I wish...

...I could become a doctor when I’m older.

Novo Nordisk is a focused healthcare company and a world leader in diabetes care. We believe that significant improvements in diabetes care will occur not only through better medical treatment but also through greater awareness of diabetes. In addition to increasing our efforts to identify better treatments, we are therefore taking an integrated approach to diabetes care. We will work actively to promote collaboration between all parties in the healthcare system in order to achieve our common goal: To defeat diabetes.

www.novonordisk.com
DIABETES VIEWS

The people at the centre of care .................. 2
Pierre Lefèbvre

It is all about the people. .... 3
Philip Home

ASKING, LISTENING AND RESPONDING

Diabetes Attitudes, Wishes and Needs .................. 4
Søren Skovlund

A world-wide call to action .... 12
The DAWN International Expert Advisory Board

TURNING EMPATHY INTO ACTION

Diabetes, fear, and self-loathing: one person’s story .......... 15
Ray ka Msengana

Understanding the psychological barriers to effective diabetes therapy .......... 16
Torsten Lauritzen and Vibeke Zoffmann

Quality communication improving quality of life .......... 19
HBM van de Wiel and BMJ Wijnberg-Williams

Diabetes education: overcoming affective roadblocks .......... 22
Martha Funnell and Linda Siminerio

Empowering children with diabetes and their parents .......... 25
Hilary MCV Hoey

CHANGING OUR HEALTH SYSTEMS

Psycho-social care for people with diabetes: what the guidelines say .......... 28
Frank J Snoek and Elize M van Ballegooie

Integrating psycho-social issues into national diabetes programmes .......... 31
Ruth Colagiuri

ACHIEVING OPTIMUM CARE

Keeping people at the centre of care: a challenge to health professionals? .......... 34
Arun K Baksi

In practice: DAWN in Latin America and the Caribbean .......... 37
Juan José Gagliardino

Enhancing health communication: the German experience .......... 41
Susan Woods-Büggeln

© International Diabetes Federation, 2004
The findings of the Diabetes Attitudes, Wishes and Needs (DAWN) Study confirmed the belief of many health carers and of perhaps many more people with diabetes: there is something wrong with the way we manage diabetes. The Study provided the evidence from around the world to prove that diabetes care which focuses only on achieving medical targets is seriously flawed. Ray Msengana’s article in this issue of Diabetes Voice is a powerful reminder (or wake-up call) to those of us who do not have diabetes of the negative effects on people's health and well-being of health systems which ignore the affective and social impact of the condition.

We now know that more than half the people with diabetes do not enjoy good health and quality of life. With the number of people with the condition growing to over 200 million, this presents a major global problem, both in terms of the human impact, and the growing burden to health systems of complications resulting from poor diabetes management.

The only way to change the major problems of this world is through partnership. This is particularly true in diabetes care. The only way to resolve the problems associated with ineffective diabetes care is through partnerships between people with diabetes and the other stakeholders in diabetes care (people with diabetes, health-care providers, researchers, and Industry) at an individual, local, national and international level. The achievements of the DAWN Programme are a result of a powerful union between all these stakeholders.

In order to improve diabetes management, the focus must remain at all times on the whole person behind the condition. Diabetes causes stress. In his personal account, Ray Msengana drives home key insights from the DAWN Study; the fears and uncertainties of people with diabetes are compounded by poor communication with their health-care provider and a lack of diabetes education. Sadly, our health systems often produce as many problems as they resolve. As Ray Msengana’s experience shows, the limited time a health-care provider is able to spend with people with diabetes can result in huge communication barriers.

As Arun Baksi demonstrates in this issue, the changes necessary to improve diabetes care do not require large investments in resources. Like the model for the enhancement of national diabetes initiatives offered by Ruth Colagiuri, the concept of 'expert patients’ described by Arun Baksi is transferable to the developed and the resource-limited developing countries.

However, these changes somehow have to be implemented. Support is provided through DAWN to find the necessary tools to enhance patient-centred care in the clinics, such as the quality-of-life questionnaire described by Juan José Gagliardino. The global reach of DAWN enables the sharing of these tools. I am sure readers of Diabetes Voice would like to hear more in the future about the successes of programmes to implement DAWN, such as the achievements in India which are mentioned in this issue.

In order to facilitate effective patient-centred care, a fundamental change in the thinking of health-care professionals is necessary. The concepts behind patient-centred care must be disseminated. Those of us who are doctors and who do not have diabetes must learn to approach diabetes care from the point of view of the people with the condition. But we must not wait for this to happen; doctors must learn to empathize. One solution is in behavioural training programmes, like the one described by Susan Woods-Büggeln in this issue.
Some dawns are slow and prolonged, while others positively explode upon the world. The DAWN (Diabetes Attitudes, Wishes and Needs) behind this issue of Diabetes Voice has radiated activity thanks to the energies of a few individuals, and the response to those energies by a sector of the diabetes community. But another dawn remains protracted, indeed faltering. That is the dawn of the significance and importance of patient-centred care in the thinking of many health professionals.

Has your Editor-in-Chief the right to be so negative about overall progress in this area, and if so what might be the solutions to the problem? After all there are many examples of good practice (turn to the articles in this issue of Diabetes Voice). However, the evidence is overwhelming that people with diabetes are not getting the advice they need to start insulin at an appropriate time, that they are generally not involved in determining any kind of care plan for their diabetes, and that therapies and monitoring are dictated rather than negotiated. One does not have to search too far to meet health professionals who hold the old attitudes of ‘My patients expect me to tell them what to do’. Little importance is given by these doctors to life-impacting issues beyond the level of glucose control or blood pressure.

Change is occurring, and professionals are listening. The enlightened are trying to spread the message. That is evident from comments made over the last decade in meetings of professional societies and the like in Asia, for example – where some of these ideas have come from nowhere to being widely voiced. But it is also obvious even to the casual observer that it is only where diabetes care is centred on the multidisciplinary team, with a large element of education input from specialist nurses, that patient-centred care begins to have some meaning (I generalize of course). This may be because that environment fosters more liberal and lateral thinking about health care. Or it may simply be that the people who create and effect such teams more easily advocate modern ideas.

So how do we reach out to the broader diabetes community, in particular the primary health-care team and the office-based endocrinologist? Appropriate guidelines can help (Frank Snoek and Elize van Ballegooie in this issue note that the ideas are appearing in modern guidelines), particularly as these tend to be read and assimilated by non-medically qualified professionals. And so can national initiatives along the lines described by Ruth Colagiuri. Better tools are needed too, and the WHO-5 Index seems to be a step towards producing a psychological well-being instrument that is easily administered in any health-care environment and easily understood by any health-care professional (see the article by JJ Gagliardino on page 37 of this issue).

