

news

## DAWN Summit puts people first

On 5th November 2003, over 150 delegates from 31 countries met at the second DAWN Summit in London to discuss how diabetes care across the world must change to take into account the huge psychosocial impact diabetes has on its sufferers. The DAWN Summit has been developed to bring attention to the fact that the diabetes problem is much more than a need for medical treatment.

The Summit provided two days of presentations, panel debates, workshops and interactive sessions at which delegates could share best practice and discuss new approaches to dealing with

the growing burden of diabetes. Some of the world's foremost diabetes professionals from all five continents participated in the event. The summit resulted in a DAWN Call to Action in which the key messages and goals for better diabetes care were agreed upon (see back page) and all delegates made a commitment to be advocates for DAWN in their own countries.

The DAWN programme began with a study which set out to explore the attitudes, wishes and needs of all stakeholders in diabetes care.

The results of this study provided a blueprint of the current situation and exposed the gaps in support given to people with diabetes worldwide. Now, DAWN has moved on to find ways of addressing the needs of people with diabetes by focusing attention on the people behind the disease. •

Delegates share a thought at the 2nd International DAWN Summit



feature

## WHO calls for patient-centred care



Rafael Bengoa, the global director of the Department of Management of Noncommunicable Diseases at the World Health Organisation (WHO) has called for a complete change in the way chronic conditions such as diabetes are managed.

"Globally we need to 'scale-up' our efforts on diabetes as much as on other chronic diseases. Much of that will be about improving access to treatments in poorer countries and complementarily improving the management of diabetes," he says.

Speaking at the DAWN Summit, Rafael outlined the incredible threat chronic diseases are posing to the world. The WHO estimates that the burden of noncommunicable diseases, such as diabetes, will rise for developing and newly industrialised countries to 43 percent by 2020 and globally these conditions will account for more than 50 percent of the burden. He says that current healthcare models just do not work for chronic diseases and new patient-centred care plans need to be put in place.

"In general, a patient appears with a condition, is treated and then discharged. He then disappears from the radar screen," Rafael says. This is highly inappropriate for chronic conditions and could explain why only half of people with these diseases adhere to their treatments. "Current healthcare models are oriented to acute illnesses with a focus on symptoms and lab results. The patient's role in managing a condition is not emphasized and follow-up is often sporadic," he adds.

Also, one of the biggest attitude shifts he advocates is to realise that cure is no longer the determining outcome for many conditions; it is the quality of life of the patient and family that should be considered, and the vital role that the patient has in providing their care must be understood.

"Living with long-term conditions has made

patients experts in their own right," he says, "and so authoritarian interactions by health providers should be replaced with supportive and co-operative encounters"

"In a world in which healthcare systems are failing people with chronic diseases, we need a new paradigm in which patients with chronic conditions like diabetes become their own healthcare providers, with healthcare professionals playing a supporting role. This patient-centered healthcare model will depend more than ever on partnerships. It is important that we get it right," he says.

"The DAWN Summit convened by Novo Nordisk is one example of a partnership event around global advocacy and insights to improve diabetes care that will surely have implications for the general approach to improving patient-centred care for chronic diseases," he says, adding that the outcomes of the DAWN Summit would be taken into account at the WHO in developing new policy principles. "At the WHO we have to make sure that we are putting the patient first. Patient-centred care is the main paradigm that is guiding the WHO healthcare model we are coming up with," Rafael says. •

news

## The DAWN award

At the 2nd International DAWN Summit, Novo Nordisk invited individuals and organisations to submit examples of how they have contributed to improve diabetes care by addressing the people behind the disease.

"The award will be given to outstanding examples of concrete action that others can take inspiration from and follow as a model", Lise Kingo, Senior Vice President of Stakeholder Relations, Novo Nordisk says.

The winner of the DAWN award will be granted €10,000 for the continued improvement of diabetes care. Additionally, the five best examples,

including the winner, will be described and shared with all DAWN partners to take inspiration from.

A DAWN award submission form is available from [www.dawnstudy.com](http://www.dawnstudy.com), and submissions must be returned by August 1st 2004. The best examples will be selected by the DAWN advisory board and will be announced in November 2004. •

## European meetings on DAWN implications

At the 2nd DAWN Summit, representatives from the Federation of European Nurses in Diabetes (FEND) and Primary Care Diabetes Europe (PCDE) agreed to pursue a joint meeting in September 2004 in Munich to follow-up on the actions set forth at the DAWN Summit.

The programme will be finalised in Spring 2004 and is intended to focus on the training and practical tools needed to implement the DAWN Call to Action.

In addition, the European Association for the Study of Diabetes (EASD) study groups on psychosocial aspects (PSAD) and education (DESG) will include DAWN in their scientific symposium during the annual EASD meeting in Munich next September.

More information on these and other DAWN events will be available from [www.dawnstudy.com](http://www.dawnstudy.com).

## Diabetes Voice Special Issue

In a joint collaboration of Novo Nordisk and IDF, a special issue of *Diabetes Voice* will be published to create awareness about the need to address the people behind the disease across the world and encourage action.

The issue will address both the practical and system approaches to addressing the people behind the disease, and follow up on the many outcomes of the DAWN Summit.

