

Global DAWN movement continues to grow



Key opinion leaders have a chat during an international DAWN event for 270 diabetes nurse specialists from 14 countries (May 2005 in Amsterdam).

From right: Anne-Marie Felton, Chairman of the Federation of European Nurses in Diabetes (FEND), Harry van der Wiel, Professor, expert in patient-professional communication, Martha Funnel, leading expert in patient empowerment and self-management education, Associate Professor Richard Rubin, leading expert in psychosocial diabetes care and research, Lisbeth Vang, former chief diabetes nurse, Steno Diabetes Center, and co-developer of DAWN interactive training workshops.

"In 2005, the DAWN programme together with the International Diabetes Federation is taking the vital step forward in organising action at many levels to address the need for more patient involvement in diabetes care both in rich and less rich countries. It is only through new partnerships between organised bodies, academia and industry that diabetes can be defeated."

Professor Pierre Lefèbvre, President of the International Diabetes Federation

"DAWN has shed a new light on the challenge and possible solutions to solving the attitude and behavioural gaps between and within healthcare professionals and people with diabetes. The potential for a more creative alliance is emerging."

Anne-Marie Felton, President of FEND, Federation of European Nurses in Diabetes, United Kingdom

Today, more than 194 million people worldwide have diabetes. Twenty years from now, that number is expected to reach 330 million – over 6% of the planet's population.

The numbers are chilling, because despite the growing quality and availability of treatment, most people with diabetes still don't achieve optimum blood sugar control. The resulting long-term complications are burdensome for both patients and society in general, in terms of quality of life and ballooning healthcare costs. As the diabetes population grows, so will the burden.

The 2001 DAWN study sponsored by Novo Nordisk helped identify some of the reasons why optimum diabetes care can be so difficult. It is a stressful and demanding disease that requires a lot of effort to manage, which can lead to depression. It is also a misunderstood disease – in some cultures, it is still seen as debilitating, offering no hope of leading a healthy, productive

life. Dealing with these and other psychosocial factors is as important as treating the physical symptoms of diabetes, because successful management of the disease depends on the patient's ability and willingness to take responsibility for his or her own care.

On November 5, 2003, 150 delegates from around the world gathered at the second DAWN summit in London to learn more about psychosocial issues in diabetes and plan for ways to incorporate their treatment into regular diabetes care. A little over a year later, the practices, tools and advocacy plans that were agreed on are being put into action in positive initiatives worldwide. Making the problem a priority with governments and healthcare agencies is one part of

the DAWN Call To Action that has seen much progress in the last year. Countries such as Germany and the Netherlands are in the process of finalising national guidelines for the treatment of psychosocial issues of people with diabetes. Australia has incorporated psychosocial aspects into its national diabetes care strategy, and Japan recently incorporated psychosocial aspects into their national treatment guidelines. The issue was also raised during EU diabetes working group sessions, making politicians aware of the problem and the need to invest in it.

Improving diabetes care requires both policy changes and the creation of local solutions to raise awareness and foster new attitudes toward psychosocial issues. Through DAWN conferences, workshops, events and publications, millions of people in more than 20 countries have been made aware of the importance of patient-centred care.

But while progress is being made, there is still much more to do. Government, for instance, can be reluctant to invest in improving psychosocial care when there are line-ups in surgeries – even though they would save more money in the long run. Even GPs can be resistant, simply because they believe treating the physical symptoms of diabetes is the more pressing issue during a busy day. Physical care of diabetes is the priority. Psychosocial issues get the back seat.

"That's the good thing about DAWN," says Professor David Matthews of the Oxford Centre for Diabetes, Endocrinology and Metabolism (OCDEM). "It keeps the pressure up. It raises the flag that we can't just talk about treating the physical symptoms of diabetes. Good care must incorporate the psychosocial as well."

News

Egyptian project wins 2004 DAWN award

Assistance to Young Diabetics (AYD), an education and support project for Egyptian children with diabetes and their parents, is the winner of the first international DAWN award.

The ceremony awarding the €10,000 first prize was held in Cairo in January 2005. Diabetes leaders from Egypt and Europe, journalists, IDF President Pierre Lefèbvre, Novo Nordisk representatives and other officials were on hand to celebrate the winning entry. French representatives, who collaborated in the establishment of the programme, participated via satellite video link.

Ms Laila Sioufi, the programme's founder and president, accepted the award. "This award encourages us even more in our efforts to help young people with diabetes feel as normal as any other child. With the invaluable support of the Novo Nordisk DAWN programme, we will have access to the knowledge and resources that help us better address the attitudes, wishes and needs of our young people with diabetes."

The AYD programme directly addresses key goals of DAWN, including promoting active self-management, enabling better psychological care for people with diabetes and their families, and improving communication.

The aim of the award is to stimulate, acknowledge and reward outstanding effort to improve the health and quality of life of people with

diabetes. This year's winning programme deals with the cultural and educational challenges for children living with diabetes in Egypt and Arabic cultures in general. It has helped more than 2,000 children and their parents since its inception (see page 2). The programme will be featured in-depth in an upcoming issue of Diabetes Voice, the official magazine of the International Diabetes Federation.

More than 60 projects representing 30 countries applied for the 2004 DAWN Award. Among the top five programmes the award committee chose as outstanding examples of best DAWN practice include initiatives in Poland (featured on page 2), Mexico (page 6), New Zealand and the Netherlands (both on page 3). Application forms for the DAWN 2005 award will be available at www.dawnstudy.com in May 2005.



Ms Laila Sioufi accepts the 2004 DAWN award from Professor Pierre Lefèbvre, president of the International Diabetes Federation.

In brief

DAWN actions launch in Brazil

The Latin American Diabetes Association conference was held in September 2004 in Sao Paulo, Brazil. The event attracted 2,200 physicians and healthcare providers, and journalists from major Sao Paulo newspapers and national healthcare magazines.

One programme highlight was the DAWN Symposium, where the DAWN Call to Action was presented to 200–300 people. Hosted by the president of the Latin American Diabetes Association and the vice-president of the International Diabetes Federation for Latin America, the symposium set the stage for new DAWN initiatives in the Latin American region, especially Argentina and Brazil. The DAWN message reached millions of people in the region through media coverage of the event.