But we do need more than guidelines and tools. Essentially we need more published and presented examples of best practice and what it can achieve. At the last DAWN meeting in London in November 2003 there was a call to action (in itself a statement of the problem), but successful action must be given the widest publicity if it is to be disseminated. I hope that some of the projects will be brought to light in future editions of Diabetes Voice.
“In a world in which health-care systems are failing people with chronic health conditions, we need a new paradigm in which people with diabetes become their own health-care providers, with health-care professionals playing a supporting role. This model will depend more than ever on partnerships. It is important that we get it right”, stated Rafael Bengoa, Global Director, Management of Non-communicable Diseases at WHO last year.

The overall objective of Diabetes Attitudes, Wishes and Needs (DAWN) is to improve the psycho-social support for people with diabetes. This global Programme is led by Novo Nordisk, in partnership with the International Diabetes Federation (IDF), and an advisory panel of leading diabetes experts. The DAWN activities began with the DAWN Study in 2001. This global investigation into the affective aspects of the condition facilitated comparisons and cross-referencing between the key players in the diabetes community. The key finding was that critical gaps exist in diabetes care, and that an increased focus should be placed on the psycho-social issues.

The key is in empathy
Chronic medical conditions are managed successfully when all the members of the disease management team collaborate effectively. This is particularly relevant to diabetes care. The most important member of the management team is the person with the condition. The key to improving the management of diabetes lies in effecting the change from an acute to a chronic model of care which is person-centred rather than disease-centred.

The DAWN Study has highlighted some important gaps in current diabetes care practices. The DAWN Programme now aims to translate these insights into actions in order to improve the quality of life of people with diabetes and those who care for them.

Background to the Study
Despite the availability of effective medical treatments, more than half of people with diabetes do not achieve good health and quality of life. Psycho-social issues were identified in a considerable amount of research as a key factor in poor diabetes outcomes.
However, no large-scale global studies had been carried out to ascertain the actual dimensions of this problem. The compilation of psycho-social data in the DAWN Study would:

- facilitate international comparisons of the different approaches to diabetes management
- examine the complex relationships between the stakeholders – the people with diabetes and their families, and the health-care providers
- enable policy makers and other stakeholders to recommend changes where needed.

**Global findings**

The DAWN Study was conducted in 2001 in 13 countries and involved a total of 5426 people with diabetes, 2194 primary care doctors, 1122 nurses, and 566 endocrinologists and diabetologists. It was the largest study of its kind ever conducted. A wealth of information was produced about the wishes and needs of people with diabetes and their health-care providers (see page 6). DAWN offered insights into the unmet needs of people with diabetes and the critical weaknesses in diabetes care. As a result, the Study has proved an important decision-making and health policy tool.

**Translating DAWN into action**

The DAWN Programme aims to translate into concrete actions the many findings from the DAWN Study.

The Programme facilitates new partnerships and national initiatives to change diabetes care practices and structures according to a new chronic care model which focusses on addressing the psycho-social needs of the people with the condition.

Examples of ongoing concrete actions are:

- education and communication training programmes offered for thousands of health-care professionals which builds on the DAWN Study findings
- simple daily tools for health-care professionals to better support people with diabetes
- raising public awareness of the importance of addressing psycho-social issues
- revising diabetes care guidelines to include psychological recommendations.
Asking, listening and responding

Key DAWN insights

The key insight from the DAWN Study is that to improve the health and quality of life of people with diabetes, increased focus must be placed on the psychological issues related to living with the condition.

Global insights from the DAWN Study

- Enhanced communication between health-care providers and people with diabetes is needed. A good patient/health-care provider relationship was associated with less distress and better self-management. More than 60% of health-care providers looked for ways to enhance communication.

- Promotion of team-based care is needed. More than half of all the health-care providers recognized that better communication is needed within the team. More than half of people with diabetes did not experience that their health-care providers communicated well about their treatment. Self-management was best for those people who felt they received co-ordinated team-based care.

- Improved self-management is needed. Self-management was poor according to both people with diabetes and their health-care providers. Psychological well-being and social support was associated with good self-management. Health-care providers agreed psychological factors plays an important role for effective self-management.

- The barriers to effective therapy must be overcome. Significant affective barriers were seen among both health-care professionals and people with diabetes to the timely use of insulin therapy. More than half of people with Type 2 diabetes worried very much about having to start insulin and saw it as a failure if they had to do so. Only a fifth were aware of the benefits of insulin. Many carers used insulin as a threat to motivate their patients to follow their diet and tablet therapy.

- Improving psychological assessment and care is needed. More than 40% had poor psychological well-being and carers estimated that about 15% of the people in their care had depression. About 40% reported various anxieties, such as being constantly afraid of their condition getting worse. Many carers across the world said they were able to both identify and address the psychological needs of people with diabetes and very few had opportunity to refer to psychologists.
The Second International DAWN Summit

In November 2003, more than 150 delegates from 31 countries met in London for the 2nd International DAWN Summit. Summit delegates included people with diabetes, healthcare providers, researchers and policy makers; many delegates represented national and international health organizations, such as IDF, the World Health Organization (WHO), the Federation of European Nurses in Diabetes (FEND), the International Society for Pediatric and Adolescent Diabetes Research (ISPAD), the European Association for the Study of Diabetes (EASD), and national associations such as the American Diabetes Association (ADA).

During the Summit, delegates heard presentations on the psycho-social impact of diabetes from some of the world’s leading diabetes specialists, nurses, and people with diabetes. Workshops and interactive sessions provided a setting for the discussion of new approaches to diabetes management.

Day 1: key issues

The key lessons for the stakeholders in diabetes care which emerged from the DAWN Study were presented on the first day of the Summit. The sessions looked at the practical challenges to enhancing psycho-social care for people with diabetes:

- improving the interaction between people with diabetes and their health-care providers
- enhancing communication and co-ordination among healthcare professionals
- improving support for effective self-management
- overcoming the many barriers to the timely use of effective therapies
- offering improved psychological support where needed.

A number of the key issues were addressed:

**Improved communication**

A common theme of the insights from the DAWN Study was the need for health-care professionals to empathize with people with diabetes before offering advice or specific therapy. Communicative activities were undertaken by the delegates to practise active supportive listening skills.

Related to this was the identified need to increase communication and co-ordination among the diabetes health-care providers and improve access for people with diabetes to all the diabetes care team members. The DAWN Study findings confirmed a perceived lack of communication among the health-care professions involved in diabetes care.

**Roadblocks to effective therapy**

Compared with people who do not have the condition, people with diabetes are at double the risk of depression. The growing evidence was explored which suggests that important improvements to diabetes care can be made by the monitoring of psychological well-being on a regular basis, and the provision of adequate psychological and social support services.

**The importance of partnership**

The importance of dialogue and partnership to reduce the global burden of diabetes was stressed by speakers from WHO, IDF, and Novo Nordisk. The DAWN Programme is seen by Novo Nordisk as an important investment to help facilitate new partnerships which will improve diabetes care and reduce the global burden of the condition.

