventing the person with diabetes from realising his/her full potential as a member of society.

In return for these rights, people with diabetes have rights to:

- keep their healthcare providers fully informed on their state of health, medication and lifestyle behaviour, to manage their agreed treatment plan, and to implement and monitor a healthy lifestyle as part of that self-management. Any problems in maintaining the treatment should be shared with their healthcare providers, and that includes psychosocial barriers. And family, school, work and social colleagues should be told they have diabetes, so they can be supportive when and if they are needed.
- to optimise their treatment plan, and to implement and monitor a healthy lifestyle as part of that self-management. Any problems in maintaining the treatment should be shared with their healthcare providers, and that includes psychosocial barriers. And family, school, work and social colleagues should be told they have diabetes, so they can be supportive when and if they are needed.
- to optimise the health and quality of life of people with diabetes
- to enable the person with diabetes to have as normal a life as possible
- to reduce or eliminate barriers preventing the person with diabetes from realising his/her full potential as a member of society.

For the above rights to be realised, people with diabetes also have responsibilities – to keep their healthcare providers fully informed on their state of health, medication and lifestyle behaviour, to manage their agreed treatment plan, and to implement and monitor a healthy lifestyle as part of that self-management. Any problems in maintaining the treatment should be shared with their healthcare providers, and that includes psychosocial barriers. And family, school, work and social colleagues should be told they have diabetes, so they can be supportive when and if they are needed.

Raising awareness about the rights of people with diabetes is a key element of IDFs call for coordinated and concerted international action to tackle the diabetes epidemic. It is the reason IDF has supported the key messages of the DAWN initiative since its inception in 2001. DAWN has contributed so much to a wider understanding of the difficulties people with diabetes face and helped inspire initiatives throughout the world towards solving them. The DAWN 2 initiative provides a unique opportunity, on an international scale, to highlight again, to all the stakeholders in diabetes, how far we have come in realising the rights of people with diabetes to live a normal life, and what we have to do to still improve further.

Author: Dr Wim Wientjens, Vice President, International Diabetes Federation (IDF) Special Ambassador 2010–2012 for the Rights and Responsibilities of People with Diabetes.
Most day-to-day care for diabetes comes from patients themselves. This is demanding, as it requires constant attention, every day of the year. To manage diabetes successfully, people with diabetes depend on support from many different sources. They depend on access to proper healthcare and treatment, and also on access to the right kind of emotional, social and societal support to live full and healthy lives.

Everyone has a role to play in making life better for people with diabetes. The starting point for change is an understanding of their needs.

The ‘patient needs’ model, on the next page, is one of several developed from the DAWN study results and highlights these key needs. The model illustrates the different types of support from family, friends, healthcare, work, school and society at large.

Naturally, the needs outlined here vary in importance according to circumstances and location of the person with diabetes.

Within the model, it is possible to examine the problems and the resources of support that are presented to a person with diabetes from each of these layers. Starting with the person with diabetes at the centre, the model highlights needs in relation to:

- **Me**: Many people with diabetes are anxious about their diabetes getting worse, about it restricting what they want to do or about their weight. These anxieties interfere with self-management, and only half of young people can cope emotionally with their diabetes.

- **Family and friends**: A stable home life helps diabetes patients of all ages to manage, but they can still worry excessively about financially dependent relatives and the future. Young people often suffer over-protective or nagging parents, while others have little support from parents.

- **Medical care and treatment**: Patients do trust their healthcare team, and need easy access to well-trained doctors and nurses, specialists and psychologists. HCPs should help to allay patients’ fears of insulin, and communicate effectively with other team members. Ideally HCPs should be easy to talk to, give enough time, discuss emotional problems, help their patients to overcome their fears and involve them in decision-making. Many patients feel their medication is too complicated. They should also give access to professional psychological support where needed.

- **Work/School**: Both employers and schools should offer time out and a place for treatment, snacks and exercise. Over half of young people with diabetes miss work or school, or perform less well, and often worry about finding or keeping employment. Teachers of young children with diabetes should be better informed about diabetes and its emergencies.

- **Living**: Over a third of adults with diabetes feel it prevents them from doing what they want. Changes to diet and exercise patterns; even basic self-care for those with diabetes complications need support from HCPs, dieticians, the community or friends and family. Patients also benefit greatly from contact with other people with diabetes, through support groups, online communities or youth camps.

- **Society**: People with diabetes need equal opportunities in healthcare, employment and education; without discrimination, stigma or embarrassment. The healthcare system should provide accessible and affordable diabetes care – four out of five HCPs in the DAWN study called for a higher priority for diabetes in their systems, and for better care in the transition from paediatric to adult services.

© Novo Nordisk 2011 Patient Needs Model based on the DAWN study

### Patient Needs Model

- **Me**: Being able to cope with my condition, and living a full, healthy and productive life

- **Community**: Medical care and treatment: Access to quality diagnosis, treatment, care and information

- **Work/School**: Obtaining support for, and understanding of, my condition

- **Living**: Having the same opportunities to enjoy life as everybody else

- **Family and friends**: Emotional and practical support in all aspects of my condition

- **Society**: A healthcare system, government and public willing to listen, and to change, to be supportive of my condition
THE DAWN PROGRAMME

DAWN is about Diabetes Attitudes, Wishes and Needs initiated by Novo Nordisk in partnership with the International Diabetes Federation (IDF) and an international advisory panel of leading diabetes experts and patient advocates in 2001, the first DAWN study became the largest study of its kind carried out to uncover the psychosocial challenges faced by people with diabetes and the people helping them, and explore new avenues for improving care.

The study was undertaken in response to the fact that despite the availability of effective therapies, less than half of people with diabetes were achieving adequate glycaemic control. It was realised by the funding organisations and experts that new global and national knowledge was needed, taking a 360° view, to explore the barriers limiting more effective delivery of diabetes care and ongoing support to those in need. At that time there were no global studies like this, focusing on the non-medical attitudinal and psychosocial aspects of diabetes management in multiple countries.

A multi-stakeholder approach to better diabetes care

The DAWN study set out to identify the barriers and facilitators of effective self-management and to shed light on the wishes and needs of people with diabetes and their healthcare providers. Through the strong endorsement of key organisations and thought leaders in the field, DAWN grew into a global framework of studies and collaborative initiatives, translating the insight gained from the DAWN study into a wide range of actions including publications, advocacy, new research and sharing of best practices.

Several multinational efforts were undertaken in follow-up to the DAWN study, including the DAWN Youth study on the needs of children and young people with diabetes and their families, DAWN surveys in Asia, and the DAWN MIND initiative, facilitating monitoring of wellbeing of people with diabetes as part of their regular diabetes care. Since the original study, the DAWN study findings have been cited by more than 300 scientific publications worldwide.

The DAWN advocacy programme works in partnership with other organisations in the diabetes community worldwide to call for concerted action to promote people-centred diabetes care and overcome the psychosocial barriers to effective self-management. It offers understanding that has since been built into national and international care guidelines, and inspired practical tools and best practices across the world. Among these are national training programmes for primary care physicians on the psychological aspects of care, and quality-of-life questionnaires for people with diabetes that are now used by many countries in routine health evaluations.

In 2011, a new era of the DAWN initiative begins with the launch of the 18-country DAWN 2 study.

DAWN STUDY, 2001

The first and largest study of its kind to date, the DAWN study set out to determine how and why more than half of people with diabetes do not achieve optimal glycaemic control and a good quality of life, despite the availability of effective therapy. The study examined the many factors influencing self-management and quality of life among people with diabetes, the quality of their relationships with healthcare professionals (HCPs), the level of collaboration among HCPs in the care team, and the barriers preventing access to and use of effective therapy.

The 13-country study was carried out through telephone and face-to-face interviews with 5,426 diabetes patients (half type 1, half type 2) and almost 4,000 healthcare professionals and policymakers. Respondents were from Australia, Denmark, France, Germany, India, Japan, Norway, Poland, Spain, Sweden, the Netherlands, the UK and the USA.

Diabetes-related stress hinders self-management

Most people with diabetes felt that diabetes is demanding and prevents them from doing what they want; many said they did not follow all their prescribed treatment. HCPs recognised that psychological issues strongly influence how well patients manage their diabetes – only 8% of HCPs felt that type 1 patients followed treatment fully; and 3% for type 2 patients1.12.

Diabetes-related emotional distress is common – over 40% of patients reported poor psychological wellbeing1,13. Doctors recognised that this distress interfered with effective self-management1,14, and more than a third of HCPs did not feel adequately equipped to address patients’ psychological needs.

Nurses were more likely than doctors to recognise problems and respond to them1,12.

Better communication is needed

HCPs felt they did not have enough time for talking with their patients, and often had different views on the problems of managing diabetes. Almost two thirds of HCPs said they would like to communicate better with their patients and to increase their understanding of psychosocial issues and different cultures1,12.

Most patients saw only one or two HCPs about their diabetes, and less than half believed that their problems were discussed between care team members, although type 1 patients were twice as likely to have access to a larger team1,12. HCPs generally recognised that more effective communication is needed within the diabetes team1,12.

The possibility of insulin treatment was a worry to more than half of the type 2 patients; half believed that starting insulin meant they had failed to manage their diabetes. Only one in five believed that insulin would help them manage their diabetes better1,13. Many HCPs were also reluctant to start insulin and a third of them postponed insulin as absolutely essential1,12. Some even used insulin as a threat to encourage diet and exercise1,13.

The findings of the study prompted the identification of five goals that shape the DAWN programme today. Together, these goals form the DAWN Call to Action:

- enhance communication between people with diabetes and healthcare providers
- promote communication and coordination between healthcare providers
- promote active self-management
- reduce barriers to effective therapy
- enable better psychological care for people with diabetes.
DAWN Youth is an international framework enabling initiatives in individual countries to improve psychosocial support for young people with diabetes. The DAWN Youth initiative was initiated in partnership with the International Society for Paediatric and Adolescent Diabetes (ISPAD), IDF and an international DAWN Youth advisory board composed of patient advocates and experts in paediatric diabetes. Its key priority areas were defined at the 2007 International DAWN Youth Summit as support for children with diabetes in schools; age-appropriate diabetes education and psychosocial care, and support for parents and families. The DAWN Youth WebTalk survey, carried out in Brazil, Denmark, Germany, Italy, Japan, the Netherlands, Spain and the USA explored the attitudes, wishes and needs of a total of almost 7,000 young adults with diabetes, parents and carers of children with diabetes, and HCPS. A separate Fact-Finding survey examined national strategies supporting young people with diabetes and their families.