It is estimated that 5.4% of the Brazilian population has diabetes – approximately 9.5 million people. Only 37% of type 2 diabetes patients are currently receiving treatment.

Testing starts for satellite learning

CNES, the French space agency, is exploring a distance education programme for people with diabetes. Modules on health issues such as diabetes will be beamed via satellite directly into specially-adapted home televisions. The programme is scheduled to start testing in Spring 2005.

Initially, modules will be produced in French, but other languages will be added soon after. "Video is more intimate and interactive than just internet," explains Dr Line Kleinebreil, International Adviser and French National Adviser for DAWN. "You feel like you're part of it, and can put a face to the other person, whether caregiver or patient."

The system allows individualised information to be beamed right into the patient's home, where it can also be shared with the family. Programmes will help educate patients on a variety of diabetes issues, including psychosocial, and provide the support they need in the language and context that makes understanding much easier. The TV-CNES platform provides an opportunity to go global with existing educational material produced in the Middle East, Asia, Africa, or Latin America. International collaboration is already planned with Assistance to Young Diabetics (AYD) in Cairo.

To find out more about participating in the programme, contact Dr Line Kleinebreil linekl@club-internet.fr or hubert.diez@cnes.fr

France announces DAWN Award

The French chapter of DAWN has announced its own version of the DAWN Award for 2005. The award of €5,000 will go to the best example of innovation for better psychosocial management of people with diabetes. Full details and an application form are available at www.novonordisk.fr under "à propos de Novo Nordisk".

Education • Tools

Egyptian children find the support they need

The story of how young Egyptians with diabetes are getting psychosocial support and other help starts with a visit to Paris. That's where Ms Laila Sioufi, president of Assistance to Young Diabetics (AYD), found the materials that form the base of a therapeutic education programme she started for young people with diabetes in Cairo.

"It's like a fairytale," says Dr Line Kleinebreil, who is French National Adviser for DAWN and close to the project. "Here's this retired business manager with no past history of diabetes care setting up a successful education programme from nothing."

Ms Sioufi, inspired by friends whose children had diabetes and sensitive to the stress it caused in their lives, asked the French organisation of L'Aide des Jeunes Diabétiques (AJD) if she could translate and use their educational materials to start her own programme in Egypt. AJD quickly agreed.

From there, Ms Sioufi recruited physicians, psychologists and assistants and opened an office in Cairo. She and her team then set about translating and adapting the printed materials from France to make them more relevant for an Egyptian audience. The first training course in 2002 included 20 children.

Sixty percent of Egypt's population of 70 million is under the age of 20. It's estimated that 7 million Egyptians have diabetes, with 700,000 having type 1 diabetes. And those numbers are expected to increase rapidly. Psychosocial issues are especially relevant, because despite the high number of people with diabetes, the culture has a very negative outlook on the disease, or illness of any kind. In a country where poverty is also an issue, families can even come to resent

the fact that one member takes an unfair share of time and money for health issues. Traditionally, there's also been an unwillingness to invest in the education or careers of people with diabetes, as their futures are seen as uncertain.

In this context, the AYD programme takes on even more significance. Now in its fourth year, the programme is run by 20 full-time trainers, and more than 2,000 children have been helped. Additionally, its reach now extends to other parts of the country, where children and their parents can get help or general self-care recommendations and free materials for testing blood glucose through local churches and mosques.

The programme is also being expanded to address the needs of children and parents on-site in hospitals. Staff will be available to answer questions, share materials and offer support at the time of diagnosis or physical treatment.

Outside Egypt, the AYD programme is seen as an important model for dealing with psychosocial issues in Arabic cultures around the world. France, for instance, has a large Arabic population, and French organisations are keeping their ties with the Egyptian team strong. "We are currently testing the feasibility of having Arabic educational modules beamed via satellite right onto the



Ankh, the symbol of life, painted on Egyptian papyrus.

television sets of patients in France," says Dr Kleinebreil. "This will allow us to share DAWN tools and knowledge in their first language, and with a sensitivity to cultural issues they might not find otherwise." The initiative is a cooperation among AYD, AJD and CNES, the French space agency.

In 2004, AYD was chosen to receive the first annual DAWN award. The money will be used to continue and expand their work, and promote its wider use in the Arab-speaking world.

Research • Advocacy • Training • Tools • Education

DAWN inspires successful campaign in Poland

The 2001 DAWN study offered a broad overview of global attitudes to psychosocial issues. But it also afforded individual countries a chance to see how they compared with other nations. In Poland's case, it allowed local healthcare specialists and decision-makers to see just how serious their own situation was.

Polish diabetes patients responding to the survey showed consistently higher concern for psychosocial issues than respondents in other countries. For instance, 60% of Polish patients declared impaired well-being, compared with 25% and 26% in Spain and Germany respectively. And 72% reported being constantly worried that their condition will deteriorate, compared to 35% in the UK.

The numbers clearly showed the importance of addressing psychosocial issues at every level of healthcare service in Poland. They also inspired the Polish Diabetic Society, Polish Diabetes Association and Novo Nordisk to team up and create the National Programme to Support People with Diabetes (NPSPD). The programme aims to improve quality of life and treatment outcomes of people with diabetes in Poland, help overcome communication or other barriers in doctor-patient relationships and increase general social awareness of the disease.

A multifaceted educational approach was put into action during 2003/2004, aimed at

different caregiver levels and at patients. Special training and information-sharing conferences were organised for specialists. Primary physicians and nurses received training through practical workshops. An effective Hb A1c screening test was developed for the population. And special studies to identify personality types in Polish patients were commissioned so that support materials could be targeted to their individual needs. A general awareness campaign was also launched to promote early diagnosis, treatment and prevention of diabetes and to improve community acceptance of people with diabetes.

To date, more than 3,500 doctors and 300 nurses have been trained in the use of psychosocial assessment tools during patient visits. Diabetologists and other specialists throughout the country continue to organise workshops that address psychosocial issues and teach the use of psychosocial assessment tools.