“It is quite appropriate that we partner with each other to review our approach to the way diabetes is currently managed. We need to pay more attention to the psycho-social aspects of diabetes.”

Pierre Lefebvre, President of IDF
Asking, listening and responding

DAWN Study findings: Psychological barriers to effective therapy

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

<table>
<thead>
<tr>
<th>People with Type 2 diabetes agreeing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Primary care physicians estimates of how many of the people in their care they think would agree</td>
</tr>
<tr>
<td>0 20 40 60 80 100</td>
</tr>
<tr>
<td>% agreeing</td>
</tr>
</tbody>
</table>

DAWN successes in Europe

Examples were presented of the successful translation of DAWN into practice in Poland and Germany. In Poland, the DAWN Study forms the basis for a national support programme to improve diabetes care. This contains new day-to-day management tools, and train-the-trainer programmes which use innovative methods for training health-care professionals across the country to improve social support for people with Type 2 diabetes. For a description of the German experience, see the article by Susan Woods-Büggeln on page 41.

Day 2: advocacy and action

The focus of the second day of the Summit was on global advocacy and the actions needed to translate DAWN into practice. Models of improved care were presented and examples were provided of the modifications to health-care systems which enhance the prevention and treatment of the psychological complications of diabetes.

Changing the system

The focus of the DAWN Programme is now on ensuring that its initiatives will result in health benefits for the greatest number of people. DAWN Summit delegates proposed to balance the ‘reach’ of new DAWN interventions with the effectiveness of that intervention to maximize the public health benefit of the Programme. One particular future task is to overcome the barriers to full health among ethnic minorities and low-income groups with diabetes and initiate projects in developing countries. Discussion took place on the changes to health-care systems that are required to translate DAWN into practice. The specific changes needed for moving to a patient-centred diabetes care model were outlined. Politicians explained how they might facilitate funding.

DAWN Study findings: Communication and co-ordination between health-care providers

A nurse is available in primary care practice

My diabetes care providers talk to each other

All my diabetes care providers are under one roof

<table>
<thead>
<tr>
<th>% of people with diabetes agreeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 20 40 60 80 100</td>
</tr>
</tbody>
</table>

Guidelines and strategy

To effect these changes in the health-care systems, diabetes care guidelines must be changed accordingly. A review was offered from the DAWN Programme of the guidelines from 42 different countries on the psychological
Asking, listening and responding

Aspects of diabetes care. Only five included an extensive section on the psycho-social issues in diabetes care – Australia, Germany, the Netherlands, Romania, and the UK (for a description of psycho-social care in diabetes guidelines, see the article by Frank Snoek and Elize van Ballegooie on page 28).

Individual countries can now incorporate the DAWN findings and actions into their national diabetes programmes. A strategy was presented which can be adopted by any country or region (see the article by Ruth Colagiuri on page 31). It was agreed that psychological assessment must form an integral part of national diabetes programmes in the future.

DAWN successes in India
The recent achievements with DAWN in India were described; the DAWN insights were translated into activities that have reached thousands of people around the country.

The Indian model is a particularly strong one, since these actions were accomplished without extra resources.

The lessons
All the workshop teams (see adjacent box) embraced and endorsed the need for a major shift in the philosophy and focus of diabetes care. The DAWN Programme must lead the way by promoting a focus on communication with people with diabetes. Many participants felt that this shift must be driven by

DAWN Summit workshops
All delegates took part in several workshops, each consisting of people with diabetes, health carers, and decision makers or health-care administrators.

On the first day of the Summit, teams drafted mission statements to serve as a starting point for the DAWN global call to action (see page 12). On the second day, the teams specified concrete actions required to accomplish this mission.

Snapshots

“Our task is to ensure the adoption of a diabetes care model which promotes dialogue between health-care providers and people living with diabetes to reach shared goals. The achievement of these goals enables people with diabetes to make informed choices about self-management which improve health and quality of life.”

“The roles of the members of the diabetes care team should be developed and maximized. This will ensure flexible and consistent care for people with diabetes.”

“Improved self-management requires a host of initiatives, including awareness-raising, education, and policy development.”

“There is a need to take action to reduce the affective and educational barriers that exist among health-care providers to using effective therapies.”

“The affective barriers among people with diabetes to effective therapies are significant and pose a major barrier to better health. We must therefore aim to identify and overcome these barriers.”

“The psychological, social, and physical factors in diabetes management should be given equal value. This should translate into improved awareness, and appropriate management of psychological issues.”
Asking, listening and responding

**DAWN Study findings: DAWN shows the need for concerted advocacy**

- "Health care in this country is well organized for the management of chronic conditions including diabetes" - 30%
- "Diabetes should be given higher priority than it currently receives compared with other conditions" - 61%
- "Policy makers should understand diabetes better" - 73%

Source: Nova Norisk

*N = 3,000 health professionals from 13 countries*

people with diabetes, supported by DAWN ambassadors around the world. The perspective of people with diabetes should be included at every level of diabetes care, and in every diabetes care decision.

There was overall agreement on the need for continued promotion of multi-practice diabetes teams, and that a model should be proposed which clearly places the person with diabetes at the centre of such teams.

**Simplicity**

Several workshop groups specified the need to put into practice the use of simple and easy-to-access tools. These tools should be for the use of all parties, and should help to build bridges between health-care professionals and people with diabetes.

**Policy change**

Increased resources and changes in health policy and systems are essential. These will require evidence-based justification. Therefore, the compilation of additional evidence and scientific systems for benchmarking outcomes was agreed. Many proposals from workshop participants advocate the launch of manageable pilot programmes and the use of the examples of best practice to provoke a snow-ball effect which will lead to improvements in diabetes care.

**New collaborations**

The workshop groups agreed that new collaborations between diabetes associations, professional organizations, industry, and government bodies is urgently needed.

**Individual commitments**

In order to better address the people behind the condition, the DAWN Summit delegates each defined a concrete action that they would undertake in their local setting within the six months following the Summit.

**A call to action**

The summit concluded with panel discussions and feedback from workshops that formed the basis for the global call to action (see page 12). This sets clear goals and identifies the key steps to be taken to address the psycho-social needs of people with diabetes.

**What next?**

In 2004, the DAWN Programme aims to facilitate the integration of the philosophy which underpins DAWN into national diabetes programmes throughout the world. Based on the outcome of the DAWN Summit and the DAWN call to action, leading
experts from several countries have developed train-the-trainer workshops and innovative learning tools for health-care professionals. These will enable the carers to understand the practical uses of the many DAWN findings and address more effectively in their daily practice the affective issues related to living with diabetes.