*Diabetes Voice* is a magazine of the IDF and reaches many stakeholders, including patient organisations, member associations, IDF officers, individual and life members in 142 countries.

## A European study on the well-being of people with diabetes

Sue Shea, a health psychologist living in Greece has implemented the WHO-5 well-being questionnaire across six countries as a follow-up to the DAWN study together with the World Health Organization and Novo Nordisk. It has been used to assess psychosocial well-being amongst people with diabetes.

A total of 624 people with diabetes responded to the questionnaire, and Sue's analysis showed that it is a very good way of spotting those people who may need more support.

"We showed that it was very reliable and able to distinguish between patient groups. The main findings are that it's very quick and easy to use and involves patient in the care process," she says.

The next stage of the project is to continue our partnership with the DAWN programme and develop the questionnaire further.

"The intention is to do a new survey involving more countries using the WHO-5 questionnaire with some added questions," says Sue.



### interview

## Let's make a difference

As delegates gathered to begin their discussions on the future of diabetes care, Lise Kingo, executive vice president of stakeholder relations at Novo Nordisk outlined her vision for the changes the DAWN programme could deliver. "DAWN is about realising real issues and problems that affect people with diabetes and making a difference," she explained.



Although Novo Nordisk has been operating for 80 years, treating people with diabetes, and providing new insulin therapies and methods of delivery, Lise is keen to point out that there is

a whole other side to dealing with the growing threat of diabetes: "Diabetes is our challenge, our passion, and our business. We believe as a company that we need to not only treat diabetes with better drugs, but we need to address the people behind the condition."

To that end, Novo Nordisk convened the DAWN Summit to discuss the real issues that affect people with diabetes and their carers and to develop a plan of action to create a healthcare platform that would serve the needs of all people with diabetes in both the developed and developing worlds.

"Diabetes is the world's fastest growing chronic disease, and needs a greater degree of focus from all stakeholders in healthcare across the

world," Lise says. "We have to take action to lighten the burden or reverse the trend totally."

Through DAWN, healthcare professionals can start to more effectively address the barriers to effective treatment and self-management of diabetes, making current treatments more effective and improving the quality of life of all people with diabetes.

Lise explains that this is much more than a PR exercise: "What we hope to achieve in this summit is to make a difference. We cannot hope to change the major problems of this world, particularly in diabetes care, without partnerships. DAWN has given us a platform to develop these partnerships and collaborations, which we can now use to put the wheels of change in motion to improve the quality of life of people with diabetes. It is about asking, listening and responding to people's needs and acting accordingly."

The partnerships forged through DAWN between all the stakeholders in diabetes care will create a whole new level of understanding that can be used to improve the day-to-day treatment and support offered to people with diabetes. Novo Nordisk is determined to help this process along, as Lise explains: "It is a fair question to ask us why a business like Novo Nordisk is so interested in improving the lives of people with diabetes over and above offering products. The answer is, simply, that we feel it is our responsibility, as leaders in diabetes care. DAWN is an attempt to take our understanding of the human behind diabetes to another level. It makes moral sense, it makes social sense, and it makes sense from the perspective of a long-term business."

Lise is well aware of the criticisms levelled at pharmaceutical companies: "Pricing in developing countries, intellectual property rights and marketing ethics are some of the dilemmas that the pharmaceutical industry is facing today. As a guide to help us deal with these dilemmas, more than a decade ago, we decided to adopt a Triple Bottom Line to ensure that we would always balance the social, ethical and environmental concerns with our financial performance.

"DAWN is an excellent example of how we put the Triple Bottom Line into practice. We must earn stakeholder's trust to run a successful business. We understand that in today's complex society our perspective is only one of many. We have to listen and learn."

### interview

## The global importance of DAWN

Pierre Lefebvre, president of the International Diabetes Federation, spoke to the delegates about the importance of collaboration in the fight against diabetes.

"The mission of the IDF is to work with its member associations to enhance the lives of people with diabetes," he said. He pointed to the three main types of bodies that the IDF believes are crucial to improving the lives of people with diabetes: academy, organised bodies and industry.

By working together, it really is possible to put the person with diabetes at the centre of the care system and each of the different kind of organisations can play a part. As an example of the kind of things that can be achieved, Pierre explained how the IDF was partnering with the World Health Organisation on a campaign entitled "Global Awareness Advocacy and Action in Diabetes". Through initiatives like this attitudes and awareness in diabetes can be changed on a global level.



He finished his talk with an acknowledgement that, with partnerships, the DAWN programme could herald a new era in the care of people with diabetes.

## interview

# Why DAWN?



David Matthews, Professor of Diabetic Medicine at the University of Oxford and Chairman of the Oxford Centre for Diabetes, Endocrinology & Metabolism opened the DAWN Summit with an outline of some of the issues that the DAWN Study had revealed and some of the challenges facing diabetes healthcare.

"The key DAWN findings are that we can, and should, change the way we manage diabetes," he says. This can be done by not just focusing on the condition, but the whole person, he points out.