Tools • Education

Breaking down the language barrier

Screening for depression in New Zealand's multicultural population

For people with diabetes, depression is an often underestimated but very real threat. It can lead to mismanagement of the disease and poor behaviour choices – the results of which can have very serious physical consequences. Worse, depression is at least twice as likely to occur in people with diabetes as it is in the rest of the population.

That's why identifying and treating depression can be just as important as any physical treatment. The Auckland Diabetes Centre in New Zealand is one clinic where voluntary screening for depression is now an important part of the patient visit.

The screening tool they've developed is based on the WHO-5 well-being questionnaire, with an additional five questions that address diabetes specifically. "The sheet was effective in screening for depression and very useful in prompting discussions of psychosocial issues between patients and caregivers," says intern health psychologist Tanaya Skerrett, who helped implement the programme.

Ms Skerrett developed the additional diabetes-related questions and format for the questionnaire. She also educated the clinic's receptionists on its rationale and procedure for use, supervised its launch and gained feedback from staff regarding its efficacy. "The majority of healthcare providers found it helpful, and half of them found it useful in screening for depression," says Ms Skerrett.

Patients who understood the questionnaire reported no confusion or complaints when filling it out. However, an estimated 30% of patients simply couldn't understand it due to language barriers. Maori, Polynesian, Asian

and Indian ethnic groups all make up part of New Zealand's diverse cultural landscape. The incidence of diabetes is rising dramatically in these groups. Some also have cultural barriers, such as a mistrust of Western medicine, which make screening for and treating depression more difficult.

"That's why our next step is to translate the questionnaire into Maori, Samoan, Tongan, Niuaen, Japanese, Chinese and Gujurati for now, and into other languages if we see we need them later," says Ms Skerrett.

The programme has also created an additional positive spin-off, inspiring a survey to assess the level of psychological service provision nationwide. The results will be used to promote awareness at national diabetes conferences.

But the screening's success is still measured on the impact it has on the day-to-day lives of patients. "We had one high-achiever who, at least outwardly, gave the impression that he was on top of everything," says Ms Skerrett. "The questionnaire prompted him to talk about issues that were bothering him, and the caregiver to give him the option of a health psychology appointment – something the patient wouldn't previously have known was available to him."

Patient Questionnaire

Please circle the number that is closest to how you have been feeling in the past two weeks?

Over the last two weeks	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1 I have felt cheerful and in good spirits	5	4	3	2	1	0
2 I have felt calm and relaxed	5	4	3	2	1	0
3 I have felt active and vigorous	5	4	3	2	1	0
4 I woke up feeling fresh and rested	5	4	3	2	1	0
5 My daily life has been filled with things that interest me	5	4	3	2	1	0

Additional Questions:

Is there anything about your diabetes that has been worrying you lately?
 What is the hardest thing about looking after your diabetes?
 How is diabetes affecting your life at the moment? (for example work, study, recreation, relationships)
 Is there any part of your diabetes care you would like to improve?
 Are there any questions you would like to ask the doctor/nurse/dietitian today?

A reproduction of the depression screening tool in use at the Auckland Diabetes Centre. The questionnaire is being translated into seven additional languages.

In brief

EU Diabetes Working Group meets in Strasbourg

Members of European Parliament, International Diabetes Federation (IDF) Europe and other diabetes associations gathered in Strasbourg on November 17, 2004, for the first EU Diabetes Working Group. The goal of the working group is to develop an effective strategy toward the growing diabetes epidemic in Europe.

Discussion and presentations included subjects such as the growing threat of diabetes in Europe, access to animal insulin, diabetes control and new products, research and testing, and nutrition. Ms Anne Marie Felton of FEND pointed out the importance of self-management for good diabetes control, referring to the DAWN study as an important tool in understanding the psychosocial issues surrounding the disease. The meeting will be followed up with further dialogue in 2005.

Japan adopts national treatment guidelines

The Japan Diabetes Society has created official guidelines for the treatment of psychosocial issues in patients with diabetes. The treatment guidelines are included in the 74-page *Diabetes Treatment Guide 2004-2005* which is used as a reference tool by healthcare providers nationally.

The guidelines include sections on patient education, psychological and behavioral approaches to facilitate self-management, special considerations in diabetes treatment and the importance of team care. The initiative is the first to officially recognise and deal with the importance of treating psychological issues as part of standard diabetes care in Japan.

Israeli nurse conference takes DAWN focus

Leading diabetes care nurses in Israel were part of an intensive, hands-on national diabetes nurses' conference in November 2004. The event, with a motto of "Address the person behind the disease", was organised to share DAWN findings and practical tools for overcoming treatment barriers in patients and healthcare professionals.

Nurses were divided into work groups led by peers in their field and professional moderators. Groups used real case studies in role-play situations to practise psychosocial assessment in the clinic environment. The results from each group were later shared with everyone, along with DAWN study results and assessment tools.

Tools

Passport to better health

Dutch self-management booklet gives patients better control

Diabetes patients in the Netherlands can now keep test results, self-management tips and healthcare contacts in one easy-to-use passport. The DiaCard is designed to promote communication between people with diabetes and healthcare providers, and among all members of the healthcare team. The all-inclusive document also stresses the importance of self-management of the disease and puts patients in charge of their own care.

The DiaCard, now in its second generation, contains 16 pages of tips and information, and includes space for keeping annual test and examination results. It also features key information on the passport holder, diabetes care team and medication. Advice ranges from tips on staying healthy, both physically and psychologically, to travel considerations and ways to stay out of the hospital. There's also a section with key information on diabetes devices, such as meters, pumps, pens and needles.

Within two months of its introduction in June 2004, more than 25,000 passports had been shipped out. The goal is to distribute 275,000 passports by 2007, which would mean reaching 50% of the Dutch population living with diabetes. Patients and healthcare providers can find more information, or get a DiaCard, by visiting www.diacard.nl



Voices: Young people with type 1 dia

The following interviews are extracted from a student-led qualitative study on the patient experience of living with diabetes. The goal is to gain a better understanding of diabetes from the patient perspective. Names have been changed to respect the anonymity of the interviewees.

Interestingly, all participants in the study say that this is the first time anybody cared to listen or was interested in his or her every day experience of life with diabetes.