Diabetes causes problems at school and at work

About half of the young people surveyed missed work or school at least once a year because of diabetes, and it affected their performance, caused embarrassment, discrimination and affected their friendships. Many parents or carers had to reduce or give up work to care for a child with diabetes, and almost half suffered financial problems. About 20% of the young adults surveyed were not happy with their treatment at school, and together with parents and almost 90% of HCPS, called for urgent improvement in schools’ understanding of diabetes, especially emergencies.

Only half of young people with diabetes achieved adequate blood glucose control. Depression and anxiety were common, and almost 20% were referred to psychologists. Only 20% of the HCPS routinely used structured psychosocial assessment, although most would be willing to do so and over 80% felt that healthcare teams should offer better psychosocial support. One third of young people with diabetes were not satisfied with resources available for treating their diabetes, and over 85% of HCPS called for more effective transition from paediatric to adult care.

Most support for young people with diabetes came from parents and spouses, followed by siblings and friends, and least from their schools and the community. Only a third of parents talked to their HCPS. Two thirds of young adults, parents and carers also used online discussion groups or camps, and most HCPS (70%) supported networking.

DAWN YOUTH CALL TO ACTION

Based on the study findings from the WebTalk and the Fact-Finding study, the following action areas were defined:

- improving support for children with diabetes in schools
- providing age-appropriate education and psychosocial diabetes care
- supporting parents and families
- peer support and networking for young people with diabetes
- addressing obesity and type 2 diabetes in young people.

DAWN Youth in action

Since the surveys, the results have inspired further research, initiatives to improve diabetes support in schools, national policy reforms and public awareness campaigns. Diabetes camps, particularly in Germany and the USA, have provided practical knowledge and confidence-building for young people with diabetes.

DAWN MIND (Monitoring Individual Needs in Diabetes) set out to implement and evaluate the monitoring of emotional wellbeing in people with diabetes. It is one of the most significant initiatives to address the DAWN Call to Action, and gave rise to the DAWN MIND tool (see page 60).

Regular checks lead to better self-care

A number of formal evaluation methods have already been developed to assess psychosocial problems, and it is known that regular assessment promotes better patient care. The DAWN and DAWN Youth surveys showed that few HCPS were using structured psychosocial assessment methods, but most would consider doing so. In order to determine the level of support that patients need, which changes from time to time, it is essential that their psychological needs are assessed as a part of regular care.

The DAWN MIND assessment tool consists of the validated psychological assessment tools for wellbeing (WHO-5) and diabetes-related distress (PAID) (see pages 50–51), plus a general questionnaire. A study to evaluate and test it was conducted with more than 1,500 patients in Croatia, Denmark, Germany, Ireland, Israel, Luxembourg, Poland, Spain and the UK. The results confirmed that almost a quarter of diabetes patients in all countries suffered from either depressive symptoms or high diabetes-related distress. More than three quarters of these emotional problems were newly identified, and all of those assessed as in need of psychological care responded positively to discussing their scores. This suggests that a large proportion of people with diabetes are not receiving attention to their psychological needs alongside their medical treatment.

DAWN MIND in action

The DAWN MIND online tool is now ready for implementation to encourage and accelerate the adoption of psychological needs assessment into routine care. This action endorses the recommendation by IDF of annual psychosocial assessment in its guidelines for care of type 2 diabetes.

A special DAWN MIND Youth initiative (DM-Y) has also been developed to extend DAWN MIND to young people with diabetes and their families. DM-Y includes the questionnaire, a web-based software program to complete and evaluate it, evidence-based pre- to in-service training for HCPS and a manual for HCPS on scoring the results and communicating effectively with patients (see page 61).
2002 – Recognising the problem
The First DAWN Summit in 2002 brought together healthcare professionals, behavioural scientists, patients and policymakers from many parts of the world to consider the implications of the DAWN study, and decide how to put its recommendations into practice. The Summit established that much improvement was needed in the professional training and procedures of HCPs, and there was a general lack of awareness and leadership from health policymakers. Patient education was inadequate, and the awareness and understanding of diabetes in the general population was low. A multi-dimensional approach was therefore needed to address all these separate issues.

2003 – Calling for action
In 2003 the Second Summit attracted diabetes experts and policymakers from 32 countries, with the involvement of the IDF and other key organisations. Participants examined potential ways to use the DAWN study findings to achieve better care for people with diabetes and studied reports from programmes already implementing the findings. The Summit adopted the worldwide DAWN Call to Action with five specific goals: to tackle inadequate communication between patients and healthcare professionals, to improve multidisciplinary care, to support self-management, to address emotional barriers to effective treatment, and to help HCPs provide better psychological care in diabetes.

2006 – Widespread implementation
The Third Summit, held in 2006 with support from WHO, IDF, EASD, FEND, and the Italian Diabetes Society, linked with the 2006 Therapeutic Patient Education (TPE) Congress. It focused on large-scale implementation of the Call to Action through both practical initiatives and further research; outlining plans for DAWN Youth. Many examples of diabetes care in different countries illustrated how innovative tools and systems were being introduced and were beginning to improve patient-centred care. But participants agreed that the majority of diabetes patients still did not receive optimal care.

2008 – Results and commitment
The Fourth DAWN Summit in 2008, again linked with the TPE Congress, was able to see the results of the DAWN MIND and DAWN Youth initiatives. The DAWN MIND study showed that the psychological needs of diabetes patients are often neglected and demonstrated the DAWN MIND tool as an easy way for HCPs to build psychosocial monitoring into routine care. The DAWN Youth study revealed the special, largely unmet needs of young people in school and work, and also of their families. As a result of the Summit, organisations and delegations made commitments to monitor and publish information on the progress of countries worldwide in patient-centred diabetes care.
The findings of the DAWN study prompted the identification of five goals that form the DAWN Call to Action. The essence of DAWN, it was developed at the First two DAWN Summits in 2002 and 2003, and has won endorsement from diabetes organisations worldwide. The DAWN Call to Action defines the key action areas of DAWN:

- **Goal 1:** Improving communication between people with diabetes and healthcare professionals
  Understanding and addressing psychosocial problems needs effective communication between doctor and patient. People with diabetes need to be supported in taking responsibility and in conveying their medical and social needs. HCPs should develop their skills in motivating and empowering patients to become more active partners in the relationship.

- **Goal 2:** Improving team-based care and communication between healthcare professionals
  Effective management of a condition as complex as diabetes requires input from a wide range of medical professionals – primary care doctor, diabetes specialist, nurse, dietitian, ophthalmologist, podiatrist, psychologist and sometimes other specialists. Because it is a long-term, chronic condition, the skills of many of these HCPs will be needed as part of a coordinated, multidisciplinary team. Each member should be aware of the importance of dialogue between them, and be guided by a strategy to ensure a coherent, integrated approach to optimising treatment for the individual patient.

- **Goal 3:** Providing individual support for more active self-management and a healthier lifestyle
  The success of the diabetes care team in motivating and supporting active self-management is central to achieving effective care and good outcomes. HCPs should take the patient’s individual circumstances, needs, resources and problems into account when creating treatment plans, since this is essential if they are to be followed effectively.

- **Goal 4:** Overcoming psychosocial barriers to optimal therapy, in both patients and HCPs
  HCPs should be aware of the value of ensuring rather than postponing effective treatment at an early stage of diabetes, in delaying or preventing the onset of complications. Acting in partnership, they should make sure that patients have the information and support needed to make informed decisions about the reasons for intensifying treatment. This means that HCPs should keep themselves and patients fully informed about the diabetes treatment options that would best suit individual lifestyles and treatment needs.

- **Goal 5:** Enabling HCPs to assess and address patients’ needs for psychological support and treatment
  While many people with diabetes cope with it well and live normal, healthy lives, DAWN studies have shown that many others suffer emotional stresses and do not benefit from even basic psychosocial support. The problem is not just one of access to specialist psychologist support. Instead it is vital that HCPs in primary care should be more aware of psychosocial problems and given the information and training to be able to detect them. In many cases they are then able to provide the level of support needed to overcome the problem, or otherwise to refer patients for specialist psychological counselling and support.
Healthcare provider-patient relationships are critical

Although the individual with diabetes makes all the important decisions that affect the daily course of their disease, these decisions are informed by their consultations with healthcare providers. Healthcare providers can provide up-to-date, evidence-based information on what is likely to be the best medication regimen for the management of diabetes, the effects of different dietary approaches, how activity affects diabetes control, and how to use different monitoring tools (blood glucose, urine glucose, blood pressure) to inform their decisions.

Therefore, constructive relationships between people with diabetes, their carers and healthcare providers are critical, to make the most of the healthcare team’s expertise. The person with diabetes could have to manage relationships with a number of different healthcare professionals in his medical team. The nature of these relationships, and how they are perceived by the individual, is critical to how he makes sense of all the information, advice and support given.

A paradigm shift

At the time of the DAWN study in 2001, possibly the most important relevant issue was the debate around empowerment, and the perceived disempowering nature of interactions with health professionals. The importance of this issue is possibly best highlighted by the UK’s National Service Framework for Diabetes (NSF), published in 2001. This set clear quality requirements for care, based on the best available evidence of the most effective treatments and services. It articulated the National Health Service’s intentions on empowerment of people with diabetes as a core standard for diabetes care:

Goal: Patient and professional communication ensures that patients feel able to participate in the decision-making process for their health-related treatment decisions.

This third core standard comes before the standards relating to clinical care. Its emphasis on encouraging partnership and shared decision-making was, and continues to be, a challenge for a paradigm shift for diabetes care, as policy and evidence pointed to the need for professionals to move away from their authoritarian and acute care model of diabetes care.

The DAWN study was apposite to the debate around empowerment and the patient-provider relationship. According to the DAWN study, most patients (88.8%) felt that their relationship with their provider was good. However, this was countered by the high number of providers reporting a need for better understanding of different cultures and the psychosocial issues their patients were facing. Other research has shown the importance of effective communication for optimal treatment outcomes. The DAWN study revealed major differences in perspectives on diabetes management between medical professionals and patients.