David Matthews believes that one of the most difficult aspects of dealing with the growing diabetes epidemic is to convince governments to spend money on the problem. "Conditions like AIDS take up huge amounts of budgets. AIDS has advocacy and it is dramatic. It's the equivalent of the black death right now. But diabetes is something that is relatively quiet and doesn't generate the same kind of stories in the media that propel governments into action," he explains. "So what we're seeing, in cash-strapped health services, is a lot of resources put into these more visible areas, such as AIDS, acute medicine and surgery."

For Professor Matthews, DAWN is an opportunity to make a difference to the quality of life for people with diabetes despite the resource constraints. "What does DAWN have to do with this? Well, it can help build teams of people, both in the developed and developing worlds that are knowledgeable about various aspects of diabetes. These people can spend time explaining best-practice and disseminating their knowledge. This doesn't have to cost a lot of money. For example, educational teams, even visiting for a short time and training people to become experts in best practice is something that can be done for very little investment," he explains.

At the Summit, Professor Matthews outlined the goals that he wanted all the delegates to concentrate on: "Why is it that over half of people with diabetes do not experience full health and

quality of life despite the availability of effective medicines? We have to look at the issues here and see how we can change things." He asked the delegates to consider five main goals:

- How to enhance communication between people with diabetes and those that provide their healthcare?
- In what ways can we enhance the communication between team-members working in diabetes care?
- How can we help people with diabetes to improve the self-management of their condition?

- What is stopping doctors from using the most effective therapies at the appropriate time, and how can we go about changing that?
- Diabetes can have a devastating psychological impact on people with the condition. How can we provide them with better psychological support to cope with this?

Over the two days at the DAWN Summit, delegates discussed these issues and formulated ideas for further actions to achieve the five goals. •

## news

## Experiences from Poland

To demonstrate how DAWN can be translated into practice on a large scale, Andrzej Kokoszka, Professor of Psychiatry at the Medical University of Warsaw, shared his experience in Poland with delegates.



The DAWN Study in Poland showed some alarming trends. Almost three quarters of people with diabetes were constantly afraid of their disease getting worse and even more were worried about having to start insulin.

Among the doctors surveyed, a staggering 85 percent were using threats to encourage patients to follow their recommendations and 29 percent said that they would prefer to delay insulin treatment until it was absolutely necessary.

As a result of these findings a national programme was set up to support people with diabetes. Training courses began last September to teach diabetes specialists and general practitioners about the psychosocial needs of people with chronic illnesses and how to tailor treatment to each patient's needs and personality.

The courses use findings from the DAWN study

and engage physicians to train other diabetes health professionals in Poland.

The programme is on-going and will reach several thousand primary care physicians in 2004. For more information go to: [www.novonordisk.pl](http://www.novonordisk.pl) •



## interview

# Mind over matter



Martha Funnell, a clinical nurse specialist and diabetes educator at the University of Michigan School of Nursing, USA, explains the psychological impact diabetes can have.

It's easy to think of diabetes in pure medical terms, concentrating on blood glucose levels and medicines, but for Martha Funnell, the real picture is much more complex.

"There are so many extra pressures diabetes puts on people's lives. The first one is that you're faced with a life threatening disease. It's upsetting and its frightening," she says.

It's a pressure that never goes away, even after the initial shock wears off. "Living with diabetes means facing the fact that you're having these potentially fatal complications hanging over your head all the time. You might be able to prevent them, but there's no guarantee. It's this uncertain future that creates a lot of the stress associated with the condition," Martha explains. Coping with this black cloud on the horizon would be bad enough, but Martha points out that the day-to-day practicalities of dealing with diabetes causes just as much anxiety. "It effects your whole life," she says. "You have to factor it into all the major decisions you make. You have the usual pressures of jobs and families,

and on top of that you're having to constantly think about and manage your diabetes. It's a strain."

One of the things she knows from speaking to many people with diabetes is that it is often other stresses in life that push people over the edge. "People tell me that they use up so much energy dealing with diabetes that when another problem comes along, it hits them really hard."

Martha thinks that it is hard for health professionals to really understand just how overwhelmed some people with diabetes feel. "People can get overwhelmed with the facts and the figures. One of the things that we have learned is to give people the information they want when they want it and when they're ready for it." Day-to-day management of glucose levels is another big cause of stress. People want a perfect treatment that they know will work in a particular way. "But we don't have perfect therapies yet. So a person can manage their diabetes in exactly the same way on two separate days, but on the second day their results may go haywire for seemingly no reason. When that happens they feel frustrated and angry and often assume that they have done something wrong."

It's this feeling of failure that Martha plants firmly at the door of healthcare professionals.

"I think we have fostered that 'failure feeling'," she says. "We have often used the phrase 'having to go on insulin' rather than explain that insulin is just the next step in the treatment path. The ultimate goal is to keep blood glucose controlled and that should be the focus of our messages."

She also feels strongly that the psychological aspect of living with diabetes can be integrated into the regular medical maintenance of the condition. "We tend to put things into categories. This is diet, this is psychosocial, this is medical. I don't think it has to be like that."

As a starting point, Martha advises asking everyone who comes to a clinic what they want to achieve by the end of this particular appointment and centre that meeting around those needs. "I think, as professionals, we need to learn to listen. People tell us what they need, they show us in many ways but we need to be sure we're listening."