The interviews are part of the 'Diabetes: Living with risk' project managed by Anja Dahl and Anders Ellegaard Hansen, students in the Department of Sociology at the University of Copenhagen.



Q. Do you recall how you felt when you were told you had diabetes, and the first weeks afterwards?

Sara: I was seven years old, and it was somewhat of a shock. Well, it was horrible... and it was horrible to be committed to the hospital, it is perhaps one of the most traumatic experiences in my life, feeling so alone and abandoned. I remember a particular situation with a night nurse, where I got up to pee at night and she chased me back to bed. I don't recall what she said, but I lay there all night and held back, and it was terrible because when you are diagnosed with diabetes, you drink an awful lot... Overall, there were some good moments at the hospital but there were also some less good experiences, I would say.

Mads: I was diagnosed when I was 25 years old. I remember it was a Wednesday because there was a national soccer game, so I was furious that they wouldn't let me leave the hospital. I was told that I had to wear a white coat and that I needed a tube in my arm, and I could not in my wildest imagination see any reason for that. So I said no, and then I actually wanted to get home because I had guests coming over. I figured that if I had gotten by with this for the past three weeks, it should be possible to manage one more day. I had a big quarrel with the chief nurse, which ended with my having to stay, but being allowed to keep my own clothes and just drinking water from a glass... After I calmed down and realised how serious it was and that I was really sick, I got very sad of course. For the first while after, it was all so unreal because I had no sense that I was actually sick, other than that I was drinking and peeing a lot more.

Q. In what ways did being diagnosed with diabetes immediately change your life?

Sara: I think my diabetes made me grow up and become responsible very early on, in terms of taking care of myself. But it was extremely difficult back then, and of course there were a few years where I ate candy secretly. In practice, the rules were very strict in regard to your diet. They were totally impossible to follow as a child.

Thomas: I was 13 years old. In the beginning, I was very sad, of course, when I was abandoned at the hospital. There you break down, but afterwards you get back up again. For the first little while, it was kind of exciting, with the blood sugar measurements and the things one has to watch out not to eat and things like that.

"I find it most irritating to have to think about managing my diabetes when I'm in a situation where I have to be at my best. I would not want to be burdened by it, for instance, in a meeting. Then I choose a high blood sugar level."

Training • Tools

Video diaries offer an inside look at living with diabetes

The DAWN study showed caregivers that people with diabetes cope in a wide range of different ways with their disease. But the study dealt in numbers that, by default, could not offer insight into the personal experiences of individual patients. Now a component of the new Oxford Tutorials at the Oxford Centre for Diabetes, Endocrinology and Metabolism (OCDEM) takes that next step by sharing personal patient stories – in video diaries.

"We're capturing the stories of people who've lived with diabetes, and, in some cases, the stories of people who've managed their disease for up to 70 years," explains the chairman of OCDEM and International DAWN Adviser, Professor David Matthews. "For the GPs and other healthcare providers who are watching, there's no finger-pointing, or telling you what type of treatment you should or shouldn't pursue. You simply take what you want or is relevant to your own experiences from these real stories. In that way, we think you end up taking in more."



Professore David Matthews, chairman of OCDEM and International DAWN Adviser.

Inspiration for the videos came from a BBC news report on Aids in China. "We noticed that they didn't use the three minutes to tell us about Aids prevention, or even hard facts about the disease. Instead, they told us the story of one person living with the disease. In those three minutes, we viewers learned nothing about Aids, but at the same time, we learned everything about it. It's that type of learning we hope to encourage with the video diaries."

of caregivers could load a disc into a computer during a working lunch. They could easily view three or four vignettes, and still have time left over for a discussion of the issues they raise. It puts the onus on learning more about psychosocial issues back on the GPs."

"Instead of a didactic approach of explaining how many calories are in a burger, or telling the viewer – who is a trained healthcare provider, remember – the specific steps that should be taken to manage the disease, our vignettes demonstrate how real people feel about their diabetes, and the issues they have to cope with. It's poignant, engaging and very moving."

Each vignette is about three minutes long. An accredited oral historian guides the interview, exploring issues based on questions from the DAWN model, and a professional film crew captures the session on tape.

Eventually, the goal is to use the same methodology to get the stories of caregivers' experiences over the decades. But for now, an oral historian is capturing patient stories only and also filing them with the British Library Sound Archive.

The diaries are being recorded in English, using patients from existing contacts at the Centre, but the hope is to eventually adapt them to German and French. For now, they'll have a tremendous impact with English GPs and diabetes caregivers.

"They're very moving stories, and interesting from a historical perspective," says Professor Matthews. "But they're also invaluable educational tools, because they give GPs real insight into the psychosocial issues their patients face every day."

"These stories will be available online and on disc, but the discs are especially interesting," says Professor Matthews. "For instance, a group

Sara Sara is a 28-year-old psychology major living and studying in Denmark. She doesn't see her diabetes as a disease, but more as a condition she needs to manage. She was diagnosed with diabetes when she was seven years old, and can't remember what life was like without it. Her acceptance of her condition means she no longer fights it, which she had a tendency to do in her teenage years. In fact, her choice to study and work in the field of psychology is a direct result of her disease: She understands and knows how to deal with emotional instability because of the many times she has been hypoglycemic.

Sara considers herself intelligent, strong, responsible and in control of her diabetes – and wants her healthcare provider to understand and respect that as well.

Thomas Thomas is 28 years old and married with two children. His life revolves around full-time work and taking care of the two girls, leaving no time at all for sports or physical fitness.

Thomas was diagnosed with diabetes when he was 13 years old. Back then he found it exciting to have to measure everything and test himself, but today it is something he would prefer to forget about. Thomas feels that if he followed the recommendations from his healthcare professionals, life wouldn't be worthwhile.

Mads Mads is a 32-year-old journalism student living in Denmark, where he shares an apartment with his girlfriend. He found out he had diabetes when he was 25 years old, as he was being treated for a sports injury. He and his family know about diabetes because his grandfather also had it.