Developments since the Call to Action

Since then, studies on the relationships between people with diabetes and their healthcare team have grown, but have largely moved towards attempts to change the nature of the interaction between the provider and patient living with diabetes. The use of patient-centred communication techniques, such as asking patients what they find hardest about managing their diabetes, and what they view as successes and failures in making treatment plans, has been shown to improve patient-provider understanding. The patient-provider relationship is also enhanced by offering diabetes education, to enable the patient to be more informed and develop a more effective interaction with the HCP, with mutual agreement of goals.

Attempts to change the behaviour of healthcare professionals have had limited success, but many have also had some negative effects, suggesting a need for professionals to work collaboratively to change. However, interventions that have focused on training the person with diabetes to manage the relationship differently have been far more productive, with little if any adverse consequences, and many benefits.

I benefit from the doctor’s knowledge, but I too have an important role to play, and that role can only be effective if I know what is happening. I am the main player in this, so I have to know what I am doing because it’s for my own benefit.

Nearly every intervention in the literature is focused on training healthcare professionals, largely using trainer-centred approaches, rather than changing behaviour which is perhaps the more fundamental issue. More recently, programmes are using behaviour change methods, and more medical student approaches. The literature suggests that most consultations and educational interactions are not meeting the NSF standard of empowerment. We continue to focus on how to change this dynamic, and how to generate a paradigm shift to empowerment as the norm for diabetes care.

Why is team-based care important?
Diabetes care through a team approach has been shown to be more effective than that from a single provider, and efforts to raise the quality of care by team improvements are more effective on blood glucose control than any other quality improvement.1 But the DAWN study revealed that primary care physicians noted a lack of routine multidisciplinary care and a need for more support. Nurses reported that they generally provided better education, spent more time with patients, were better listeners, provided support to family and came to know patients better than physicians.2

However many nurses reported that their expertise was not valued and their skills underused. As only a third of diabetes specialist nurses were managing medication, nurses and physicians in the DAWN study agreed that nurses should take on a larger role in diabetes management. Most were willing to embrace more responsibility, but out of the patients who had better outcomes when they had access to a nurse, less than half had nurses’ services available.3

While the DAWN study confirmed that physicians and patients recognise the importance of team management, including nurses, dieticians and pharmacists, it is rarely available in primary care where 90% of diabetes care is provided. Only 60% of the patients with type 2 diabetes had all team members in one location, and fewer than 50% of patients reported that their healthcare team members communicated with one another. Patients who reported better access to healthcare had better diabetes control, better adherence, and lower stress, regardless of their type of diabetes. Also, patients who reported a better relationship with their healthcare professional had better diabetes control, better adherence, and less diabetes distress. Patients with good support systems from their community, spouse, or children were also taking medication more consistently.4

Developments since the Call to Action
At the time of the DAWN study, healthcare providers reported that their chronic care systems and remuneration were mediocre, but the care systems more highly in countries with socialised systems (eg the Nordic and Scandinavian) than in those with payer systems (eg the USA). Since the 2003 Call to Action, countries with payer systems have been exploring other models. In the USA, the chronic care model and the patient-centred medical home have been widely adopted. Both approaches focus on the delivery of team-based care, self-management and community resources. Payers and government have been enthusiastic, and in many cases are reimbursing for these models.

Self-management education is considered a critical component of diabetes care and many countries are providing training courses and workshops for diabetes educators. In many places where other disciplines were not formerly highly valued, today health systems are seeing opportunities to train and expand the role of nurses and dieticians in the diabetes team.

Non-communicable diseases (NCDs), including diabetes, have received increasing international attention since 2013. The United Nations adopted its Resolution on diabetes in 2006 and the World Health Organization has organised an NCD Summit in 2011 to address chronic care. The World Diabetes Foundation and the International Diabetes Federation are directing funds to translational research programmes studying healthcare delivery models. National and international diabetes conference symposia are addressing models for healthcare delivery and networking forums are discussing plans for sustainability, government support and widespread adoption of team-based care.

Team support strategies are also being explored, and communication, coordination and access between people with diabetes and healthcare providers are benefiting from internet and mobile phone technologies.

More challenges prevent fully functioning team support
Team-based care and Diabetes Self-Management Education are both critical in overcoming the barriers associated with the skills and complexities of diabetes management. But access, poor reimbursement, limited HCP training in psychological management, and limited time with patients are challenges still to be overcome. When these issues are addressed, patients can be educated and supported to handle their complex disease successfully.

Healthcare decision-makers and providers need to mobilise efforts to provide care of sufficient quality to meet the complex needs of people living with chronic diseases. Partnering with primary care physicians to provide patient education, patient incentives, reimbursement models for team members, and technological approaches for the creation of virtual teams are all avenues that should be explored.

You need to know your doctor, because those that don’t know you, don’t know my fears. They have loads of flashy theories but you can’t use everything on everyone. We are all different. It’s vital your doctor knows you and that you don’t see a new doctor at every visit.

Marianne, Denmark, type 1 diabetes

Managing diabetes is not easy. Diabetes is a multi-faceted, complex and demanding chronic disease. It is also largely self-managed, with about 99% of the care provided by the patient. As a result, understanding and improving self-management is essential for improving diabetes outcomes. Because of the serious nature and complexity of treating diabetes and the multiple self-care decisions required of patients, self-management has also traditionally been one of the most difficult aspects of diabetes care for both patients and healthcare professionals.

The DAWN study confirmed what many healthcare professionals already suspected: less than 20% of the patients (type 1=19.4%; type 2=16.2%) reported that they completely followed all aspects of their treatment recommendations. DAWN also provided insights about what could be done to promote and facilitate self-management. Many clinical and research efforts directed towards improving self-management since then have incorporated these findings.

Active self-management through diabetes education

Patient education has long been considered the cornerstone of self-management, and is effective for improving metabolic and psychosocial outcomes and reducing costs1. Initially, Diabetes Self-Management Education (DSME) was primarily lecture-based and disease-focused. Patients were expected to adjust their lives to deal of interest since DAWN. Effective peer-led self-management support programmes have been developed and disseminated, and other models, including the use of technology are currently being tested2.

Active self-management through continuing support

DAWN reinforced the importance of ongoing Diabetes Self Management Support (DSMS), which is now part of national and international standards for diabetes education3,4. The purpose of DSMS is to provide the psychosocial and behavioural support needed to enhance and sustain active self-management throughout a lifetime of diabetes4. Effective DSMS reflects the dynamic and evolving conditions of both the treatment of diabetes and the patient’s life circumstances, priorities and goals.

A variety of DSMS approaches have been recommended4. Clearly all members of the healthcare team have the opportunity to promote self-management at each patient encounter. Development and implementation of peer DSMS programmes have also gained a great deal of interest since DAWN. Effective peer-led self-management support programmes have been developed and disseminated, and other models, including the use of technology are currently being tested.

One of the most difficult things about diabetes is that you constantly feel guilty – are you doing well enough? Do you take your levels often enough? Do you eat properly? Exercise?

Marianne, Denmark, type 1 diabetes

Active self-management through patient-centered collaboration

Self-managements efforts have often been described as the most frustrating aspect of diabetes care. The health professional participants in DAWN indicated they believed that less than 8% of type 1 and 3% of type 2 patients followed all of their treatment recommendations2. It is difficult for healthcare professionals when they feel helpless to influence their patient’s self-management decisions, and are concerned about the long-term consequences of those choices. It is equally frustrating for people with diabetes when they feel that their needs, goals and priorities are not considered and valued, or when their self-management efforts are not recognised or do not result in hoped-for improvements.

The basis for promoting and sustaining active self-management is a collaborative partnership between patients and healthcare professionals. An empowerment-based, patient-centred communication strategy that can be used to create this type of partnership is the ALE (Ask, Listen, Empathise and Encourage) method as demonstrated in the DAWN experiment (see page 56). Self-directed behavioural goal-setting is an additional strategy for promoting active self-management. Starting an encounter by asking the patient what is hardest in terms of self-management, listening to the patient’s concerns, encouraging through additional questions or reflections and then closing the loop at the end of the visit by setting a goal, is an effective approach for promoting active self-management.

I was always afraid of doing something wrong, that I would have to go into hospital because I wasn’t doing something right, and that I would eat something I wasn’t allowed to and it would affect me; that’s my biggest fear.

Matthew, UK, type 1 diabetes

Active self-management is the result of a partnership between patients and their healthcare team. The expertise of the patient about himself, and the diabetes management expertise of health professionals are of equal importance. In this relationship, collaboration results in an effective and sustainable self-management plan. The result is decreased frustration for both patients and healthcare professionals, and more importantly: improved outcomes for people with diabetes.
Anxieties and resistance contribute to poor control
It is now understood that good clinical outcomes in diabetes are challenged by a range of psychosocial barriers, on the part of both the patient and the healthcare professional. Patients are anxious about their current and long-term health, treatment procedures, complications like hypoglycaemia, and general difficulties of coping with everyday life. The healthcare professional is often more concerned with clinical measurements and treatments than with ensuring that he understands the factors hindering the patient’s adherence to his recommendations. Two-way communication with patients is not always effective, and doctors’ reluctance to make timely use of insulin and other modern therapies in primary care is well known.

The DAWN study in 2001 was the first international study to show the effect of these barriers on clinical practice. More than half of patients with diabetes on other, less effective therapies were reluctant to begin insulin therapy. DAWN also shed light on the psychological resistance to insulin therapy among doctors. Almost half reported delaying insulin until it was ‘absolutely necessary’, and many providers, especially those in the USA, used an insulin regimen as a threat to encourage improved diet and exercise. As a consequence, many people with type 2 diabetes remained in poor control, when insulin could help them manage their diabetes more effectively.

There needs to be a strategy where if a doctor sees that, he would take time to sit down with me and counsel me, give me a way to understand that moving from oral to insulin is not the end. Had it been done the very first day, I wouldn’t have had six months of heavy burden.