Diabetes can only be defeated in partnership. Diabetes associations, professional associations, research initiatives, and governments are involved in effecting changes based on the DAWN findings. IDF, together with the Psycho-social Aspects of Diabetes (PSAD) study group of EASD, is working to reach international consensus on recommendations for including psychological issues in the global IDF guidelines.

FEND, together with Primary Care in Diabetes Europe (PCDE), have invited their members to discuss the practical implications of the recommendations of the DAWN Programme at upcoming conference events.

The DAWN Programme is the sole sponsor of the European Depression in Diabetes Research Consortium (EDID), which aims to enhance cross-national research and health-care action to improve the detection and treatment of depression in diabetes.

The DAWN Programme has led to the development of simple questionnaires to assess psycho-social status of people with diabetes. These questionnaires make it easier to identify the specific needs of people with diabetes who require clinical support.

A new DAWN communication training course has been developed for health-care professionals. The course uses video, CD-ROM, and group activities to help all diabetes team members improve their skills in addressing the critical psycho-social issues of diabetes care. Scientific tools have been created for assessing and monitoring the psycho-social status of people with diabetes.

Only through sharing knowledge and experiences among professions, countries and organizations, can the DAWN call to action be effectively brought to life. Through the DAWN website (www.dawnstudy.com), it is hoped that people from across the world will come together to learn from each other and share ways to change diabetes care.

Editorials and feature articles about DAWN are being published by experts in a number of countries. The Study findings and their implications will be discussed at several scientific meetings throughout the year.

The DAWN findings make it clear that we must change the way we manage diabetes. Through DAWN, health-care professionals can begin to address the barriers to effective treatment and self-management of diabetes. This will make current treatments more effective and improve the quality of life of all people with diabetes.

"DAWN has given us a platform to develop 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."

Lise Kingo, Executive Vice President of Stakeholder Relations, Novo Nordisk

Søren E Skovlund
Søren E Skovlund is Senior Adviser and Manager of the DAWN Programme in Novo Nordisk. He has an international background in mental health promotion, health psychology and quality-of-life research.

Acknowledgement
The author would like to thank the DAWN Summit chairmen, David Matthews, Richard Ruini and Philip Home for their valuable contribution to the meeting.

For more information about DAWN, visit www.dawnstudy.com
The scale of the problem that diabetes poses to world health is still widely under-recognized. The International Diabetes Federation (IDF) estimates that if current trends continue, the number of people with diabetes will almost double; from 194 million people in 2003 to 333 million by the year 2025. Diabetes is already the most costly health-care problem in the westernized and ‘westernizing’ countries.

This calls for improved measures to curb the human and economic burden of this chronic condition – through prevention, detection, and effective self-management. As a result of the work done by leading experts in diabetes from around the world, a call to action was made at the 2nd International Diabetes Attitudes, Wishes and Needs (DAWN) Summit: in order to improve the health and quality of life of people with diabetes, we must address the people behind the condition.

**Improved care: five goals**

Five goals for improved diabetes care were identified from the global DAWN Study findings. The global relevance and importance of these were confirmed at the DAWN Summit.

To improve the health and quality of life of people with diabetes we must:

- enhance the communication between people with diabetes and health-care providers
- promote improved communication and co-ordination between health-care providers
- promote effective self-management
- reduce the barriers to effective therapy
- improve psychological care for people with diabetes.

**Stakeholder action**

All stakeholders in diabetes care must work together in a new collaborative framework. These stakeholders include:

- people with diabetes
- families, friends and carers
- health-care providers
- payers
- policy makers
- industry
- non-government organizations.

Our work should focus on the following issues:

**Awareness-raising and advocacy**

Those individuals and organizations with an understanding of the benefits of providing psycho-social support for people with diabetes must play an active role in sharing their knowledge with their peers. These people with knowledge of the affective issues around the condition should collaborate to raise awareness and promote advocacy for improved psycho-social support in diabetes care.
As experts in the management of their own condition, people with diabetes must be involved in informing health-care providers, policy makers, and others about the psycho-social needs and wants of people with the condition.

Training for health-care providers
In order to place people with diabetes at the centre of health-care provision, health-care providers must develop a new set of skills. This includes the development and practice of listening and communications skills. These will enable the carers to understand, assess, and address the psycho-social needs of people with diabetes.

A team-based approach should be promoted within the diabetes care team. In order to do this, professional training programmes must allow for the exchange of knowledge and the enhancement of cross-practice competencies. This training should include basic psycho-social intervention skills.

Practical tools and systems
Diabetes care teams must have a number of practical tools and systems to support the effective management of the psycho-social needs of people with the condition. Such tools and systems include:

- strategies for psychological intervention
- referral guidelines
- listening and communications skills
- scales for the assessment of quality of life
- electronic individual care records

Policy and health-care system changes
People with diabetes and those at risk of developing diabetes must have the necessary opportunities for healthy living, adequate health-care services, and treatments to achieve optimum health and quality of life. In diabetes management guidelines, treatment approaches and resource provision, the psycho-social needs of people with the condition must be approached with the same degree of urgency as that relating to their treatment needs.

Governments and health-care systems must be lobbied to adopt the chronic care model developed by WHO.

Psycho-social research
More research must be conducted in the field of diabetes to demonstrate the health and economic benefits to society of improved psycho-social and behavioural care. A better understanding is required of effective approaches to support self-care and thus enhance the quality of life of people with diabetes.

Research and knowledge, including the findings of feasibility studies and best-practice pilots, must be shared between health-care disciplines and across geographic boundaries. This will enable the formation of a sustainable platform of knowledge of new strategies and approaches.

The DAWN International Expert Advisory Board
Ib Brorly,
Person with Type 2 diabetes, Denmark

Ruth Colagiuri,
Australian Centre for Diabetes Strategies, Australia

PHLM Geelhoed Duijvestijn,
Haaglanden Hospital, the Netherlands

Hitoshi Ishii,
Tenri Yorozu Soudanjyo Hospital, Japan

Line Kleinebreil,
Jean Verdier Hospital, France

Rüdiger Landgraf,
University of Munich, Germany

Torsten Lauritzen,
Aarhus University, Denmark

David Matthews,
Oxford Centre for Diabetes, Endocrinology and Metabolism, UK

Richard Rubin,
Johns Hopkins University School of Medicine, USA

Frank Snoek,
Vrije Universiteit, the Netherlands

Giacomo Vespasiani,
Centro di Diabetologia e Malattie del Ricambio, Italy
How to get Diabetes Voice

Either

Become a member of the International Diabetes Federation (IDF)

As well as receiving Diabetes Voice four to six times a year in English, French or Spanish, IDF membership also entitles you to:

- become part of an international network of health-care professionals and people who care about diabetes;
- a lower registration fee at the next IDF World Congress;
- receive other IDF materials containing the latest information on a wide range of diabetes-related issues;
- join a dedicated and proactive organization and add your voice to the millions concerned with diabetes.