At the DAWN Summit, Martha invited participants to join in on the DAWN Experiment to show how easy it can be to get to the heart of the psychosocial problems a person with diabetes may be having.

For details of the experiment and a chance to try it out for yourself, see the back page. •

the data

**A global initiative to improve psychosocial support for people with diabetes**

**Introduction**

The very fact that more than half of people with diabetes do not achieve good health and quality of life, despite the availability of effective medical treatments, was the reason of the DAWN study was initiated. Although a considerable amount of psychosocial research had been carried out which pointed to psychosocial issues as one reason for poor treatment outcomes, there were no large, truly global studies to map out the problem. Important gaps in knowledge existed, particularly concerning data which would (a) allow for international comparisons of management approaches to diabetes, (b) examine the complex relationships between the stakeholders – people with diabetes and their families, the physicians, the nurses and their support teams, and (c) enable policy makers and other stakeholders to recommend changes where needed.

**Methodology**

The DAWN study was conducted in 13 countries, including Australia, Denmark, France, Germany, India, Japan, Netherlands, Norway, Poland, Spain, Sweden, United Kingdom, and the United States. It included a total of 5,426 people with diabetes. Among respondents with type 2 diabetes, 1,370 used insulin and 2,056 did not use insulin. The study also included 2,194 primary care physicians, 1,122 nurses and 566 specialists, including endocrinologists and diabetologists.

The DAWN study included a literature survey; an initial qualitative mapping of attitudes and perceptions, involving policy makers, and a large scale interview survey. The patient population included sample sizes that allowed for statistical analysis.

The DAWN questionnaire was designed based on the qualitative mapping and the literature review to assess the following areas in some detail: diabetes self-management, psychological health, physical health, everyday life patterns, diabetes knowledge and beliefs, diabetes history, perceptions of healthcare provision, and the sociocultural environment.

Specific questionnaires were designed for nurses, diabetes nurses, general practitioners and specialist doctors, and people with diabetes to obtain a 360 degree view of the psychosocial issues of diabetes care.

The graphs on these pages are examples of the multitude of data collected for DAWN within the five key areas of diabetes care that were identified for future action by the DAWN programme. •

**Communication between with people with diabetes and healthcare providers**

**The data:** The good news is that the majority of people report having a good relationship with their healthcare providers. However, those who have a poor relationship with their healthcare provider are more likely to claim to be stressed and in poor control. Related DAWN data show that 60% of healthcare providers look for ways to communicate better with their patients and more than a third do not feel able to address all the psychosocial needs of their patients.

**Implications:** Enhanced communications between people with diabetes and healthcare providers is required to better understand and address the individual needs of people with diabetes. The adoption of a diabetes care model that promotes dialogue between healthcare providers and people at risk of, or living with, diabetes can enable people with diabetes to make more informed choices about their self-management and thereby achieve better health and quality of life.

People with diabetes who agree to: "I have a good relationship with the people I see about my diabetes"

Country	Agreement (%)
Japan	49%
India	81%
Scandinavia	91%
Netherlands	92%
USA	92%
Australia	93%
Poland	93%
UK	93%
France	95%
Germany	95%
Spain	95%

People with diabetes reporting good diabetes control

Relationship	Good Control (%)
POOR	37%
GOOD	53%

People with diabetes reporting diabetes distress

Relationship	Diabetes Distress (%)
POOR	37%
GOOD	25%

**Communication and coordination between healthcare providers**

**The data:** Only half of people with diabetes believe the members of their healthcare team talk to one another about their diabetes problems. Even in the best region, Scandinavia, around a third of people with diabetes feel their diabetes healthcare providers communicate with each other. Almost three out of every five persons with diabetes say they have poor access to a nurse in their primary health-care practice. Related DAWN data show that the majority of healthcare providers recognize that more communication is needed within the diabetes team

**Implications:** Effective care for diabetes requires a multi-disciplinary team-based approach to ensure seamless and consistent care which is centered on the patient. Initiatives are needed to improve communication between all the members of the diabetes care team and to develop and optimise the role of each member of the team.

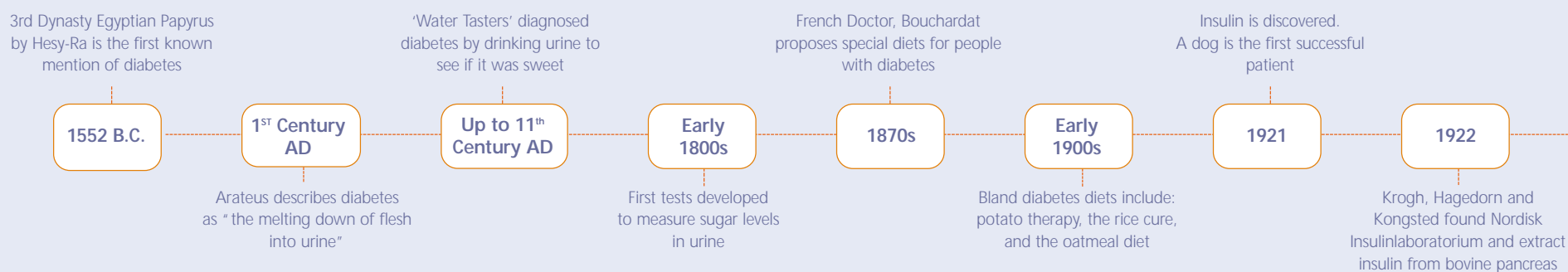
People with diabetes who agree to: "I think the people involved in my diabetes treatment talk with each other"