Ray, USA, type 2 diabetes

Developments since the Call to Action
Since then, continued research has confirmed that key barriers persist, but numerous research initiatives in many countries have been conducted to understand the barriers further. One key study looking specifically at the use of insulin for type 2 diabetes was conducted in Japan. Doctors resisted use of insulin because they were inexperienced in initiating/inviable to support or guide patients anxious about the burden to the patient/concerned about use in the elderly/anxious about the risk of hypoglycaemia. A higher level of responses about lack of experience and resources, and worries about the difficulty of insulin initiation, was closely correlated with lower use of insulin therapy. Although more than half of these patients responded that insulin would give better glucose control, most had negative views: fear of injection or pain/fear of the reactions of other people/belief that the diabetes was getting worse/fear of hypoglycaemia. There is clearly a long way to go if these attitudes are to be overcome.

Between 2008 and 2010, the DAWN initiative has focused on evaluating and validating approaches to enable psychosocial monitoring in regular diabetes care, and cost-effective resources to help patients cope with their individual psychosocial issues. These include the DAWN MIND toolkit and the insulin dialogue toolkit developed in Japan. To overcome barriers to effective therapy, the DAWN advisory board in Japan developed a tool to promote communication, using a simplified version of the Insulin Treatment Appraisal Scale (ITAS) to understand patients’ anxieties. The tool enables not only physicians but also other HCPs to communicate more effectively with patients and providing the information that help them implement new routines (see more on pages 60–61).

A small number of countries, including Germany and the UK, have adopted patient-centred, evidence-based guidelines, and the IDF has addressed the need for measures to overcome psychosocial barriers in its guidelines for type 2 diabetes.

In the USA, DAWN studies have contributed to the position statements from the American Association of Diabetes Educators, on psychosocial issues of diabetes management, the chronic care model, and the role of pharmacists in type 2 diabetes management, and also to annual national standards for Diabetes Self-Management Education.

Putting the ideas into practice
But even where these guidelines exist, clinical practice lags behind in taking up the principles of psychosocial support. Much more of the work of DAWN is needed, in encouraging healthcare professionals to be open to the concept of partnership with the patient, and shared decision-making. One simple example would be to explain at diagnosis that diabetes is progressive, and introduce the idea of insulinisation from the start—avoiding patients interpreting the change as their own failed self-management. More action is also needed in adopting regular psychological monitoring, using psychometric tools in routine practice, training healthcare professionals to address the anxieties around insulin initiation, and improving patient education and information to empower them to meet the challenge. Patients will become more active partners in treatment decisions, and healthcare professionals will have the tools, communication skills and education to provide the best emotional and medical support, rather than a less-than-optimal, medical-focused approximation.

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GOAL 4: OVERCOMING PSYCHOSOCIAL BARRIERS TO OPTIMAL THERAPY

Author: Dr. Hitoshi Ishii, Tenri Yorozu Soudanjyo Hospital, Japan

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GOAL 5: PROVIDING PSYCHOSOCIAL SUPPORT

Author: Frank Snoek, Professor of Medical Psychology, VU University Medical Centre, The Netherlands

Balancing diabetes with daily life
Living with diabetes – like any chronic disease – can be emotionally demanding, and at times overwhelming. Some patients report they have a hard time ‘staying sane’ when experiencing the daily consequences of fluctuating blood glucose levels, despite their best efforts to stay in control of the diabetes. Patients with diabetes and their families may feel burned out at times by the demands of having to self-manage while coping at the same time with the daily stresses of everyday life. Diabetes is very definitely a balancing act.

Fortunately, although a cure for diabetes still appears to be a long way ahead, medical care for diabetes patients has improved significantly in the past decades. Better, safer medications and more convenient medical technologies are available to the patient. Still, as shown by the DAWN study, both medical and psychosocial outcomes of diabetes care are suboptimal in a substantial minority of people living with diabetes. These findings call attention to the need of providing adequate psychosocial support to patients as integral part of ongoing diabetes care.

Importantly, the DAWN study revealed that the vast majority of healthcare professionals acknowledged the importance of offering psychosocial care to their patients, but felt they lacked the necessary skills and resources. In response to these findings DAWN has taken several initiatives to help improve the quality of psychosocial care for people with diabetes. Among these are actions to raise awareness of the issue among stakeholders, promoting international guidelines and disseminating tools and training programmes. The international DAWN programme has in the past ten years provided an important, action-oriented platform to promote recognition of the psychosocial needs of people with diabetes and stimulated research in the field. DAWN has not only helped to set the agenda, but also to take action.

Developments since the Call to Action
Inspired by DAWN, several studies have been conducted confirming the high prevalence of coping problems and affective disorders in both type 1 and type 2 diabetes patients, underscoring the need to improve detection rates and mental health services. International guidelines have been developed advocating a multidisciplinary, holistic approach to diabetes, addressing both the medical and the psychological needs of patients. It is recommended that mental health experts are part of the diabetes team, to offer support to patients with psychological co-morbidities, and to assist diabetes professionals in their efforts to help patients make important behaviour changes that can significantly reduce health risks. But do these guidelines actually work in practice? Doctors are faced with increasing numbers of patients and have only a few minutes to spend with their patients. Is DAWN a reality or a dream?

I didn’t tell anyone. I went to school and told my teachers, but I asked them to keep it a secret. Sitting there in class I would worry constantly while my friends were goofing off.

To demonstrate the validity of DAWN and inspire dissemination of best practices, the multinational DAWN MIND study – Monitoring of Individual Needs in Diabetes – was initiated. I am proud to have coordinated MIND, building on our previous work and showing that monitoring and discussing wellbeing as part of the diabetes annual review significantly improves the recognition of emotional distress by diabetes professionals, and effectively helps to address the unmet needs of many patients.

A new approach that really works
The outcomes are clear: putting the IDF guidelines on psychological care into practice is feasible and actually works. Simply listening and acknowledging the emotional needs of patients is helpful for many, while others need professional psychological and psychiatric services while others need professional counselling or medication. In many countries such professional psychological and psychiatric services are scarce, underscoring the need to seek innovative ways to expand their reach at low cost; for example by offering peer support programmes, e-learning modules and web-based psychological support. New times are ahead of us, presenting new challenges, raising new questions, prompting us to search for new answers.

This is exactly what DAWN is about. Hopefully the findings will inspire patients, professionals and policymakers to set the stage for the coming years, securing psychosocial support for all people with diabetes. To quote the World Health Organization: “Mental health is an integral part of health; indeed, there is no health without mental health.”

Nobody else I knew had diabetes. I walked about almost in a coma. To me it felt like I’d been kicked out of normal society. It came as a shock to be kicked out of society.

Dana, USA, type 2 diabetes


Learn to live in harmony with your diabetes

Rogério has type 2 diabetes

Six strategies were recommended by the DAWN International Advisory Board\(^\text{1}\), to achieve the DAWN goals for improving psychosocial care in diabetes:

**Strategy 1: Raise awareness and build concerted advocacy and action**

It is vital that the importance of the emotional aspects of diabetes becomes better known, both in the medical profession and the general public. Individuals and organisations who are knowledgeable about the need for, and benefits of providing psychosocial support for people with diabetes should actively work to spread that awareness with colleagues and the general public. This principle has been put into action by DAWN Youth’s Young Voices – young people with diabetes using their own experience to raise awareness.

**Strategy 2: Educate and mobilise people with diabetes**

Diabetes patients and people at risk of diabetes need a wide range of information to help them make informed decisions about their health, treatment and quality of life. Information can empower and motivate them to take effective control of the condition, so they need all available information about new approaches, tools, and guidelines to support patient-centred care. As the major task of care falls to patients themselves, the patients need to be (and are) the experts, making use of printed, television and internet sources.

**Strategy 3: Train healthcare providers and enhance their abilities**

Diabetes treatment often meets psychosocial problems which hamper patients’ attempts at self-management. It is important to find better ways to identify these problems at an early stage, and to address them in the primary care setting. Healthcare professionals providing diabetes care should be offered training in communication, motivation and identification of psychological problems. The attitudes of HCPs towards patient-centred care are crucial to its success\(^\text{2}\).

**Strategy 4: Implement practical tools and systems**

Identifying the psychosocial and educational needs of people with diabetes calls for effective listening and communication skills in healthcare professionals. Simple, non-invasive tools are invaluable to help them to build psychological monitoring into routine practice\(^\text{3}\). These are best used as an integral part of comprehensive diabetes care, in the hands of competent healthcare professionals.

**Strategy 5: Promote policy and healthcare system changes**

The psychosocial wellbeing of people with diabetes should be granted the same priority as their medical needs, within diabetes management guidelines, reimbursement systems, and healthcare quality systems. Adoption of the chronic care model supported by the World Health Organization\(^\text{4}\) should be advocated with governments and healthcare policymakers. A number of countries have adopted psychosocial chapters into diabetes care guidelines, as well as the IDF global guideline for type 2 diabetes\(^\text{5}\). The challenge remains to build those guidelines into clinical routine.

**Strategy 6: Take part in psychosocial research in diabetes**

Further collaborative clinical research on psychosocial aspects of diabetes is needed to demonstrate the benefits to society of patient-centred diabetes care. In order to achieve the DAWN objectives, research now needs to focus on more practical behavioural and diabetes trials, determination of the public health impact, wide use of psychometric measures, with benchmarking, and more effective external reporting\(^\text{6}\).

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\(^1\) Rogério Silva

\(^2\) DAWN International Advisory Board

\(^3\) Simple, non-invasive tools

\(^4\) The World Health Organization

\(^5\) IDF global guideline

\(^6\) More effective external reporting
The DAWN Study results for Poland showed a particularly striking need for psychosocial support. Almost three-quarters of patients consulted were worried about the prospect of starting insulin therapy. 86% said that insulin therapy was used as a threat to make them comply with other treatment. There was clearly an urgent need to improve the understanding of healthcare professionals as well as patients’ needs.

In 2003 the multi-initiative National Programme to support People with Diabetes was established by the Polish Diabetes Association, the National Consultant on Diabetology, the Polish Diabetics’ Association and sponsored by Novo Nordisk. One aspect focused on overcoming the psychosocial barriers in doctor-patient communication. To do this it was first necessary to give healthcare professionals a greater understanding of how to identify psychological distress and offer support. It would provide simple tools for assessment, and show how to adapt treatment and offer education to suit the individual patient.