Yes, I would like to become an IDF member. Please enrol me as:
- Life member (600 EUR)
- Three-year member (195 EUR)

Please send me Diabetes Voice in:
- English
- French
- Spanish

Or

Subscribe to Diabetes Voice without joining IDF

Subscription entitles you to receive Diabetes Voice four to six times a year in English, French or Spanish. You can also subscribe online at www.diabetesvoice.org.

Yes, I would like to subscribe to Diabetes Voice without joining IDF. Please enrol me as:
- Three-year subscriber (100 EUR)
- Annual subscriber (40 EUR)

Please send me Diabetes Voice in:
- English
- French
- Spanish

YOUR CONTACT DETAILS

MS  MR  DR  PROF

FAMILY NAME(S):

FIRST NAME(S):

ORGANIZATION / COMPANY:

ADDRESS:

POSTAL CODE:  TOWN:

COUNTRY:

PHONE:  FAX:

E-MAIL:

OCCUPATION:

VAT:

Do you have diabetes?  Yes  No

PAYMENT DETAILS

I will pay by credit card, to be billed in euros. Please charge to my card:
- American Express  Mastercard  Visa

Name of cardholder:

My card number is:

Expiry Date:

Signature on card:

I will pay by direct bank transfer to the IDF account
IBAN: BE03-6451-4103-3284; BIC: JVBABE22
VAT: BE433.674.528

Please return this form to: INTERNATIONAL DIABETES FEDERATION
Executive Office • Avenue Emile de Mot 19 • 1000 Brussels • Belgium • Phone: +32-2-5385511 • Fax: +32-2-5385114 • idf@idf.org
**Diabetes, fear, and self-loathing: one person's story**  
☆ Ray ka Msengana

When he left home to attend his regular diabetes clinic, Ray Msengana was already feeling unwell. But when he was told that the treatment of his Type 2 diabetes was to change from tablets to insulin therapy, he rapidly felt a lot worse. In this candid account of life with diabetes, Ray Msengana describes the affective impact of the condition, and makes a call for changes in the way diabetes is managed.

When my doctor informed me that I was to start insulin therapy, I was so shocked that I cannot remember much of our conversation. Before I knew it, I was collecting vials of insulin and syringes, nodding blankly at the instructions for their use. But I could not listen; I was in a daze. To my knowledge, an early death was the only possible outcome for people who need insulin injections to live. I had been given a death sentence.

My fear was closely followed by intense feelings of guilt. I had failed to stick to the diet recommended by my doctor, and now I was going to pay the price. Overwhelmed by powerful emotions of rage and hopelessness, I withdrew from social life.

My family also suffered. I projected onto my wife, Norma, the anger I felt at myself. This was exacerbated by the humiliation I felt at having her inject the insulin into my backside before every meal. I was terrified of injections, and believed I was incapable of piercing my own skin with a needle. My levels of self esteem were reaching unexplored low points; I had lost all my sexual energy. Far from enjoying sex, I could not even perform adequately. I found myself making excuses or pretending to be asleep rather than go through another frustrating episode with my partner.

After nearly a year of unhappiness, I had a conversation which completely changed the way I felt about my condition with an old school friend who had become a health professional. He calmly explained why my doctor had recommended insulin. We went on to discuss the many questions I had about my treatment and its side-effects. I began to realize that my fears were misplaced and terribly exaggerated.

Had my doctor and I discussed these issues openly ten months before, I would not have experienced the trauma described above. I believe that people with diabetes often cannot care for themselves properly because they simply do not understand what is happening to them. Fortunately, I am literate and I live in a city. I can only imagine with sadness the problems faced by those with my condition in the poor rural areas. It comes as no surprise to me that many of these people with diabetes are easily persuaded to abandon the treatment recommended by the health professionals in favour of alternative medicines.

A model for health care must be found in which communication between people with diabetes and health carers (particularly the doctors) is enhanced. Change is necessary in terms of both the individuals involved in care and the health systems. It is important for the doctors to be able to put themselves in the position of the person in their care. In resource-limited countries such as South Africa, solutions must be found to improve communication without important extra expense to the health-care service. An inexpensive solution could be the use of volunteer counsellors or expert ‘patients’ (to read about example of this idea in practice, see the article by Arun Baksi on page 34). Important support could be provided by the incorporation of people with diabetes who have previously received diabetes education and some training in counselling.

☆ Ray ka Msengana

Ray ka Msengana is a former President of the South African Red Cross Society and a member of the International Red Cross and Red Crescent Movement Advisory Commission.
In routine care, only about 20% of people with Type 2 diabetes achieve good blood sugar control – defined as HbA1c levels (a measurement of blood glucose over the past 2-3 months) of below 7.0%. However, up to 50% of people achieve good glycaemic control when prescribed supplementary insulin treatment. Such therapy has the potential to improve not only long-term health outcomes but also immediate well-being. In spite of these potential benefits, few people with Type 2 diabetes are offered supplementary insulin therapy.

Flawed foundations
If a general practitioner (family physician) uses terminology such as ‘mild diabetes’, ‘a little sugar in the blood’, or ‘non-insulin-dependent diabetes’, the foundations of psychological barriers to insulin therapy can be laid at the time of diagnosis. In one study into the causes of the barriers to insulin therapy in...
people with Type 2 diabetes, few of the general practitioners in five countries approached the subject of insulin therapy with people with Type 2 diabetes in their care. Reference to insulin was commonly made in the context of a ‘threat’ to enforce adherence to therapy.2

In that study, the attitudes to insulin therapy of people with Type 2 diabetes were further explored. Half of the people involved were receiving treatment with tablets, the other half with insulin. On the whole, those taking tablets displayed negative feelings about insulin therapy. The principal emotion to be expressed was fear. It was common for people to report a fear of dying while asleep due to hypoglycaemia induced by insulin. A person from Germany described a fear of pain: “…being confronted with the fear of constantly injuring, hurting myself”.

An Italian person articulated a common fear of traumatic lifestyle change: “It means that the illness has worsened. Then you become a slave to the little black box. You have to carry it in your pocket all the time.” These feelings were echoed by another person: “You are no longer as independent as before. When you leave the house you will constantly worry about having forgotten something.”

Other reactions to insulin therapy included feelings of frustration. One person described a perceived lack of control over the progression of a condition which was previously perceived as ‘mild’: "Insulin is the final step that forces you to face the whole disease much more intensely. Taking tablets makes diabetes seem not too serious, if serious at all."

From fear to familiarity
In contrast, people with Type 2 diabetes undergoing insulin therapy typically reacted positively to the topic. However, many acknowledged that they had experienced anxieties before beginning treatment with insulin. In the words of a person from France, "it’s like anything else; we erect barriers around things which are not familiar to us."