Country	Agreement (%)
Poland	28%
Japan	38%
India	42%
Spain	45%
France	50%
USA	53%
Australia	55%
Netherlands	58%
UK	60%
Germany	61%
Scandinavia	67%

People who say that:

Statement	Percentage (%)
Nurse available in primary care practice	41%
All providers under one roof	60%
Providers talk to each other	52%

**Diabetes Timeline**

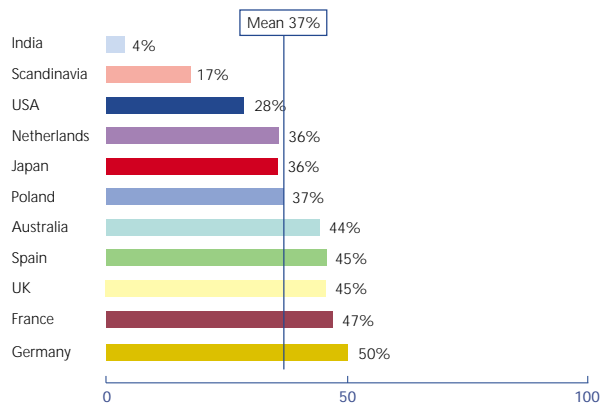


## Diabetes self-management

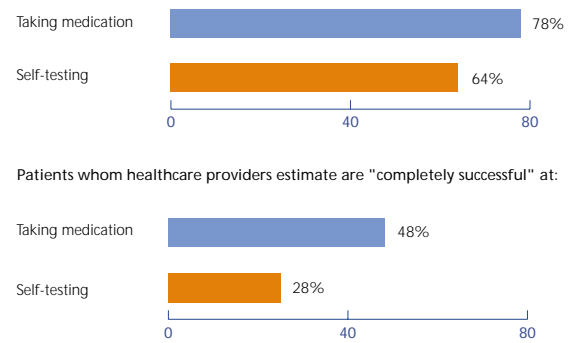
**The data:** People with diabetes as well as healthcare providers report that self-management of diabetes is poor and a major obstacle to achieving better glycemic control and quality of life. People with diabetes report much greater success with their self-management than estimated by healthcare providers. Related DAWN data show that the majority of healthcare providers believe that psychosocial problems play a role for their patients' ability to manage their treatment.

**Implications:** Self-management is essential to the management of diabetes to obtain optimal control of diabetes and quality of life. Through a better understanding of the importance of psychosocial issues for people with diabetes, healthcare providers may become better coaches for their patients and enable them to identify agreed on goals for self-management that will improve their health and quality of life.

People with diabetes reporting completely following their diet recommendations



People with diabetes who say they are "completely successful" at:

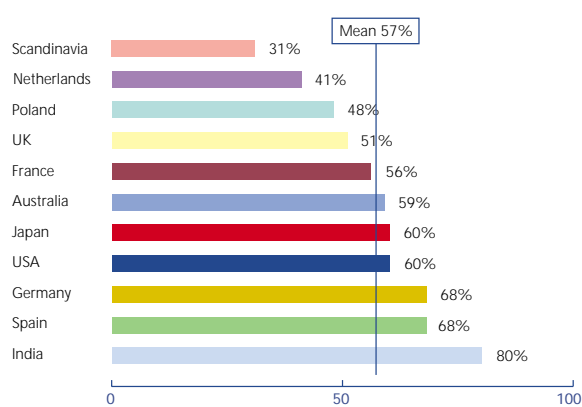


## Barriers to effective therapy

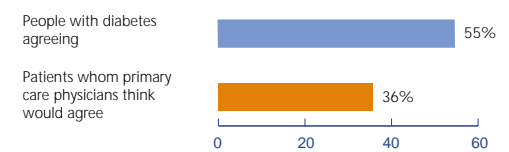
**The data:** 55% of people with type 2 diabetes not on insulin believe that starting insulin would mean they had failed their own management of the disease. Healthcare providers are not fully aware of this problem, estimating this problem to occur in only about a third of their patients. Related DAWN data show that more than half of people with type 2 diabetes not on insulin worry about having to start insulin therapy and that about half of all healthcare providers use insulin therapy as a "threat" to encourage adherence to tablet and diet recommendations.

**Implications:** Effective therapies in diabetes are often delayed in people with type 2 diabetes because of misconceptions and emotional barriers. Delaying good therapy can lead to increased risk of disabling and costly diabetes complications. The cognitive, emotional, and educational barriers that exist among stakeholders in diabetes to use of effective therapies need to be addressed.