Training – and much more

The programme provided training for healthcare professionals in the use of a published method of evaluating how patients are coping with diabetes, and a practical schema for using psychotherapeutic management within regular medical visits. Workshops for more than 30 clinical psychologists and a similar number of diabetes specialists were run for 540 HCPs on the principle of training the trainer, so that these participants would be able to train general practitioners. The special workshops they provided trained more than 3,500 GPs and 80 nurses.

But the training sessions were only part of the activities to raise awareness in healthcare professionals. Formal publications about the methods in medical journals provided the full background and details, while brochures for doctors were published about the psychological aspects of diabetes, depression in diabetes and its evaluation, techniques for handling stress in diabetes, and the value of physical exercise. A series of lectures on the positive effect of exercise on anxiety, depression and mood in people with diabetes was held in 13 locations throughout Poland, and practical workshops for 800 healthcare professionals on using relaxation techniques to help diabetes patients to handle stress.

A preliminary survey among physicians who received training showed that almost 70% were using the method of evaluating coping and the practical schema, and most found them very valuable or moderately so. Well over 90% were interested in further training or consultation with experts.

STRATEGY 1: RAISE AWARENESS AND BUILD CONCERTED ADVOCACY

Best practice: Poland – Awareness of healthcare professionals

DAWN Strategy 1 calls for the use of advocacy to raise awareness of the need for psychosocial support in diabetes and its benefits.

The DAWN Study results for Poland showed a particularly striking need for psychosocial support. Almost three-quarters of patients consulted were concerned that their diabetes would get worse, but at the same time were worried about the prospect of starting insulin therapy. 86% said that insulin therapy was used as a threat to make them comply with other treatment. There was clearly an urgent need to improve the understanding of healthcare professionals as well as patients’ needs.

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Best practice: Camp D, Germany

DAWN Strategy 2 is to provide information and education to people with diabetes and those at risk of developing it.

Camp D – the DAWN Youth Camp in Germany – is one of the most effective examples of informing and motivating people with diabetes. Children with diabetes are generally well managed in experienced paediatric teams and are able to enjoy special activities. But many patients become ‘lost in real life’ in the time between paediatric and adult care, when personality development, job and partners gain priority over diabetes. There were previously no existing activities especially intended for young people with diabetes in that age group, so the idea of a four-day tent camp was developed as an environment where adolescents and young adults could focus on diabetes again.

Camp D – ‘Live your life’ was first run in 2006 in Bad Segeberg, Germany, with 650 participants. In 2008 the second – ‘My Camp D’ attracted nearly 700 young people with diabetes aged between 16 and 25, from Austria, Switzerland and Germany. The 2011 Camp D will have more participants than any have previously, and is jointly organised by Novo Nordisk with Bayer HealthCare, and co-sponsored by Medtronic and the German umbrella organisation diabetesDE, with the theme: ‘Changing diabetes together’.

Fun and learning
As well as sports and games, the camp gives plenty of opportunity for workshops and discussions on aspects of living with diabetes as a young person – coping with the practicalities of testing and injecting at school, college or work, and matching insulin to food intake and sport: also social and emotional issues like dealing with stigma or criticism, and sex. The key throughout is building friendships and confidence to deal with diabetes – talking with others who share the same difficulties and feelings is an invaluable source of comfort and support.

At the camps, participants are supported by up to 200 experienced staff including 35 diabetologists and psychologists to resolve any problems, and a number of trained diabetes educators. All healthcare professionals wear red shirts with a slogan informally encouraging camp participants to chat – breaking the communication barrier often felt between patient and doctor.

Boosting confidence
Participants are invited at each camp to take part in a DAWN Youth survey about their metabolic control and psychological wellbeing, and these have found increased motivation and self-confidence in managing diabetes. Camp D has generated much interest from the press and politicians, and has raised public awareness, in central Europe in particular, for the challenges facing young people with diabetes. Similar diabetes camps are organised in the USA.
STRATEGY 3: TRAIN HEALTHCARE PROVIDERS AND ENHANCE THEIR ABILITIES

Best practice: Denmark – Training the trainer

DAWN Strategy 3 calls for healthcare professionals to receive training in the psychosocial aspects of diabetes in order to enhance their skills.

As a result of the DAWN Study, a concerted programme to provide training for healthcare professionals in psychosocial support and improving communication has been running in Denmark. Active partnership between Novo Nordisk, the Danish DAWN Steering Committee which has members from hospitals, and the Danish Diabetes Association has led to systematic use of this method in training staff in Danish diabetes departments, in cooperation with Danish communication and psychosocial experts.

Courses have been held throughout hospitals in Denmark to educate healthcare providers, who are then able to convey their new understanding to others – the DAWN courses are training the trainer and the HCP. The aim is to generate and cascade awareness of the importance of effective communication between healthcare professional and the patient, in order to take full account of the problems and worries that may be preventing them from managing their diabetes effectively and have quality in their lives from day to day. Healthcare professionals from both primary and secondary care have been able to benefit from these courses.

Spreading the word

The teaching courses have been backed by further meetings and seminars with healthcare professionals, in order to extend the findings from DAWN and DAWN Youth. The results of the teaching programme have been published to spread the word even further, and to inspire clinical practice in diabetes departments throughout the country. It is anticipated that together these approaches will enable widespread implementation of psychosocial screening tools such as DAWN MIND online, including use of PAID, WHO-5 and the children’s circle tool (see pages 50, 51 and 55). They should also develop skills and encourage allocation of resources to ensure improved treatment for psychosocial needs. Denmark is also the first country to implement the online version of DAWN MIND, which includes HCP training.

The Danish training programme has been particularly successful for several reasons. First, it did not attempt to educate all healthcare professionals, but instead opted for training the first tier who could then train further groups, and so on. Novo Nordisk Denmark has been very committed to this project and that the method (Calgary Cambridge) is an important part of Novo Care Education in primary and secondary care. Involving commitment from all the different organisations with an interest in diabetes, including medical practitioners, strengthened the programmer’s credibility and potential for success; and gave access to a broad range of interested parties. Information campaigns were held in all the regions of Denmark, with face-to-face meetings with policymakers and written information that led to solid implementation of changes. The programme has, with support from the Danish Diabetes Association, raised awareness among HCPs and the general public of the importance of feelings and emotions in effective diabetes management.

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Best practice: Denmark – Training the trainer

DAWN Strategy 3 calls for healthcare professionals to receive training in the psychosocial aspects of diabetes in order to enhance their skills.

As a result of the DAWN Study, a concerted programme to provide training for healthcare professionals in psychosocial support and improving communication has been running in Denmark. Active partnership between Novo Nordisk, the Danish DAWN Steering Committee which has members from hospitals, and the Danish Diabetes Association has led to systematic use of this method in training staff in Danish diabetes departments, in cooperation with Danish communication and psychosocial experts.

Courses have been held throughout hospitals in Denmark to educate healthcare providers, who are then able to convey their new understanding to others – the DAWN courses are training the trainer and the HCP. The aim is to generate and cascade awareness of the importance of effective communication between healthcare professional and the patient, in order to take full account of the problems and worries that may be preventing them from managing their diabetes effectively and have quality in their lives from day to day. Healthcare professionals from both primary and secondary care have been able to benefit from these courses.

Spreading the word

The teaching courses have been backed by further meetings and seminars with healthcare professionals, in order to extend the findings from DAWN and DAWN Youth. The results of the teaching programme have been published to spread the word even further, and to inspire clinical practice in diabetes departments throughout the country. It is anticipated that together these approaches will enable widespread implementation of psychosocial screening tools such as DAWN MIND online, including use of PAID, WHO-5 and the children’s circle tool (see pages 50, 51 and 55). They should also develop skills and encourage allocation of resources to ensure improved treatment for psychosocial needs. Denmark is also the first country to implement the online version of DAWN MIND, which includes HCP training.

The Danish training programme has been particularly successful for several reasons. First, it did not attempt to educate all healthcare professionals, but instead opted for training the first tier who could then train further groups, and so on. Novo Nordisk Denmark has been very committed to this project and that the method (Calgary Cambridge) is an important part of Novo Care Education in primary and secondary care. Involving commitment from all the different organisations with an interest in diabetes, including medical practitioners, strengthened the programmer’s credibility and potential for success; and gave access to a broad range of interested parties. Information campaigns were held in all the regions of Denmark, with face-to-face meetings with policymakers and written information that led to solid implementation of changes. The programme has, with support from the Danish Diabetes Association, raised awareness among HCPs and the general public of the importance of feelings and emotions in effective diabetes management.
STRATEGY 4: IMPLEMENT PRACTICAL TOOLS AND SYSTEMS

Best practice: Taiwanese – Insulin dialogue toolkit

DAWN Strategy 4 calls for the development and application of practical, patient-centred tools and systems

In an initiative to identify the aspects of diabetes care in Taiwan where improvement was most needed, three diabetes associations worked together to conduct a national survey of patients, healthcare professionals and policymakers. The survey showed that psychosocial aspects were the least well provided for for people with diabetes in Taiwan.

The associations behind the survey were the Chinese Taiwanese Diabetes Association (CTDA), the Taiwanese Association of Diabetes Educators (TADE) and the Formosan Diabetes Care Foundation (FDCF). Together with an educational foundation (Kung Tai), which supports young people with diabetes, the three associations had developed the 2007 Taiwan Declaration on Diabetes and its action plan38, with a broad range of programmes to improve diabetes care.

Finding out the root of fears

One of the most ambitious of these programmes was the START programme (Start insulin). It set out to understand and address the emotional and social needs of patients, with the support of healthcare professionals and diabetes educators. In 2009 START introduced the DAWN insulin dialogue toolkit (see page 59) to evaluate patient perceptions and attitudes towards starting insulin therapy, and the fears that hold them back from insulin treatment. The understanding gained would enable healthcare professionals to allay these fears, in order to contribute to reducing the blood glucose level from the average HbA1c of 8.9% recorded by TADE in 200639.

Following the training of 300 diabetes educators from TADE in three workshops island-wide, the toolkit was used with hospital patients. Their responses were able to help the doctors to evaluate their concerns and attitudes towards treatment, such as fear of needles or fear that they had failed in their diabetes management so far.