Having commenced insulin therapy, the people with diabetes reported that their fears were replaced by positive perceptions. Another person said, "it’s even a kind of freedom now. It’s totally up to you when and how much you use it”. An English person with Type 2 diabetes compared the benefits of treatment with tablets and insulin: "You learn how to compensate. That’s the best thing. We are in control, but if you are on tablets, you have no control over your blood sugar.”

A fear of traumatic lifestyle change as a consequence of insulin therapy was common.
In general, the people with Type 2 diabetes receiving tablets seemed to be surprised at the positive reaction of those receiving insulin therapy. A change in attitudes towards insulin therapy appeared to occur within people who experienced the treatment. Because these had been expressed by people with Type 2 diabetes, insulin therapy appeared more credible to those taking tablets to control their blood glucose levels. Communication with general practitioners was identified as the major source of the reluctance and anxieties towards insulin therapy of people with Type 2 diabetes.

A change in attitudes towards insulin therapy appeared to occur within people who experienced the treatment.

**Self-management has the key**

Results from the *Diabetes Attitudes, Wishes and Needs* (DAWN) Study indicate that psychological problems are common among people with the condition. These problems are recognized by both people with diabetes and health providers in all countries. The psychological problems impact negatively on diabetes self-management. Reports from DAWN suggest that health-care providers are lacking in the adequate skills and resources to manage these problems.

The diabetes community faces the challenge of enhancing diabetes management. This can be achieved by breaking down the psychological barriers to improving self-management. Anderson and Funnell state that the principle of self-management is underpinned by three basic affirmations:

- people with diabetes make the important choices
- people with diabetes have control
- people with diabetes live with the consequences.3

Self-management is defined as the active involvement of the individual in the management of their diabetes. The findings of the DAWN Study and the global call to action put forward in this special issue may be helpful to establish new approaches to breaking the psychological barriers to improving diabetes self-management, therapy and outcomes.

Anderson and Funnell describe the self-management behaviour of people with diabetes and the role of health-care providers.4 Diabetes care is viewed as collaboration between equals. The role of diabetes health-care providers is to facilitate people with diabetes with the knowledge they need to successfully take responsibility for the management of their condition. In this model, health-care providers help people with diabetes to reflect on their situation in order to make informed health choices. The aim is to collaboratively develop a realistic self-management plan that fits each person clinically, socially, and psychologically.

Studies offer evidence that emotional health, symptom resolution, and physiological aspects (blood pressure and blood sugar) all benefit from improved communication between people with diabetes and health-care providers, patient empowerment programmes, and training in coping skills.5

---

**References**


---

**Torsten Lauritzen and Vibeke Zoffmann**

*Torsten Lauritzen is a General Practitioner and Professor in the Department of General Practice, University of Aarhus, Denmark.*

*Vibeke Zoffmann is a Registered Nurse. She is completing a PhD in the Department of Nursing Science, University of Aarhus, Denmark.*
The ultimate goal of diabetes care is to enhance the quality of life of people with the condition. Quality of life is increasingly used as a factor in the evaluation of the quality of care. The results of this evaluation are used by health-care providers in order to make recommendations for future care. Only the person receiving care is capable of evaluating their quality of life during and following medical care.

In diabetes care, self-report questionnaires are employed in large-scale inventory research into the human experience of people living with the condition. While this approach is both logical and positive, HBM van de Wiel and BMJ Wijnberg-Williams emphasize that it cannot replace effective communication between people as a means of understanding the individual needs of each person.

In order to evaluate the benefits to quality of life and clinical outcomes of treatments and educational services, a number of different self-report questionnaires have been developed; some very specifically focussing on diabetes, others using broader concepts such as chronic illness. The primary aim of these questionnaires is to evaluate the feelings and thoughts of a person with diabetes. Self-report questionnaires are convenient to administer and allow for quantification, which is useful for policy discussions to promote the perspective of the person living with the condition.

Used in isolation, the self-report questionnaires cannot facilitate the processes of interaction and mutual learning afforded by dialogue.

However, in quality-of-life questionnaires the communication is 'one-way': used in isolation, these cannot facilitate the processes of interaction and mutual learning afforded by a dialogue between two people. While their use is important, quality-of-life instruments do not relieve the health-care professionals of their duty to effectively communicate.
and empathize with each of the people in their care.

Towards an interactive approach
It is important for people to express themselves freely, without censorship from health-care providers. However, the autonomy of a person receiving care is best served when they are able to discuss feelings and worries with a health carer who is able to recognize unrefined expressions.

The health-care providers should be able to support a person in the translation of their concerns into an articulate evaluation in terms of quality-of-life and care needs. The lack of these qualities in health-care providers seems to constitute the crux of the problem; people with diabetes report a lack of emotional involvement on the part of health-care providers.

Health problems have an existential, as well as a medical aspect. Dealing with deeply felt worries and so-called ultimate concerns requires a complex approach by people with diabetes and health carers. In order to discuss the major themes in life, such as freedom and restriction, intimacy and isolation, both groups require a high level of competence in communication skills.

While at some point everybody has to cope with so-called existential themes such as powerlessness, helplessness, and isolation, people with diabetes are forced to face these issues more frequently than those without the condition, and often at an inappropriate age.

Diabetes is more than just an inconvenience; the condition impacts strongly upon all aspects of a person’s life. The intense feelings, such as fear, grief and anger, which accompany existential problems are nearly always very difficult, even initially impossible, to express accurately: people are often limited to pre-verbal terms such as ‘a ball in my stomach’, or ‘my heart sank’. Only writers and poets appear able to verbalize what others can only feel physically. Furthermore, existential problems affect different people to varying degrees.

In brief, words nearly always fail us, at least initially. A part of diagnosis and treatment should therefore be aimed at finding the adequate terminology for the expression of a person’s actual experience. Self-report questionnaires are not capable of solving this challenge.

Professional communication
Health carers who are committed to providing quality diabetes care must be prepared to spend more time mediating intense emotional interactions with people who have the condition. To achieve this, health carers require improved communication skills and adequate psychological knowledge.

In response to existential problems, a choice must ultimately be made. The exclamation ‘If only...’
I’d known!’ often reflects more our conscience than our knowledge.

From a logical point of view, the issue is relatively simple. A paradox (a preverbal expression) can only be answered with a contra-paradox (a choice based on perception rather than knowledge). The awkwardness comes not so much from the existential problems of the person with diabetes, but from those of the health-care providers: the uncertainty that ‘choices’ always have to be made in relation to existential issues, and that these choices will colour the evaluation of the person’s mood and/or care needs.

A growing group is becoming aware that investing time in talk is very worthwhile.

Unfortunately, some health-care providers tend to deny the existing problems, cling to technical solutions, or sink into apathy. Fortunately, a growing group is becoming aware that investing time in talk is very worthwhile. On a micro-level, this awareness benefits people with diabetes who are able to talk to someone who knows how to deal with existential problems; and on a macro-level, it benefits the professional group that is willing and able to explicitly describe the choices that form the basis of a health service.