Doctors delaying insulin



"Starting insulin would mean that I have not followed my treatment recommendations properly"

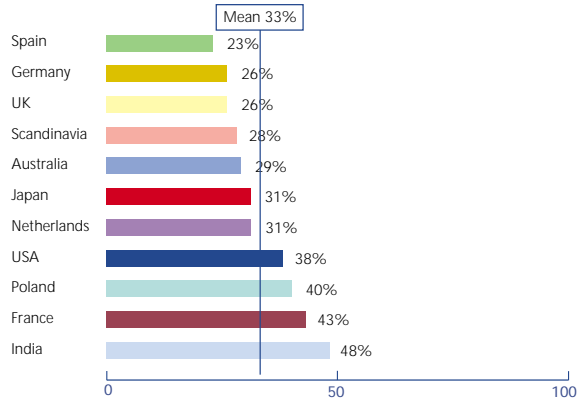


## Psychological well-being

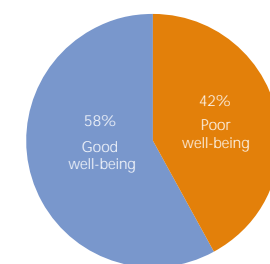
**The data:** More than two in five people with diabetes report poor psychological well-being. Many experience stress due to managing their diabetes. Related DAWN data show that the majority of healthcare providers would like to become better in identifying and managing psychological problems, and more than a third do not feel equipped to adequately address their patient's psychosocial needs.

**Implications:** There is a critical gap between the psychological treatment needs and the available psychological support. Increased awareness, identification and appropriate management of psychological issues in diabetes is called for. Healthcare providers should be supported to better assess and address the psychological treatment needs of their patients as part of their daily care.

People with diabetes who agree to: "I feel stressed because of my diabetes"



Psychological well-being of people with diabetes (Measured using the WHO-5 Well-being Index)



Source: data on file and [www.diabetes.ca](http://www.diabetes.ca)

Brothers Harald and Thorvald Pedersen put Insulin Novo and the Novo Syringe on sale

The standard insulin syringe is developed helping make diabetes management more uniform

The distinction between the two major types of diabetes are recognised

Novo Nordisk formed by the merger of the two Danish companies

1925

1940s

1944

1957

1979

1980s

1989

2003

Link made between diabetes and long-term complications in the eyes and kidneys

Oral drugs are introduced to help lower blood sugar levels

First biosynthetic human insulin is introduced and NovoPen concept developed

2nd DAWN Summit convened to mobilise concerted advocacy to address the people behind the disease

interview

# The doctor

## Workshop: communication

At the second DAWN Summit, delegates got together to discuss communication issues in a workshop. Professor Bob Anderson, an education psychologist at the University of Michigan, chaired one of these workshops.

“There are many barriers that get in the way of fruitful communication between people with diabetes and healthcare professionals,” he says. “Many of these barriers are derived from the fact that we have developed an acute care system that is built to respond to episodic, symptom driven, short-term problems. And when we try to treat diabetes in that system it often puts up as many barriers as it does solutions.”

One of the main examples of this is the time constraints put on doctors. There is a pressure to see more patients in less time, and also provide all the solutions to the patient in that very short time, and this can cause a huge communication barrier.

So one of the things that the workshop discussed was ways of helping healthcare professionals to understand the needs and wants of people with diabetes. One simple idea that came up was to encourage patients to give a list of things that they wanted to achieve in a particular visit to a clinic.

Money is another part of this equation. Unless finance is made available to give doctors the time and resources to listen to their patients, things are not going to change.

“So we have a lack of skills, a lack of time and a lack of recognition that this is important,” says Bob.

One of the first steps that can be taken is to mobilise everyone with an interest in diabetes to start discussing this problem. “So, one of the things we talked about in the workshop was that everyone should accept that they have a role in changing this situation.”

“Whether we’re talking with a healthcare professional or person with diabetes, we should accept the responsibility that this is an opportunity to try and move forward, to advance the idea of how important it is to have a good relationship and good communication between patients and healthcare professionals,” Bob says. •

Professor Philip Home, Professor of Diabetic Medicine at the University of Newcastle Upon Tyne, UK, explains some of the issues facing doctor-patient relationships today.



From the moment of diagnosis, people with diabetes are faced with a barrage of information and choices. There’s the technical aspect of diabetes to explain as well as all the lifestyle issues that have to be communicated. Professor Philip Home acknowledges that the initial meeting with a diabetes specialist can be daunting.

edges that the initial meeting with a diabetes specialist can be daunting.

“When first diagnosed, the major problem is that people are in shock. It’s not easy to listen and take in all the facts and it’s hard to appreciate the position you are in. So, one of my major frustrations is that I’m aware that there is a good deal that people should be taking in but they are not able to do that at this time. All I can do is deal with the critical issues at that first consultation.”

Of course, over time, the shock subsides, and it’s then that doctors, such as Philip, try to move the agenda on to talk in more depth about what diabetes means to someone and how they should begin to change their lifestyles to accommodate the condition.

“I explain that they are only going to see the diabetes team once every three months or so, and in the meantime diabetes will be with them. In this way I try to impress the logic of them taking control of managing their condition,” he says.

Most people accept this reasoning and Philip doesn’t think that, for the most part, there is a problem with people understanding the technical issues and grasping the knowledge associated with diabetes. “I find people pick up the understandings and knowledge quite quickly. What people have problems with is building those understandings into their current lifestyles,” he says.