PROVIDING TOOLS TO SUPPORT PSYCHOSOCIAL NEEDS

• Simple tools can be used to build psychological monitoring into routine examinations.
• As well as providing evidence for the HCP, the tools can provide a framework for enhanced communication between physician and patient.

Spreading the word

The experience of the insulin toolkit in use was shared with other healthcare professionals, diabetes educators, health authorities and policymakers in lectures and discussions. This enabled the wider audience to learn about the emotional barriers that can hinder effective treatment, and to consider trying out psychosocial assessment methods such as the insulin dialogue toolkit, and using them in their own work.

In 2010, in response to many requests from users of the toolkit, the DAWN diabetes dialogue website (www.dawnstudy.tw) was developed to communicate the toolkit online. The importance of insulin use in effective blood glucose management has been also promoted through a public awareness campaign called ‘Are you 7?’ areyou7.tw.
STRATEGY 5: PROMOTE POLICY AND HEALTHCARE SYSTEM CHANGES

Best practice: Italy – a historic agreement with the Ministry of Health

To ensure improved psychosocial care for people with diabetes, DAWN Strategy 5 sets out to drive change in healthcare policy and systems, through diabetes management guidelines, reimbursement mechanisms, and healthcare quality control.

An agreement with the Italian Ministry of Health was signed by Novo Nordisk in 2006 to begin a multi-programme Italian DAWN project. It was the first such agreement in Italy; the only country in the DAWN Study with active participation of the national health ministry.

The DAWN Italy study included some other unique aspects. As well as consulting patients, healthcare professionals and policymakers, the Italy study gathered information from non-European immigrants, regional healthcare administrators, pregnant women with diabetes, and families of people with diabetes. The study was developed with the full support of the Ministry of Health, the Italian scientific diabetology societies, leading diabetologists, behaviourists, diabetes educators, and diabetes associations.

With the momentum from the DAWN study, all interested organisations worked together to draft a Charter of Rights of people with diabetes, based on the principles of the Universal Declaration of Human Rights, and the European Charter of Patients’ Rights. The Diabetes Charter has been officially endorsed by the Italian Senate and adopted by Italian regions and local health authorities.

This Charter is an immensely important achievement. It sets clear objectives for the rights, expectations and responsibilities of people with diabetes, and also ideals for interaction between patients and HCPs, actions for controlling and preventing diabetes, the need for further research, and diabetes care in pregnancy, children and young people, and for immigrants. Based on the Charter, the Italian Senate unanimously approved a motion committing Government to guarantee people with diabetes the same level of access to care throughout Italy.

A national diabetes plan has now been drafted, including requirements for patient education, and a national committee on the rights of people with diabetes established. The Ministry is calling for cultural change by all healthcare professionals towards correct, patient-centred management of diabetes.

Other programmes include improving information systems to provide the evidence for the changes needed in diabetes care, and the Diabetes Education, Awareness and Leadership (DEAL) programme.

CHANGING HEALTHCARE SYSTEMS

- National healthcare policies should grant the same priority to psychosocial care as they do to clinical care.
- Diabetes management guidelines, reimbursement systems, and healthcare quality systems should all make provision for psychosocial wellbeing.
- Healthcare policymakers should be encouraged to adopt the WHO-supported chronic care model, and to implement its principles and those of diabetes management guidelines in clinical practice.
Best practice: USA – Coached care for underserved communities

DAWN’s strategy 6 is concerned with developing and promoting psychosocial research in diabetes.

Very substantial amounts are spent on basic research in diabetes, but much less on behavioral and psychosocial factors. Progress in terms of translation of psychological factors into routine clinical practice is slow. To lead to evidence to support procedural change, research related to the DAWN goals must be more relevant to the issues central to policymakers, clinicians, and patients.

DAWN has supported research in many aspects of psychosocial need: fundamental, clinical and practical such as:

- EURADIA – an alliance of professional diabetes organizations and companies, has developed a database of research activity and funding, and a roadmap for a recommended future strategy for diabetes research in Europe between 2010–2019. The project has recommended sustained monitoring and creation of a European Diabetes Academy to coordinate European diabetes research.
- DAWN has long worked closely with the PSAD (PsychoSocial Aspects of Diabetes) Study Group of the European Association for the Study of Diabetes (EASD). Experts in this field have examined and evaluated options for developing translational research. PSAD also contributed substantially to the DAWN MIND study and implementation of the DAWN MIND tool (see pages 14, 60).
- The European Depression in Diabetes (EDID) Research Consortium is made up of multidisciplinary groups of European scientists, joining through PSAD, DAWN also participates in the global Dialogue on Diabetes and Depression, a programme gathering and assessing scientific evidence and clinical experience from many countries.

An example of individual research supported by the DAWN programme is the minority ‘coached care’ study at the University of California, Irvine. Some minority groups in the USA are less involved in diabetes self-care than the white majority, and suffer poorer health outcomes. The project trains people with diabetes to support and encourage others of the same ethnic group to ask more when they visit the doctor. Coached patients become much better at seeking information and over time, show a dramatic improvement in their diabetes control.

Significant developments have been made in psychosocial research and clinical research, but the radical change needed in healthcare has not been widely made. Further research in this area must be focused on what would make a difference: what would provide the evidence to change practice and healthcare policy towards a view of the person with diabetes as well as their condition? Translational research must address all of these aspects. Evidence-based practice and health policy should be informed and enabled by the work of DAWN.

More research evidence is needed to demonstrate the importance of psychosocial wellbeing in overall diabetes care – vague support of the concept of wellbeing is not enough.

New research should have tangible practical relevance, e.g. trials relating movements in diabetes management, measuring the public health impact of psychological distress, comparative studies of the performance of health systems and evidence of the use in practice of psychometric methods.
and countries globally were requirements. Cultural sensitivity and easy adaptation for use in different cultures are important for effective diabetes management. In addition to being easy to use, diabetes management tools should be developed to support healthcare professionals (HCPs) and their patients to highlight problems that may interfere with the effectiveness of a new DAWN assessment tool for addressing the psychosocial barriers.

The DAWN summits: Working with two Brazilian diabetes associations, Novo Nordisk runs psychology and diabetes workshops to provide support to young people with diabetes; many of whom have an underlying depressed mood. It also educates people with diabetes in the skills for resolving conflicts – taking a positive approach can even be beneficial to their own diabetes control, and improve psychosocial support for people with diabetes. Positive psychology is used as a tool to develop the principles of positive psychology to achieve the DAWN vision.

In the Netherlands: A major education programme on diabetes is being used to promote better communication between patients and HCPs in the Netherlands. 25,000 diabetes ‘passports’ promote better communication, and improve psychological wellbeing. They also show that patients’ concerns about insulin in Turkey are very similar to those in other countries, such as Germany, the USA and Japan. In Japan: A DAWN project called HOPE (Health Opportunities for People Everywhere) is developing educational materials about diabetes to be used in health centres and schools. Young people with diabetes are being encouraged and helped to build networks for information and support, and a training programme for HCPs has also been established on addressing psychosocial barriers.

In China: A study about women with gestational diabetes. The study involved 244 pregnant women with gestational diabetes. The aim of the study was to evaluate the psychosocial problems related to gestational diabetes. The study involved a survey on challenges in school for children with diabetes, and also explored the many issues where young people with diabetes have different challenges. In D) attracted almost 700 young people with diabetes in summer 2008. Alongside a wide range of sport and leisure activities, workshops on aspects of living with diabetes are held. DAWN Youth South Africa has addressed the daily problems of young people with diabetes throughout the country. The annual DAWN Youth Camp (My Camp - Germany) attracted almost 700 young people with diabetes in summer 2008. Alongside a wide range of sport and leisure activities, workshops on aspects of living with diabetes are held. DAWN Youth South Africa has addressed the daily problems of young people with diabetes throughout the country.

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The DAWN programme has inspired the development of a wide range of tools for healthcare professionals, and the wider use of some already in evidence.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box.

The questionnaire has proven to be sensitive to detect changes over time following educational and therapeutic interventions. The scores are added up and multiplied by 1.25, generating a total score between 0 – 100. Patients scoring 40 or higher may support, health beliefs, and coping style, as well as predicts future blood glucose control of the patient.

In order to monitor possible changes in well-being, a 10% difference can be regarded as a significant improvement or decline in patients’ mood.

The achievement of good metabolic control can either follow the sequence outlined below, which is not a list but a tool to help clinics assess the level to which self-management is integrated into their care team, and also an opportunity to value from 0 to 4, with 0 representing an ideal situation.

1. What is the main goal of today’s visit? When, where?
2. What was the best thing you did 24 hours ago?
3. What is the most difficult part of having diabetes for you? •  Or ask an exploratory question such as “What’s that been like for you?”
•  “What will you do when you leave here? When, where?”
4. Have a bad night’s sleep? How much? Why?
5. What is the quality of your life if you have diabetes? What is the quality of diabetes-free life? How much?
6. How much do you exercise today? How much will you do in the next 24 hours?
7. What do you think about exercise?
8. How much more carbohydrates do you eat than normal? What is your usual carbohydrate intake?
9. I smoke. I do not adjust my intake of insulin or food enough in connection with exercise.
10. How much do you enjoy your food?
11. How much do you enjoy your life?
12. How much do you think about your diabetes?
13. How much do you think about your diabetes every day?
14. How much do you think about your diabetes every week?
15. How much do you think about your diabetes every month?
16. How much do you think about your diabetes every year?
17. How much do you think about your diabetes every day?
18. How much do you think about your diabetes every week?
19. How much do you think about your diabetes every month?
20. How much do you think about your diabetes every year?

The child or young person with diabetes is the major stakeholder and the one who carries the disease for the rest of his/her life. They have to cope with demanding and emotional aspects so they should be well aware of the potential negative changes diabetes can take up room. A negative way may for instance be taking up room in their social life. “Room for diabetes in your life” may help patients become able to distinguish between negative and positive ways that diabetes can take up room.

Some patients are intensely concerned about their disease and this may constitute a considerable part of the burden they have to carry.

The need to change will depend on nature and numbers of recommendations made during one’s clinic attendance. Both qualitative evaluation and a randomized controlled trial confirmed the impact of group training. ‘Your plans to change your way of living’ is one of 20 reflection sheets developed as a major part of a DAWN facilitators’ toolkit.