**Education in communication**

If people with diabetes and health carers are expected to discuss quality of life issues and subsequent diabetes care conditions on a sophisticated level, it is clear that current levels of competence in communication are insufficient. The classical medical didactic model (master-pupil) is not capable of meeting these communicational demands. As the name indicates, the scope of this model is determined by the expertise of the master. Since the masters were not trained at all in communication, other models will have to be adopted. There is clearly a need for the development and implementation of supplementary training programmes.

In order to help people with diabetes to make their own decisions and ultimately optimize diabetes care, future diabetes health carers must be acquainted with counselling techniques. These communications needs can no longer be met by one person, or even by a local staff. New approaches to teaching and learning, and new devices such as electronic environments or even virtual reality applications will have to be developed.

However, technical innovation is not enough. Education in communication is not a separate phenomenon. It should be incorporated into basic medical training and conform to the future practice of health-care providers. Themes such as teamwork, professional communication, coaching, and the use of self-management are current issues of interest.

There is clearly a need for the development and implementation of supplementary training programmes.

The modernization of training reflects the therapeutic process that generally takes place within diabetes care. Content and form are closely linked; adequate steering of the process of change will require multidisciplinary co-operation. In diabetes care, an extra impulse can be given to the modernization of training by exploiting the use of electronic learning environments, and applying techniques such as co-counselling from other more psychologically oriented fields.

© HBM van de Wiel and BMJ Wijnberg-Williams

HBM van de Wiel is a Professor in Medical Communication in the Department of Health Psychology in the Medical Faculty of the University of Groningen, the Netherlands.

BMJ Wijnberg-Williams is a Medical Psychologist in the Department of Social Services of the University Hospital Groningen, the Netherlands.
In diabetes care, the principal objective is to improve health outcomes and ensure the total well-being of people with the condition. In order to achieve this, it is important to reach the person beyond the laboratory results and blood glucose reports. Increasing numbers of diabetes health carers now realize that attention to psychological and social issues is essential in helping people with diabetes to live full and successful lives. In this article, Martha Funnell and Linda Siminerio report on the role of education in overcoming affective roadblocks to the realization of optimum diabetes management.

In the findings of the Diabetes Attitudes, Wishes and Needs (DAWN) Study, people with diabetes reported the need for improved emotional support and communication with their carers – particularly the doctors. People with diabetes found it difficult to assume self-care tasks, especially in areas related to nutrition. Many reported a fear of insulin injections. Although many physicians agreed that improved communication was needed, they reported that the constraints of busy schedules made this difficult.

DAWN highlighted the need to help people manage their diabetes more effectively. The results of the study demonstrated that diabetes represents a considerable burden to people with the condition. It was recorded that people with diabetes often feel alone and isolated, and at times feel overwhelmed by the responsibility for adequately managing their condition. These feelings contribute to levels of stress and anxiety.

People with diabetes often feel overwhelmed by the responsibility for managing their condition.

It has been demonstrated that education in self-management designed to improve efficacy and coping skills helps people with diabetes to overcome these affective roadblocks. A key recommendation of DAWN is that all people with diabetes have access to this type of support.

A wider role for education
There have been important developments in diabetes education over recent years. Didactic, content-
laden presentations have given way to more empowerment-based models. Provision of information and support for behaviour change, coping, psychosocial issues and goal-setting now form part of many diabetes education programmes.

Diabetes education can make an important and positive impact in a number of areas, including supporting people with Type 2 diabetes at the beginning of insulin therapy. An exaggerated fear of injections, a lack of information and understanding about insulin, and some widely held misconceptions about the functioning of the hormone often lead to 'psychological insulin resistance'. The anxieties and resistance to medication which often accompany insulin therapy can be conquered with the support of a diabetes education programme which:

- reassures people that the need for injections of insulin does not represent a personal failure
- helps them to learn about how to prevent and manage hypoglycaemia
- accompanies them through the injecting process.

Diabetes education is effective in improving both metabolic outcomes and quality of life.

However, the objective of modern diabetes education is not merely to encourage people to adhere to treatment. Those with the condition are invited to become informed and active health decision makers. The results of these programmes are impressive and exciting. Diabetes education is effective in improving both metabolic outcomes and quality of life.

**Life-long learning**

However, diabetes education is not a single-shot inoculation. If they are to be able to sustain the behavioural changes and improved self-efficacy initiated while participating in an educational programme, people with diabetes need ongoing self-management support. But self-management support includes more than just the transfer of information. This support also entails the provision of psychological and behavioural support, the importance of which was stressed in the results of the DAWN Study.

Educators have an important role to play in screening for depression and severe emotional distress. They can also help people with the condition to find the necessary resources to cope with diabetes on a daily basis.

Self-management support is often available through team care and ongoing interaction with nurses. Nurses are key players in bridging communication between doctors and people with diabetes. They play a unique role in diabetes care, offering competence, care and compassion to people with the condition. A number of studies have described the positive impact that nurses can have on outcomes. Sadly, however, most people with diabetes do not have access to a diabetes care team or to a nurse educator or dietitian. Moreover, when these critical members of the team are available, their skills are not always valued or fully exploited.

Nurses are key players in diabetes care, offering competence, care and compassion to people with the condition.

**From challenge to change**

The challenge now facing the diabetes community is to translate the many findings from DAWN into health-care decisions and actions which will improve the lives of people with the condition. This must be done at many levels: at the level of individual practices, group practices and health-care systems, and at a national level through policy changes.

**Martha Funnell and Linda Siminerio**

Martha Funnell is Clinical Nurse Specialist and Director for Administration at the Michigan Diabetes Research and Training Center, Michigan, USA. She is an Adjunct Lecturer in the Division of Critical and Long-Term Care Programs at the School of Nursing, University of Michigan, USA.

Linda Siminerio is the Director of the Diabetes Institute at the University of Pittsburgh, USA and an Assistant Professor at the University’s School of Medicine and Nursing. Dr Siminerio is Senior Vice-President of the International Diabetes Federation, and she is the first diabetes educator to serve in that capacity.
To stimulate, acknowledge and reward outstanding efforts to improve the health and quality of life of people with diabetes, Novo Nordisk will award a grant of 10 000 EUR to organizations or individuals whose projects and actions have helped address the people behind the condition, and have demonstrably achieved one or more of the five DAWN goals (see page 12).

Criteria for selection

Candidates will be selected based on their ability to achieve one or more of the five DAWN goals through actions to:

- raise diabetes awareness and promote advocacy
- educate and mobilize people with diabetes and those at risk
- train health-care providers and enhance their competencies
- provide practical diabetes management tools and systems
- drive policy for change in health-care systems
- develop psychological research in diabetes

Expert panel

All submissions will be reviewed by a panel including members of the DAWN International Expert Advisory Board and Novo Nordisk.