Philip agrees that there are always those situations where everything has been explained to the patient, they seem to have understood what is needed, but when this person returns for their next check-up it is obvious that they have not been following the recommendations.



Addressing the whole person is key to better care

“When that happens, I feel guilty,” he says. “It’s a sign that the system is failing somehow. We should be able to help these people achieve good health and for some reason it’s not happening.”

Part of the problem is time – time that many consultants don’t have. It’s a lengthy process to explain all these elements to people, and it takes time to talk to them and explore their current situation in enough depth to make sure that the advice given is relevant to them.

“The most common request we have is to help people find ways to manage their diabetes that fit into their lifestyle. We need to explore their lifestyle in detail, maybe look for other insulin dosing arrangements, really explore these solutions on an individual basis. But this takes a lot of time.”

The psychology of the patient is also something else that Philip has to keep in mind. Some people can become so stressed with their condition over a period of time that they are not taking in

any of the information given to them. “Bad news is always a worry,” Philip says, “and it’s difficult to avoid that. We have a duty to tell people what is happening to them – to offer them ways of improving their health.”

“At the other end of the spectrum, you have patients that are so laid-back that all the information just rolls off of them like water from a duck’s back. They don’t take the information in either – that’s their choice. Of course most people sit somewhere in between and take some of the information in, but maybe not all of it.”

For the future, Philip would like to see a complete shift to patient-centred treatment. “While we talk a lot about patient-centred care, it’s obvious to me, at the present, that we are not making a lot of progress achieving that. I think we have to find tools to emphasise patient-centred care within the clinics, then we have to disseminate the concepts and spread them out as widely as possible. Only then will we have a system that can provide proper individualised care.” •

### Key messages doctors would like their patients to take home:

- 1** You have diabetes, you definitely have it and it won’t go away. •
- 2** Diabetes can be a significant problem but with our assistance you can control your blood glucose levels. •
- 3** There is no reason why, with adequate control, you can’t live a good, healthy lifespan. •
- 4** You will only see our team for a limited amount every few months, but diabetes will be with you every day. It’s up to you to control it between consultations. •
- 5** It’s not just me, the doctor, who is going to be standing behind you, but the whole of my team of colleagues including nutritionists and diabetes nurses. Together we will be helping you. •

interview

# The patient



Jo Cape was diagnosed with diabetes when he was 18 years old. Now 35, Jo has had seventeen years of experience of talking to doctors, nurses and other health professionals about his condition and has found that things have not always gone well.

"At first, I didn't have much of a problem with my diabetes or the treatment I received," he says. "I suspected that I had diabetes and so it was not a great shock when it was confirmed by my doctor."

Rather than get depressed by the daily management of the disease, Jo decided to take it all in his stride. "Initially, it was not such a big deal as

I was young and pretty resilient and my blood sugar was pretty good," he explains.

However, as the years have passed, he has found dealing with his diabetes increasingly difficult and has become increasingly dissatisfied with the treatment and support offered by the healthcare system.

"I'm a dentist, and understand the importance of keeping healthy. Recently things have not been going well. I adhere strictly to my treatment regimen but am finding it difficult to stabilise my blood sugar levels, despite checking it four times a day" Jo says.

In fact despite regular exercise, and a carefully controlled diet, diabetes is taking its toll on Jo's health, leaving him feeling physically drained, suffering from constant nausea and muscle loss. It is now that things are not going so well for him that Jo has found that the healthcare professionals are letting him down.

"I've consulted various specialists about my condition, but my worries seem to get dismissed without any satisfactory improvement in my condition," he says. "I am not at all happy at the random frequency of seeing different specialists and the lack of consistency and continuity in the care that I receive."

One of the main problems that Jo highlights is that almost every time he visits the hospital he is treated by a different specialist and has to go through his history as though he is a new patient. "Every time I go, I am asked a litany of pointless questions instead of discussing the issues that are really affecting me."

"I do not feel as though I am being treated well at all," he says. "I would like to have someone who understands the challenges I face and has the patience enough to help me steer through the problems. At the moment, seeing someone for 20 minutes every six months is not nearly good enough."

The only bright spot in Jo's treatment seems to be the specialist diabetes nurses. "They are the most supportive people I see. In fact, they are the people who have constantly helped me get through my difficulties with diabetes over all these years."

So what would it take to make Jo satisfied with his care? "I suffer from chronic depression as a result of the constant physical strain of diabetes and worry about my future, I feel it would help if the doctors understood this and referred me to support groups."

In all the 17 years of living with the condition I am still not aware of any support groups to help me. My relationship with friends and family are suffering and I feel a great need for extra support.

I cannot stress enough how much more the psychological pressure of diabetes affects me, a good deal more than the need to deal with the biological effects and comply with the insulin regimen."

In short, Jo feels as though doctors concentrate too much on the purely medical side of diabetes. "I feel neglected by the system. Although I have found a number of specialists a great help over the years, in recent times the level of specialist insight into my condition falls short of treating me as a whole person." •

## Workshop: barriers to effective therapy

Another workshop at the DAWN Summit looked at the barriers to effective diabetes treatment. Sue Craddock, a consultant nurse in diabetes care in Portsmouth, UK, explored the issues with some of the delegates.