The self-rated health perception question (HRQOL) was modified and used for this purpose. It contains 16 characteristics that may be relevant.

It is not practised meeting individual needs, it is limited to a list or pamphlet. Protocols are not standardised, and the achievement of good metabolic control is not diagnosed, but reversed by giving feedback and discussing the information in constructive ways.

The DAWN TOOLS FOR HEALTHCARE PROFESSIONALS

The DAWN programme has led to the development of tools for healthcare professionals and the wider use of some already in evidence. The questionnaire has proven to be sensitive to detect changes over time following educational and therapeutic interventions. The scores are added up and multiplied by 1.25, generating a total score between 0 – 100. Patients scoring 40 or higher may support, health beliefs, and coping style, as well as predict future blood glucose control of the patient.

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**WHO-5 WELLBEING INDEX**  
(DAWN Goal 1)

**How have you been feeling?**  
WHO-5 is a short assessment, asking for responses to five statements about how the patient has felt in the last two weeks. These are designed to reveal the level of positive mood, vitality and generally being interested in life. They can be used routinely in just 2–3 minutes to detect signs of depression, and the test has been shown to be a sound measure of emotional wellbeing. It should be part of the diabetes annual review; ideally in combination with a diabetes-specific test eg PAID (Problem Areas In Diabetes).

The response to each statement, eg ‘I have felt calm and relaxed’ is chosen from 0 (never) to 5 (all of the time). The scores are added to obtain a raw score ranging from 0 to 25. Scores are summated, with raw score ranging from 0 to 25. Then the scores are transformed to 0-100 by application of a linear transformation.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Score Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have felt angry/a sense of hate/feelings of anger</td>
<td>0-5</td>
</tr>
<tr>
<td>'I have felt calm and relaxed'</td>
<td>0-5</td>
</tr>
<tr>
<td>I have felt sad, downhearted, hopeless</td>
<td>0-5</td>
</tr>
<tr>
<td>I have felt restless, anxious, agitated</td>
<td>0-5</td>
</tr>
<tr>
<td>I have felt energetic, active, vital</td>
<td>0-5</td>
</tr>
</tbody>
</table>

Each of the five items is rated on a 6-point Likert scale from 0 (= not present) to 5 (= constantly present). Feeding back WHO-5 outcome is a short assessment, asking for responses to five statements about how the patient has felt in the last two weeks. Scores are summated, with raw score ranging from 0 to 25. Then the scores are transformed to 0-100 by application of a linear transformation.

**Why measure emotional wellbeing?**
Subjective well-being is an important dimension of overall perceived quality of life and in its own right is an indicator of help-seeking. It is advised to incorporate the WHO-5 in the annual review, as a measure of emotional well-being, in particular diabetes patients who struggle with diabetes control and those on top of it may need referral to a mental health specialist.

**PROBLEM AREAS IN DIABETES QUESTIONNAIRE (PAID)**  
(DAWN Goal 1)

**Is diabetes getting you down?**
While the WHO-5 test can be used for any condition, PAID relates specifically to diabetes; it is very acceptable in use and has high scientific validity. Its results relate well to other measures of depression and style of coping, and can be even used to predict future patient blood glucose control.

PAID presents 20 statements on the patient’s possible negative feelings about diabetes, eg ‘Feeling overwhelmed by your diabetes?’, and asks for responses on a scale from 0 (no problem) to 4 (serious problem). The total score is converted to a final percentage. Scores of 40 or higher may signify emotional burnout, warranting special attention; conversely a very low score (0-10) combined with poor glycaemic control may indicate denial.

The PAID test should be part of the annual review and can also be useful occasionally as a diagnostic tool. Discussion of the results between patient and doctor can be a good opportunity to explore particular issues, and may need referral to a mental health specialist.

**PAID**
- Twenty short, negatively-worded statements
- Easy for the patient to align with his/her own feelings
- Provides the opportunity to define the greatest concerns about diabetes
- Offers basis for discussion or referral for specialist help.
ROOM FOR DIABETES IN YOUR LIFE

(DAWN Goal 1)

Is diabetes a big part of your life? This well-validated tool is designed to help diabetes patients gain understanding of the feelings about diabetes, by using a ‘reflection sheet’ developed through the decision-making method called guided self-determination (GSD). It is based on the understanding that the amount of ‘room’ diabetes takes in life can be viewed in positive ways (time taken for planning and taking action) or negative ways (disproportionate worry, guilt feelings or fear). Not having enough room in their life, patients tend to neglect their diabetes. Apparently professionals find this reaction too difficult to talk about and accordingly patients prepare themselves by filling out the sheet at home before a conversation with a professional. Patients complete the sheet in their own time before a discussion with a professional. The sheet helps patient and professionals to prioritize – where to start.

The tool involves asking the patient to shade in an area of a given oval shape that corresponds to the amount of room diabetes takes in their life, and to do the same for the amount of room they intend to give diabetes in the future. They are also asked to write about the difference. Using the reflection sheet in advance gives a structure for discussion with the healthcare professional.

ROOM FOR DIABETES IN YOUR LIFE

- Enables visual representation of feelings that are difficult to understand or convey in words
- Provides real basis for discussion and making plans.
QUALITY OF LIFE FOR YOUTH

– Questions about living with diabetes
(DAWN Goal 1)

How much does diabetes interfere with your life?
Young people often experience great difficulties in coping with diabetes, which is intrusive, demanding and interferes with their daily quality of life (QoL). Achieving a good quality of life helps with maintaining good control, so it is vital that HCPs have the means to assess QoL accurately.

The Quality of life for youth questionnaire\(^{10,11}\) has 21 questions about how diabetes affects daily life, plus one (separately-scored) on the young person’s view of their health compared to others of the same age. The main questions are framed as ‘How often ...?’ and cover the impact of diabetes symptoms and treatment, its effect on school and leisure activities, parents’ actions and specific diabetes worries. Each is scored between 0 (never) and 4 (all the time).

Young people are asked to answer the questionnaire before their routine consultation. The scores can be converted to percentages and used to derive an overall QoL score which can be monitored over time. Scores for individual sections will also highlight problems in any particular aspect.

THE CHILDREN’S CIRCLE TOOL
(DAWN Goal 1)

The child at the centre
The children’s circle tool\(^9\) was designed to help stimulate discussion between children with diabetes, their healthcare support team and their families. A map showing overlapping circles with the child at the centre shows the main non-medical areas affecting his/her life – his/her family, diabetes support team, school, local community, friends and leisure activities and cultural or local traditions. The overlap between them shows interaction between these areas of the child’s life and their influence on his/her own and his/her family’s wellbeing.

Discussing how these circles are related can reveal barriers to effective diabetes management and how the child and family could be supported in resolving them. Each of the life areas and their impact on the child can be discussed in turn or in any order, starting with open questions eg ‘In what areas are things not going so well?’, and ‘In what areas could improvement be made by the child, family and healthcare team working together?’ After the discussion, the map (and notes made on it) can be given to the child or parent as a reminder.

QUALITY OF LIFE FOR YOUTH

• Helps young people to explain how diabetes affects their life
• Helps identify areas of concern
• Provides structured basis for discussion
• Identifies issues where action (by the young person, HCP or others) would improve quality of life.
THE DAWN EXPERIMENT

(DAWN Goal 1)

Ask. Listen. Response

This tool was developed to help healthcare professionals to obtain quickly the closest possible understanding of what troubles their diabetes patients, given that most consultations only last less than ten minutes. As a result, the discussion can arrive at a treatment plan that truly addresses the patient’s priorities and also ensures quality diabetes care.

HCPs are invited to carry out an experiment by asking one searching question, eg ‘What is the most difficult part of living with diabetes?’ or ‘What are your greatest concerns about your diabetes?’ to at least three patients, followed by a further prompt for more information.

The HCP should then listen to the patient for at least five minutes without interrupting or advising, and only after that period, take the discussion into possible ways to resolve the issue.

Following the consultation, the HCP is asked to consider what was the most important information learnt about the patient, his own feelings about listening without interrupting, and how his findings will be built into the patient’s care.

THE DAWN EXPERIMENT

- Gives the opportunity for patients to pinpoint their major concerns
- Helps HCPs to get to the heart of barriers to self-management
- Enables construction of a treatment plan that meets the needs of both patient and HCP.

ASSESSMENT OF PATIENT SUPPORT AND TEAM FUNCTIONING

Assessment of Primary Care Resources and Support for chronic disease self-management (PCRS) (DAWN Goal 2)

The team’s view of its own performance

PCRS was developed by the Robert Wood Johnson Foundation for multidisciplinary medical teams to assess how well their systems support self-management by people with diabetes and other chronic conditions. Each team member is asked to assess eight aspects of patient support offered by the team (eg involving patients in treatment decisions) and eight aspects of organisational support (eg integration of self-management into primary care).

Each aspect is scored in terms of what was done in the preceding three months, and rated between 1–10. Within that scale are four bands of performance: D (1–3) means ‘not done’; C (2–4) means passive patient-provider interaction, or ‘done inconsistently’; B (5–7) indicates organised and consistent implementation, using a team approach; and A (8–10) means all the conditions of B, plus strongly integrated systems.

Individual scores are assembled and discussed with all the team members. Disparities reveal areas for where better communication or team function is needed, and low scores show widely-perceived areas for improvement. The team will agree a strategy for progress and a timetable for reassessment. Use of PCRS has been shown to improve service provision over time.

PRIMARY CARE RESOURCES AND SUPPORT

- Provides a framework for detailed assessment of both patient support and team functioning
- Covers both direct support for patient self-management, and backup team organisation and communication
- As it covers both clinical and support staff within the team, discrepancies between scores from different team members will reveal their different perceptions and suggest areas for improvement.
A GOOD LIFE WITH DIABETES

Learning ways to cope with diabetes

This online interactive programme was designed to help people with diabetes to cope with mood problems, negative emotions and everyday stresses that affect behaviour. The programme has eight modules introducing ideas and suggestions on ways to think more positively and to develop ways of coping. The modules explore how to relax and control negative thoughts, to focus on enjoyable activities now and in the future, and to deal with worries. Learning skills to become more assertive and communicate more effectively with others is also helpful in avoiding gloominess and accepting daily events without descending into depression. One week is allowed for each module, so there is plenty of time to think about the suggestions and put them into practice. Alongside the reading and video stories illustrating the ideas, homework exercises are required, which always include keeping a diary of mood throughout the whole programme.