For Mads, the diagnosis made him realise that he was not as independent and "untouchable" as he once thought. He sees diabetes as something that has ruined his life. To prove that nothing, including the disease, can control him, he tests the limits when it comes to his lifestyle and taking care of himself. This includes the use of alcohol and drugs.

betes share their thoughts

Thomas: Nothing really changed. Except for the food, which was the big topic. In the beginning when we visited the family and got dessert, there was a special ice cream for me. And I actually asked them not to think about that for my sake... it annoyed me very very much. The notion that "this is for little Thomas because he is so sick." You end up feeling more sick than you really are.

Mads: In the beginning, it was a big problem for me that I had a very strict nurse, who said I could not eat anything containing more than 3% fat. I looked around for fat-free meats and cheeses, but it didn't take particularly well.... Then I reacted: I started deciding what I wanted to eat, and the disease would have to follow me. And I may have taken that concept too far, meaning that I do whatever I feel like and then see how the disease reacts, not the other way around.

You have to realise that when I got diabetes, it was the worst thing that could happen to me. My whole life...broke down. Because the only thing I didn't want in this world was to be dependent on anything. And suddenly I was the most dependent person in the whole world.

Q. How do you now manage your diabetes day-to-day?

Sara: I know everything about what I eat and how much energy it provides. But I don't eat at fixed times during the day. It is a funny sort of paradoxical control. Today for instance, I have only eaten this morning, and then some days I may eat three meals, other days only one meal. The reason it can work is that I am usually pretty good at sensing what I need in relation to my insulin and I check my blood sugar often. I also exercise a lot. It means a great deal to me to feel good about my body.

Thomas: In the beginning, I had to measure the carbohydrates that I ate and then got insulin afterwards, but I quite quickly moved away from that and since then have pretty much just regulated myself. I still eat candy and chips. For a while, I took a measurement in the morning so I would know where I was and then took insulin after that, but otherwise I do it a few times a week... But I don't measure morning, lunch and dinner. I don't do that.

Mads: My last A1c test was 12%, it's usually between 12% and 14%. It's a little high, but with my lifestyle I have always made sure to keep it up. It is, of course, not really good, but in reality it's exactly where I want it to be. When you're a bartender or journalist and are out in the field, you have to make sure you don't go into insulin shock. There is no immediate consequence of

"...I believe that good quality of life is more important. Your health depends on your mental well-being and if you want to be happy then you must accept some variations (in your blood sugar level) and be more loose."

having too high blood sugar. You can be at 25–26, nothing will happen right now, the problems are when it is low, so I have always made sure to be between 10 and 15. Then I know where I am.

Q. Have you had trouble managing it?

Sara: At the end of high school, I developed anorexia. That was easy to get because I was so used to controlling what I was eating, and how and in what way. That was not the reason for it, but it is so easy in some way to either overdo or underdo the level of control you put on yourself when you are forced to have it all the time. Other than that, I've been good, for the most part. The only thing I don't control is that I am still smoking. It is really stupid to smoke when you have diabetes, and I've tried to stop. But it hasn't really succeeded for three months, so it is still one of my "hideouts", I would call it. It is a way to say: I know that I am dying but then let me choose the way myself. Or that I don't care. It's an outlet for rebellion or anger. A cigarette is a kind of release valve for the pressures of all the attention and care that you have to give yourself all the time.

Thomas: Even though I usually feel that my levels should be under 10, I also feel that if I get too far down I won't be able to work properly, because then I will be constantly afraid of getting too low. It is like that, that you feel better when the blood sugar is a bit higher and the body gets used to it. I feel that if I could never touch the things

that aren't good for me, I wouldn't be able to survive. If you lived according to the very strict rules, life would be unbearable. The day might come when there is a sign of problems in the eyes or kidneys. I don't think I will change anything before that.

Mads: I don't know if I ever will be able to learn to live with it. I'll try, but I'm not sure. I have to find the same strength I've always had in relation to surviving, being the centre of attention, the strong person. I need to put that strength towards my self-management, but I actually think it doesn't matter at all. I don't think it is meaningful and it may

very well be that I die at 55 years old because I never got the hang of it. But on other hand, I will have been happy. Right now I'm trying to live better, but I can't say that I'm succeeding.

Q. What would you say the impact of having diabetes has had in your life?

Sara: I feel like I'm different, an outsider, and I've felt that way since the beginning. For better and for worse. I would also say that I've grown strong from the experience in all ways, it's impossible not to.

Thomas: It annoys me. You always have to remember the insulin. If you don't, you have to drive home, otherwise things could go very wrong. If you're in the middle of something that requires your full concentration and suddenly get low blood sugar, you have to stop and get back in control. Now it is more or less a habit for me, but I can actually sometimes forget to take my insulin. I'm reminded when I feel there is a drop of some kind.

Mads: It actually hasn't played that big a role. It has meant something, and naturally it is something I am aware I have, but in reality, it is actually quite incredible because it hasn't really played that big a role for me. I have ignored it until last week. Before that, I had never experienced, or even come close to experiencing, insulin shock or anything like that. But last week it happened twice. I fainted, and that's a bit scary.

Q. How would you describe your past and present relationships with your primary care providers?

Sara: I have a doctor I always see at the main hospital, and she is the only one I have ever liked. She completely respects my way of living. I have met so many doctors who only tried to teach me, which provokes me so much – they shouldn't just sit there and act cocky. It's my life and they shouldn't try to control it. We can talk about it, and they're welcome to tell me how and what and what the consequences are. But I need to feel there is respect. I remember a doctor five years ago who started to talk about pregnancy even though I wasn't interested in getting pregnant. She just sat there and gave me a lecture. That's an example of what not to do.

Thomas: If I followed their rules, I wouldn't be doing so well today. For instance, I eat as much candy now as I did before I got diabetes, which means that I take extra insulin. They can guide me, as I tell them, but if I some day decide to eat something I'm not allowed, then I adjust the insulin myself. I feel that what the doctors tell me to do ties me up. I just can't do it. I'd like to be able to, but my intake of sugar and candy hasn't changed.

I see my doctor once every six months, but it doesn't change the way I manage my disease. The fact that I'm not writing down my blood sugar measurements gets mentioned every time. I would put it like this: When I get to the hospital and sit down in the waiting area, that's when I start to feel sick. Not that I'm feeling physically ill, but I have some strange feeling that I might be able to manage this better. You really feel more sick when you're there. But the day after, life is back to the same routine.