"What became very clear amongst the whole group was that there are barriers out there to effective medication therapy, as well as to self-management regimens like diet and exercise that we need to look at. So we spent some time thinking about the barriers for people looking after themselves effectively," says Sue.

One of the main points that came up in the workshop was the lack of information given to people with diabetes at the moment of their diagnosis. "And so, it was one of our goals to implement some effective education programmes at the moment of diagnosis so that some of the key messages get across to people. One is that diabetes is serious, it's progressive and there is no magic wand or magic bullet. However, there is a lot of complex care that needs to be undertaken by the patients themselves."

Sue's group agreed that at least 80 percent of the time people are out there looking after themselves. "We, as professionals, have very little influence on that. So we really need to educate people right from diagnosis."

The second main point to come out of the workshop was that the roles of the diabetes doctors and nurses are too compartmentalised, and that can generate some confusion about the merits of certain treatments.

"Doctors do clinical care, and nurses or diabetes educators do educational care," she says. "There was a strong belief in the workshop that these two roles should be brought together. In this way we can reduce some of the barriers to effective treatments and ensure that doctors, nurses and educators are completely clear about the benefits of today's therapies."

It is often thought that resistance to start insulin therapy comes mainly from the person with diabetes, but Sue says this isn't necessarily so. "We heard today about the barriers of using insulin therapy are often from the professional, not necessarily the patient," she says. •

### Key messages people with diabetes would like doctors to take home

- 1 Sometimes living with diabetes can be very overwhelming. •
- 2 It is very hard to express what is really bothering me about my diabetes in a five minute consultation. •
- 3 Diabetes is much more than glucose levels and laboratory results. •
- 4 Nobody likes to be told what to do all the time. It is nice to be listened to for a change. •
- 5 A treatment plan only works if it reflects the lifestyle of the person who has to follow it. •

## A Call to Action

Five goals for better diabetes care were identified using the DAWN Study findings. Their global relevance and importance were confirmed by the delegates at the 2<sup>nd</sup> DAWN Summit. These goals are:

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 2<sup>nd</sup> DAWN Summit proposed a framework for taking action, the DAWN Call to Action.

### The DAWN Call to Action

All stakeholders in diabetes, including people with diabetes, healthcare providers, payers, policy makers, industry and nongovernmental organisations must work together in a new 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



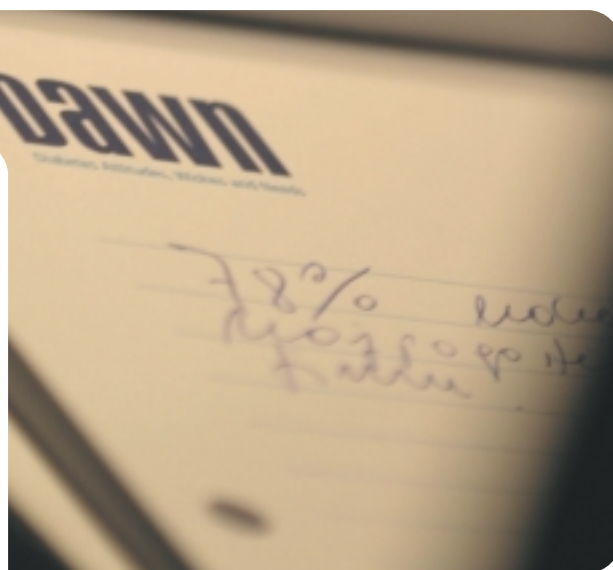
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## Test your well-being

The WHO-5 questionnaire is being used by DAWN to highlight the psychosocial needs of people with diabetes. It has been designed to assess people's well-being.

By answering just a few simple questions, you can get a good idea of just how good you feel.

Go on, give it a go!



Cast your mind back over the last two weeks, and think about how you've been feeling. Then, please indicate for each of the five statements which is closest to how you have been feeling over the last 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
I have felt cheerful and in good spirits	5	4	3	2	1	0
I have felt calm and relaxed	5	4	3	2	1	0
I have felt active and vigorous	5	4	3	2	1	0
I woke up feeling fresh and rested	5	4	3	2	1	0
My daily life has been filled with things that interest me	5	4	3	2	1	0

Now it's time to calculate your score. Add up the numbers you chose for each question. Your score will be between 0 and 25. If you scored 25 then you have the best possible quality of life!

Between 13 and 25 and you are probably getting on fine. At below 13 you may be experiencing poor well-being and should consider contacting a healthcare professional who can help determine if you would benefit from psychosocial support.

## 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 5 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 5 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?"

## We wish to continue our dialogue

We would welcome any opportunity for hearing your comments, ideas and suggestions to the future of the DAWN programme, and to continuously share the progress of DAWN. Please let us know of your interest.

- Send me more information about the DAWN programme
- I am interested in learning more about communications training programmes for healthcare professionals
- Please add me to the DAWN e-mail based newsletter (mails up to 4 times a year)
- Please ask a Novo Nordisk representative to contact me

Comments:

## Mail or fax to:

Name

Address

Telephone

E-mail