A GOOD LIFE WITH DIABETES

- Provides a solid, long-term resource for improving the patient skills needed for coping with diabetes
- Learning to maintain a more positive quality of life contributes to better self-management and better glycaemic control
- This will result in better clinical outcomes over time, achieved with low-cost intervention.

INSULIN DIALOGUE TOOLKIT

Dealing with anxieties about insulin

The DAWN study showed that most people with type 2 diabetes have anxieties and preconceptions about starting insulin, and these can be allayed by informed discussion with a healthcare professional. The insulin dialogue toolkit is designed to enable patients to identify and address their concerns, through an open and participatory discussion with the HCP.

An introduction for HCPs explains the working of the three-part toolkit. The insulin perceptions questionnaire invites the patient to identify his level of agreement or disagreement with statements about different aspects of starting insulin – its benefits, its own health including any self-blame, daily life, social issues, injection issues and possible side-effects. These different aspects are each colour-coded on the questionnaire and the other parts of the toolkit, to give the HCP rapid access to the relevant sections.

The HCP can then use suggested questions, eg ‘How do you believe taking insulin would restrict your day-to-day life?’ to explore further the patient’s reservations.

The third resource is an illustrated insulin guide providing facts to address and counter the patient’s concerns.

INSULIN DIALOGUE TOOLKIT

- Addresses type 2 patients’ concerns about the implications of starting insulin
- Resources help the HCP minimise fears about insulin initiation
- Enables the patient to decide about starting insulin, with respective options to delay the decision, or not to start, or to change their mind at any time.
DAWN MIND PROGRAMME

• Framework for routine assessment of psychological needs of patients in primary care
• Questionnaire completed in only 5–7 minutes
• Includes HCP training on assessment of results
• Report generated by software for feedback and discussion with patients
• Includes guidance for discussion and motivation

DAWN MIND YOUTH PROGRAMME

Helping young people to cope
The DAWN MIND Youth programme promotes assessment of health-related quality of life (HRQoL) as part of routine outpatient care for young people with diabetes. It uses a questionnaire for 10–18-year-olds with type 1 diabetes, known as MY-Q. The questionnaire is completed online, either at home or at the clinic, before the routine annual assessment, in a password-protected, secure environment called the MY-Q portal. Prior consent is required from both the young person and their parent or carer.

Questions in MY-Q cover general quality of life, social life at school, with friends, family and in free time; mood and feelings about their own body. They are asked how they feel about coping with diabetes, including worries and the hardest aspect of treatment. Any good or negative events in the recent past are taken into account, and the young person is invited to raise any other issues they would like to discuss.

The answers are compiled by computer software and provided to the paediatrician or diabetes nurse to follow up immediately in discussion with the young person; especially in areas where they are having particular problems. The results are filed so changes over time can be detected, and referral to a psychologist can be made if needed. Guidance for the healthcare professional in effective discussion and motivation (for both children and parents) is included in the programme.

The DAWN MIND Youth programme recommends that the quality of life of parents or carers of young people with diabetes should also be assessed at the same time, if they are willing to participate. The WHO-5 and PAID questionnaires (pages 50–51) are used, and any problems can be discussed and appropriate support offered.
Refining skills for working with young people

Also known as the DAWN Youth Train the Trainer scheme, this is a one-day training programme for healthcare professionals who diagnose, treat and care for young people with type 1 diabetes, with a follow-up one-day course taken six to 12 months later. It is a constructive resource for professionals of all disciplines, including paediatricians, psychologists, diabetes educators, diabetes nurses, dieticians and social workers. Its aim is to give a deep understanding of the psychosocial challenges faced by young people with diabetes and their families, while also offering the skills and tools that will enable them to provide the best possible psychosocial care. It is intended that the understanding and skills gained are then passed on by participants to their colleagues.

After a preparatory session examining the experiences of a young person with type 1 diabetes, four core modules address aspects of recognising and addressing the psychosocial issues. The course uses short presentations, group discussion, case studies and breakout group exercises to examine the issue of matching scientific data with real-life experiences and self-management; education and counselling at the outset of diabetes treatment; communicating effectively with children and addressing their parents’ fears; and working with adolescents with diabetes.

**DAWN YOUTH TRAIN THE TRAINER SCHEME**

- One-day interactive course of interest to all types of healthcare professionals working with children and young people with type 1 diabetes
- Generates understanding of the personal feelings and difficulties faced by children and young people in dealing with their condition and treatment
- Develops communication skills and provides access to assessment tools for better interpretation of psychosocial aspects of patient care

**DAWN FACILITATORS’ TOOLKIT**

Developing group training techniques

The DAWN Facilitators’ toolkit is a structured resource for Healthcare Professionals working with diabetes, to be used as the basis of workshops to explain the need for psychosocial support for patients, and to practise key approaches. It comprises three complete workshops, with a CD-ROM providing manuals, presentations, learning modules and videos.

The first two workshops both present the implications of the DAWN study and the DAWN Call to Action. The shorter (Basic) workshop gives participants the opportunity to try out the DAWN Experiment. In the Advanced workshop, participants interact with a video demonstration on how simple facilitation methods can improve the outcome of medical discussions; given the known medical history of the patient presented.

The Train the Trainer workshop is for HCPs who have completed the Advanced workshop and are confident to facilitate group training on the DAWN concept. It enables participants to act as trainer for groups of 6–8 people, applying facilitation methods in effective communication towards providing psychosocial support. The full-day session uses both the DAWN Experiment and facilitation practice based on video consultations.

**DAWN YOUTH TRAIN THE TRAINER SCHEME**

**DAWN FACILITATORS’ TOOLKIT**

- Provides training in the use of facilitation methods to improve communication between healthcare professionals and diabetes patients, and handling of psychosocial issues
- Three levels of workshop offer basic information, insight into simple techniques or detailed understanding and practice enabling participants to pass on facilitating skills to colleagues

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*The DAWN Facilitators’ toolkit, on a DVD developed by the DAWN programme in 2005, is available from local Novo Nordisk affiliates.*
DAWN 2, 2011–12

The original DAWN study revealed a major gap between the psychosocial and educational support needs of people with diabetes, and the care and support available in both developed and less developed countries. Despite many positive developments in the field of self-management education and psychosocial care, there are still far too many people with diabetes who are not getting the care and support they need, which could enable them to live healthier, better and more productive lives.

In contrast to the original DAWN study, the DAWN 2 study will be undertaken in an environment which is more positive towards patient-centred healthcare than was the case in 2001. The International Alliance of Patient Organizations (IAPO) developed the declaration on patient-centred healthcare in 2006, which is now more relevant than ever; calling for the involvement of patients at all levels in society for the advancement of better care.

The psychosocial aspects of managing diabetes are today incorporated into both ISPAD’s and the IDF global guidelines for diabetes. Increasingly national healthcare guidelines are recommending patient-centred care and education strategies to be further implemented; and increasingly research grants are being channelled to health services and psychosocial translational research.

DAWN is paving the way for a new paradigm in diabetes. Despite the positive developments, there are still huge challenges ahead to ensure that people with diabetes will benefit from the developments of the past decade.

For this reason, the DAWN 2 study will be undertaken as an even wider and larger undertaking than the first DAWN study. The DAWN 2 study will involve people with diabetes, family members, healthcare professionals, patient organisations, payers and policymakers in at least 18 different countries. More than 16,000 people’s views will be obtained to gather a new, updated understanding of how far we have come in meeting the needs of people with diabetes, and what needs to be done through multinational, concerted action.

The results of the DAWN 2 study will be shared through its many partnering organisations and advisers over the next few years. It is hoped that the new evidence will support very concrete educational and support programmes, making a measurable difference to the lives of millions of people with diabetes around the world.

By being the first study of its kind to include, so extensively, family members and stakeholders other than health professionals into the study, the DAWN 2 study aims to contribute radical new insights for new, sustainable ways to enable people with diabetes to live full, healthy lives and be actively involved in managing their own health.

DAWN 2 OBJECTIVES

- Advance understanding and awareness of the unmet needs of people with diabetes and their caregivers, that have evolved over the past decade, with the aim of identifying opportunities for improved self-management.
- Facilitate dialogue and collaboration among all key stakeholders around patient involvement and improvement of self-management.
- Establish a benchmarking system for psychosocial aspects of diabetes care and catalyse improvements across stakeholder groups.
- Use DAWN 2 as a lever for developing and implementing psychosocial monitoring tools and follow-up as part of regular diabetes care.
DAWN 2 aims to gain a 360° perspective on the experiences and views of all of the different stakeholders with a role in supporting people with diabetes. The aim for the international DAWN 2 initiative is that its study results will inspire and contribute to shaping local and global health policy actions that reflect the major unmet needs of those affected by the condition. They should make a valuable contribution towards achieving truly patient-centred care for people with diabetes worldwide.

The problem is bigger than diabetes: all chronic diseases need a new model of organisation of care.

Professor Marco A Comaschi, University Hospital San Martino, Italy

We are talking about the rights and responsibilities of people with diabetes – are you hiding your diabetes, or are you coming out?

Dr Wim Wientgens, Vice President IDF

Organisations in various countries have heard the DAWN message and it has changed the way people do research and think about the problems; focusing more on the psychological and humanistic aspects.

Professor Mark Peyrot, Loyola University, Maryland

We have a vision to make a map like the IDF Diabetes Atlas – not about prevalence and mortality, but a map of the psychosocial wellbeing of diabetic patients.

Professor Norbert Hermanns, University of Bamberg, Germany

I think we need to identify patients who were doing poorly and are now doing well, and zone in on what happened (to make the change) – what clicked. This is a brand new way of making use of a huge group of experts we have not looked at before.

Professor William Polonsky, Behavioural Diabetes Institute, University of California

DAWN will be judged by what it can do to make things better for the person with diabetes. That’s what it’s all about.

Professor Mark Peyrot, Loyola University, Maryland
REFERENCES