I needed to do to get them down. I didn't really need to see a doctor to be told it would be better to spread out my meals. And then there was the issue about meeting people who sit with a critical look when you finally ask about something interesting. For example, I asked, what happens if I smoke cannabis in relation to my diabetes? I got the look. Then I asked, what happens when you take cocaine? They didn't know what to do, just sat angrily and studied their books.

Of course, you can also get a nice nurse who is willing to listen to your troubles or issues, but that isn't the only thing a visit to a diabetes clinic is about. It's also about the physical disease, and they measure your levels and talk about how you live and what you do and what you can do better. I can't function like that as a human being, it's impossible for me. That is, my overall level may be at 14.7%, but on the other side of the coin, I'm having a good time. But the focus there is only on the one physical side, and that's probably why I hadn't had a check-up in three years.

"The major episodes of low blood sugar are terrifying at the personal level, but of course, it is also the awareness that other people experience you differently if you suddenly lose a bit of control."

I have just recently been in for a check-up. I have

a new girlfriend, and I'm trying to be more serious. And, of course, she wants me to show that I am more serious and, how should I put it, worth the gamble that I won't die in five years because I live on the wild side. You get older too. I've lived a hard life, and I went in and told the nurse. I told her I drink too much. She said fine, she would help me with that. And I was actually much more interested in that than in the diabetes. I still don't need her to tell me that I should eat carrots or six meals a day. I didn't come back for her to tell me how many carrots to eat.

Mads: I don't know why I stopped going for regular check-ups. I just didn't feel like it. They didn't do anything for me, and I didn't leave the visits with anything I didn't know already. I wrote my levels in this book and knew they were too high, and also knew what



"I don't live according to a book, I'm a real human being."

Leading the way in Australia

National advisory board keeps the focus on patient-centred care

One of the challenges of increasing the psychosocial support for people with diabetes is that, to do it successfully, you must convince many different levels of a national healthcare system of its importance – from politicians and policymakers to primary care doctors and nurses. Without the willing participation of all these parties, increasing the psychosocial focus in every day diabetes treatment would not be possible.

Australia provides a good model for how a national advisory board can help make psychosocial issues a priority at every level of healthcare provision and government. "Real change comes from changing attitudes, and that's what the Australian experience is focused on," says Ruth Colagiuri, Chair of the Australasian DAWN Advisory Committee (ADAC).

ADAC works in the background, providing information, support and awareness that parties at every healthcare level can use to push DAWN initiatives forward, develop tools for everyday use and make sure the psychosocial needs of patients are being met as part of the normal treatment cycle. The board is made up of prominent healthcare professionals with a range of expertise in different areas, such as communication, research or practice. They represent a broad spectrum of the Australian and New Zealand healthcare community, and carry a lot of weight with their peers. The board meets quarterly, more or less, and also before major conferences or events, to discuss psychosocial issues and strategies for addressing them.

They also produce articles and publications disseminating DAWN information for Australian healthcare professionals. One 2004 publication, *The Australian Experience*, used the Australian data from the original DAWN study to highlight

the issues that were specific to their region. "The publication has been very useful and was well-received. Healthcare providers were hungry for this type of data," says Ms Colagiuri. "These results give them good ammunition for funding

"We are trying to create a broad undercurrent of subtle change," says Ms Colagiuri. "You can't always quantify it, or measure exactly what's happening. But from feedback and anecdotal reports, we believe it is making a difference."

and resource requests to implement strategies, because concrete findings show the problem in a way you can't ignore." The results were shared at the national DAWN symposium, which featured high profile speakers from the doctor, patient and nurses' perspectives. It was the first time the Australian results from the DAWN study were presented publicly.

ADAC can also be involved in the management of specific programmes. For instance, they are currently running focus groups with clinicians to develop tools that will help healthcare providers identify and manage or appropriately refer people

who have psychosocial problems. The eventual goal is to develop and pilot test a kit of aids that diabetes care providers can use to recognise and manage such problems more effectively.

But perhaps the most important function of the board is to simply keep the subject of psychosocial issues on the table at a national level. A constant voice ensures busy caregivers continue to pay attention to the issue, or at least can't ignore it. This is especially important in a country where access to proper care isn't always easy. Australia is almost the size of the continental US, but only has 1/20th of the population – which means there are a lot of remote areas. More than 180 languages are spoken in a population of 20 million, creating language barriers as well as geographic ones, and there is a general shortage of psychologists. With these challenges, the



Ruth Colagiuri, Chair of the Australasian DAWN Advisory Committee (ADAC).

board's aim is to ensure GPs, nurses and other direct access healthcare professionals continue to incorporate psychosocial issues into primary care and make the best use of available resources.

"We are trying to create a broad undercurrent of subtle change," says Ms Colagiuri. "You can't always quantify it, or measure exactly what's happening. But from feedback and anecdotal reports, we believe it is making a difference."

Helping people help themselves in Mexico

It isn't always easy to make the distinction between a problem and a crisis. But that's not an issue in Mexico, where diabetes currently affects 12% of the total population, including 25% over the age of 50 and an incredible 33% over 65.



"5 Steps to Self Care" participants in Neza, Mexico.

Left unchecked, 25% of all Mexicans will be living with diabetes within the next 10 years. A crisis not only in the making, but one already made – diabetes was the leading cause of death nationwide in 2004.

Yet even faced with these overwhelming numbers, there is no real national effort to diagnose, educate or comprehensively treat people with diabetes. In fact, half of the estimated 10 million people living with

type 2 diabetes in Mexico are undiagnosed and unaware of their condition. "Delayed diagnosis delays treatment and accelerates complications," says Courtney Guthreau, a director with Project HOPE-Mexico. "So half of new diagnoses come about from a diabetes-related complication. One in two new cases already have ocular lesions, and 50% have heart disease."

Project HOPE (H=Health O=Opportunities for P=People E=Everywhere), a non-profit organisation based in the USA, conducted a National Diabetes Assessment in Neza, a large suburb of Mexico City, in 2001/2002.

Of all the expert recommendations for action, the need for patient education to improve health and quality of life was the strongest.

"Because of the seriousness of the patient's condition by the time a diagnosis is made, most Mexicans view diabetes as a fatal disease," explains Ms Guthreau. "Many patients are also unaware that complications can be prevented or delayed through active

self-management." Not helping matters is a prevalent view of local healthcare providers that diabetes patients are lazy and unable to manage their condition.

In 2003, Project HOPE launched a two-pronged educational programme targeting patients and healthcare professionals. The patient programme, called "5 Steps to Self-Care", involved 12 2-hour sessions learning about risk factors and disease evolution, developing skills such as monitoring glucose and meal planning, and building a positive, proactive attitude towards self-care. To avoid literacy issues, the programme was primarily based on game activities and group interaction instead of reading materials.

After the launch, "Lend A Hand in Self-Care" was developed to transfer the 5 Step methodology into local health institutions. The programme teaches primary care doctors, dentists, nurses and outreach technicians how to become effective diabetes educators and work as a team to replicate the 5 Step course in their own clinics. It also helps them move away from the "parent-



child" model of interaction with patients, and see the value of treating patients as the most important partners in their diabetes care.

Today, 50 healthcare workers are actively replicating the 5 Step course in one university and six government-run health centres. More than 600 patients have attended 5 Step sessions, and a majority of the graduates are showing better self-management of their disease and healthier average blood glucose levels. The graduates as a group show an average decrease in Hb A1c from 8.9% to 8.0%.

A local group has also created a positive spin-off of the project by establishing a community outreach programme. They've adopted HOPE materials to inform family, friends and neighbours about diabetes, and how to prevent, diagnose and self-manage the disease. To date, the 25 members of Diabetics Union of Neza have reached 3,000 area residents.

Project HOPE is making a big difference in the lives of people with diabetes living in this community. But much remains to be done on a national scale. "The magnitude of the diabetes crisis here is the most daunting," says Ms Guthreau. "The patient and health worker courses have worked well here. But we must re-double our efforts to involve peer educators and health workers in spreading awareness about adopting healthy habits. That's how we'll reduce incidence nationwide."

Advocacy

Setting the standards

More countries developing guidelines to make psychosocial care part of routine clinical treatment

Today, most of us would agree that the psychological burden of diabetes needs to be recognised and addressed alongside clinical care and education. Yet though counselling and psychological behavioural therapies are widely available, they are underused. This is because, while the problem is better understood, it is not officially incorporated into the treatment framework for diabetes.

But that is changing, thanks to the efforts of DAWN and organisations such as the International Diabetes Federation (IDF) and the PsychoSocial Aspects of Diabetes (PSAD) Study Group of the European Association for the Study of Diabetes (EASD). The DAWN programme initiated the debate at the 2nd DAWN summit in London with the revelation that only a few countries had clear psychosocial treatment recommendations for diabetes included in their national diabetes guidelines.

As a result, IDF, DAWN, and EASD joined forces to organise the first International Consensus Meeting on guidelines for psychosocial care in diabetes. The event, held in Amsterdam on April 23, 2004, attracted leading diabetes psychologists from 14 countries. Together, they set the

stage for shaping international consensus towards new global recommendations for psychosocial care in diabetes treatment.

On April 22, 2005, IDF, DAWN and EASD are meeting again – this time to organise the 2nd International Consensus Meeting on practical implementation of psychosocial treatment guidelines for diabetes.

“National adaptation of psychosocial recommendations is a vital step towards achieving the goals of the DAWN Call to Action,” says Professor Frank Snoek, DAWN International Adviser, the Netherlands.



“Through the growing DAWN network of leading experts, concrete national initiatives are taking off in countries such as Japan, Germany, the Netherlands, the United States and Australia.”

New DAWN workshops for healthcare professionals

The DAWN study confirmed the need to provide better support to healthcare professionals in adopting new patient-centred diabetes care strategies. While most healthcare professionals recognise the need for better communication, real-life limitations such as time and resources often prevent sustainable changes from taking place.

The new DAWN train-the-trainer workshops for 2005 provide a fresh, practical approach to improving diabetes care by addressing the people behind the disease.

The workshops aim to facilitate new dialogue among peers about how to address key DAWN issues. They also promote individual attitude and



behaviour change through videos, interactive learning, practical evidence-based guidelines and simple daily tools.

Using the new DAWN Interactive Learning CD, healthcare professionals are encouraged to find local sustainable solutions to implementing the DAWN Call to Action in their own clinics.

Workshops are conducted on a local needs basis. For information about programmes in your region, please contact your Novo Nordisk affiliate. To see some interactive samples of training materials, please visit www.dawnstudy.com

Advocacy • Training • Tools

Amsterdam dialogues get nurses talking

In April 2004, Amsterdam played host city to a unique 1 1/2 day Novo Nordisk-sponsored event focused on diabetes nursing care issues. More than 270 diabetes nurse specialists from 14 countries took part in an intensive learning and networking experience.

Interactive DAWN workshops focused on improving communication with the patient and within the diabetes care team. Participants analysed DAWN videos with examples of diabetes consultations and debated how nurses can become better at listening to the patient during routine visits and addressing the psychosocial barriers to acceptance of treatment.

The workshops were introduced with talks by Soren E. Skovlund, head of the DAWN

programme at Novo Nordisk, Dr Christian Binder, co-founder of Steno Diabetes Center, and Lisbeth Vang, international project manager of National Diabetes Programmes at Novo Nordisk and former director of Nursing at Steno Diabetes Center.

Feedback from the nurses was overwhelmingly positive, and many participants took back information and methodology they could share with co-workers in their home countries. Nurses from Israel, for instance, returned with new material to share through national nurse forums and at the annual Israel Diabetes Association nurses' meeting.

Mary Sullivan, a Certified Diabetes Educator (CDE) from San Francisco, USA, found the sessions particularly rewarding: “It was an excellent way to hear about psychosocial issues from around the world.” On her return home, Ms Sullivan organised a conference through her local Association of Diabetes Educators chapter to share findings and implications of the DAWN study. She also presented some of the tools that could be used to assess psychosocial issues.

During the presentation, she surveyed the 45 diabetes educators, nurses, psychologists and dieticians in attendance to find out if they used psychosocial assessment tools or questions in their own work. Only 12% said they used formal tools, and more than half never asked psychosocial-related questions of their patients. Even so, participants responded enthusiastically to the workshop. Ms Sullivan plans to question them again at upcoming events to see how much of what they learned was incorporated into their daily practices.

Novo Nordisk organises events for nurses in diabetes on a regular basis and DAWN is part of the programme due to strong demand. International events such as these allow powerful networking and participants are offered tools to work with in their home countries for continued improvement.



A Call to Action

Five goals for better diabetes care were identified using the DAWN study findings. To improve health and quality of life for people with diabetes, we must:

- 1) Enhance communications between people with diabetes and healthcare providers
- 2) Promote communication and coordination between healthcare providers
- 3) Promote active self-management
- 4) Reduce barriers to effective therapy
- 5) Enable better psychological care for people with diabetes

To reach these goals, delegates at the 2nd DAWN Summit in 2003 proposed a framework for taking action, the DAWN Call to Action, which continues to guide DAWN initiatives around the world. The complete Call to Action was published by *Practical Diabetes International* and *Diabetes Voice* in the summer of 2004. The full-length version is also available at www.dawnstudy.com

The DAWN Call to Action

All stakeholders in diabetes, including people with diabetes, healthcare providers, funding agencies, policy makers, industry and non-governmental organisations must work together in a collaborative framework to:

1. Raise awareness and build concerted advocacy
2. Educate and mobilise people with diabetes and those at risk of diabetes
3. Train healthcare providers and enhance their abilities
4. Implement practical tools and systems
5. Promote policy and healthcare system changes
6. Take part in psychosocial research in diabetes

What is DAWN?

The DAWN programme is a global Novo Nordisk initiative in collaboration with the International Diabetes Federation and an international expert advisory board. Its aim is to promote new dialogue, best practice sharing and concrete initiatives to overcome the psychosocial barriers to optimal health and quality of life for people with diabetes worldwide.

The DAWN programme is a key part of Novo Nordisk's National Diabetes Programme to improve access to healthcare for all people with diabetes.

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DAWN

Diabetes Attitudes Wishes & Needs

2005 and beyond

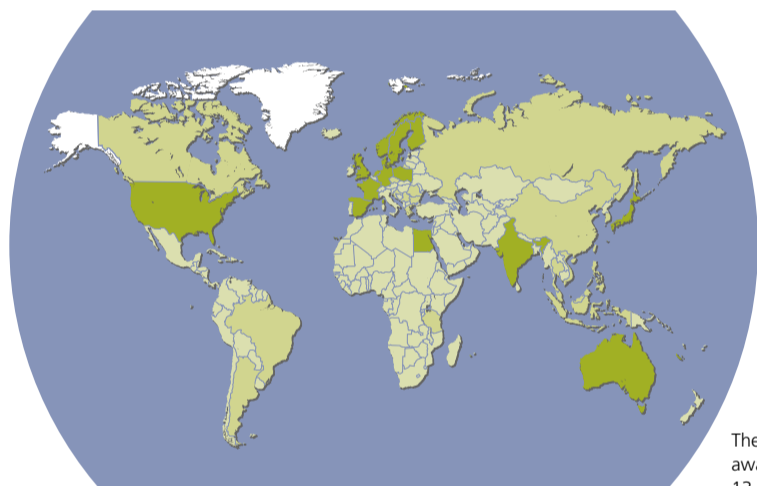
The many initiatives and actions started in 2004 are the starting points for long-term partnerships to improve diabetes care in a sustainable way. Through 2005, international and national DAWN activities will continue to bring together devoted healthcare professionals, people with diabetes, organisations and decision-makers who share the DAWN vision.

From web training of nurses in the USA, to well-being assessments in Asia and policy meetings in Ukraine, 2005 will be an exciting year aimed at changing health policies, training professionals,

engaging and empowering people with diabetes and building the socioeconomic case for investing in better diabetes care. A new focus on the attitudes, wishes and needs of underserved communities, ethnic minorities and young people with diabetes will also be introduced.

"People with diabetes deserve individual support and coaching to master their disease in daily life and deal with both the psychosocial and medical challenges it brings. Only through partnership among all stakeholders in diabetes can people with diabetes be truly empowered."

Soren Eik Skovlund, DAWN Programme Manager, Novo Nordisk A/S



The different shades of green show the level of DAWN action or awareness building in the region. Dark green represents the original 13 DAWN survey and action countries.

The DAWN Experiment

An exercise in communications for healthcare professionals.



Often the barriers to diabetes self-management remain hidden because we have not asked the right questions. Healthcare providers recognise that there is only limited time available for a meaningful dialogue between patient and provider, but as shown in the DAWN study they believe these issues are important.

The challenge is to quickly learn the most important issues from the patient's perspective so that the treatment plan can be a truly collaborative effort. We invite you to conduct an experiment with at least three people with diabetes that you see in your practice.

1. Ask

Ask your patient "What is the most difficult part of having diabetes for you?" Follow with: "Tell me more about that." and "Why is that so?"

2. Listen

Listen to your patient's story for at least five minutes without offering advice or interrupting. The goal is to learn the most difficult part of living with diabetes from the patient's point of view. If there is a pause, encourage the patient to tell you more.

3. Respond

Respond as you would naturally after the five minutes have passed.

The following questions have proved useful with some patients.

- "How would things have to change for you to feel better about this situation?"
- "Have you tried to deal with this situation in the past? If so what happened?"
- "What could I do that would help you?"

I want to know more!

To find out more about the DAWN programme or to sign up to receive this newsletter, please make your choices below, fill out your mailing details and return this form to us. You can also register online at www.dawnstudy.com

- Send me more information about the DAWN programme

Please add me to the DAWN newsletter subscription list:

- E-mail version (up to 4 times per year)
- Print version (up to 2 times per year)
- Both

- Please ask a Novo Nordisk representative to contact me

I have something to say!

Have a thought, comment, idea or suggestion to share with us? Please e-mail us at DAWNinfo@novonordisk.com and share your stories and ideas or let us know how you feel about the DAWN programme.

Mail or fax to:

Name

Address

Telephone

E-mail