Entries will be marked against the philosophy which underpins DAWN, and in line with the DAWN call to action (see page 12).

Entries for the Award must be in the hands of the DAWN award panel no later than August 1, 2004.

The recipient of the DAWN award and grant of 10 000 EUR will be announced in November 2004 alongside the four best awards entries. These five outstanding examples of best practice will be communicated through a number of channels, including Diabetes Voice.

The grant is intended for use in furthering the impact of the awarded effort as a contribution to expanding its reach and impact. To obtain a submission form, please contact:

Jeanette Sevelsted, DAWN Programme, Novo Nordisk at jsev@novonordisk.com or download it from www.dawnstudy.com.
Empowering children with diabetes and their parents

Hilary MCV Hoey

When a child is diagnosed with diabetes, the news usually comes as a shock to all family members. This often provokes a crisis which is associated with grief and sadness; a complex scenario emerges. Children with diabetes and their parents often feel overwhelmed by the amount of knowledge required to effectively manage the condition. Parents and children experience feelings of guilt. Parents sometimes feel they may have been able to prevent their child’s diabetes; children may blame themselves for an illness, and perceive the condition and its treatment as a form of punishment. In this article, Hilary Hoey explores the psycho-social issues around diabetes care and education, and the empowerment of young people with diabetes and their parents.

Diabetes can be a major cause of stress for children and their families. Young people with diabetes must adhere to a complicated management regimen, involving daily insulin injections, frequent monitoring of blood sugar levels, and regulating food intake. Children and adolescents may feel stigmatized by aspects of their illness, such as injecting themselves with insulin. They must face the possibility of diabetes complications later in life, such as renal failure, blindness, heart disease and circulatory difficulties.

Who cares?
Effective diabetes management not only reduces complications, but is also associated with an improved quality of life for children and adolescents with diabetes and their parents.1 Those involved in the treatment are mainly the child and parents. An important role may also be played by the extended family, including grandparents, aunts, uncles and cousins. The family doctor and the school are also active in the management of a child’s diabetes. Education and empowerment must therefore involve all these people.

Empowerment through education
The initial educators are the members of the multi-disciplinary diabetes clinic team, comprising medical and nursing staff, a dietitian, and a psychologist. Particularly during the early stages of care, the confidence of the child and parents is of great importance. Reassurance, praise and encouragement are necessary to boost their self-esteem.

The instruction commences when the child is diagnosed with diabetes. Further instruction is given on subsequent visits to the health clinic. The aim of diabetes education is to inform and empower the family to competently and confidently manage the condition. The education should be centred on the young person with the condition and their family, empowering the child or adolescent and the parents to adjust food intake and insulin dosage, based on blood glucose data generated by the young person. Individualized treatment...
should be determined through a close working relationship between the members of the team and the person with diabetes.

This empowerment of the young person and the family helps reduce the frustrations related to diabetes care and improves treatment outcomes. Education is ongoing, comprising of problem-solving and the identification of the psycho-social barriers to effective diabetes management. In order to embrace the diversity of learning styles of the children, adolescents and families, diabetes education and attention to learning strategies require flexibility and individual tailoring on the part of the educators.

**Shifting the centre of care**

Given the wide variations in blood sugar levels, the effects of different foods, and the response to insulin, the management of diabetes can be frustrating. This is particularly so in children and adolescents because of the wide variations in their needs relating to growth, development and puberty. The needs of a very young child, a school child, and a teenager are very different. A young child’s diabetes health is determined mainly by their parents and the health professionals involved in the child’s care.

The aim is to give responsibility for care to the older child and adolescent, and move towards increased self-management and self-efficacy. Family support during adolescence is essential and is a significant predictor of good self-management. Studies have shown that, compared with less-educated families, children with diabetes from families with more knowledge and greater perceptions of empowerment have improved diabetes management and a more positive psychological outlook on life.3

Children from families with more knowledge have improved diabetes management and a more positive psychological outlook on life.

The empowerment of the child with diabetes and the child’s family enables them to take charge of care on a daily basis. This approach is more sound than the traditional model, in which the health-care professional is perceived as active, powerful, knowledgeable, and in control of the diabetes care; while the person with the condition is viewed as passive, accepting and dependent on the health-care professional. Physicians can learn to be experts in diabetes management, but only people with the condition can become experts in the conduct of their own lives.

Although for years the members of health-care teams have been described as equals, it has been generally understood that the physician is the first among equals. In diabetes care, this status rightfully belongs to the person with the condition. Diabetes education should therefore help young people with diabetes and their parents to:

- acquire knowledge of the clinical management of diabetes
- develop behaviour-change skills
- develop the assertiveness and communication skills necessary to collaborate effectively with their health-care team
- assess whether their recommended self-care plan is realistic, relevant and sustainable.

**Teenage kicks**

At adolescence, mismanagement is common. Metabolic control generally deteriorates and this is associated with increased adolescent worries and reduced satisfaction with life.1 Worries concerning career prospects and the complications of diabetes may give rise to fear, anger, depression, and rebellion. At this age, a child seeks to gain independence, while parents often struggle to allow more freedom due to their fears
about poor diabetes control or hypoglycaemic episodes.

However, it is important for the child to take part in peer activities. Aspects of a young person’s diabetes, such as the dependence on insulin injections, and the fear of hypoglycaemia can all lead to social difficulties and to withdrawal from sports and other social activities. The emergence of sexual identity can be made more problematic in an adolescent with diabetes. For girls, eating disorders are increasing in prevalence and may be a form of compensation.4

Physicians can become experts in diabetes management, but only people with diabetes can become experts in the conduct of their own lives.

These psycho-social problems can reduce a young person’s ability to cope with the management of their diabetes. Interest, tact and consideration are necessary to encourage adolescents to take responsibility for their own care. Young people need reassurance that they have the family’s support and that attendance at the diabetes clinic is worthwhile.

Further education and widening of knowledge should be provided at subsequent visits to the clinic. New situations can be discussed which have arisen or are about to occur in the future, such as holidays and sports. It is also an opportunity to discuss new management techniques and advances in diabetes research. The family can discuss new ideas or problems with the various members of the diabetes care team.

Peer support
By joining the local diabetes association, the family can gain a considerable amount of information from meetings, literature and electronic learning facilities. Diabetes camps provide a holiday environment where initial independence can be gained by the children with diabetes. Young people can enhance their diabetes management knowledge and skills by observing the way in which others cope with their condition. They may help others who are less competent, thus increasing confidence and improving self-esteem.

Children from single-parent families and ethnic minority groups often have poor metabolic control; people from ethnic minority groups have a significantly lower quality of life.1 It is therefore very important that resources are provided to meet the needs of this particularly vulnerable group.

The challenge
The overall aim of diabetes education is to empower the young person with the condition to become independent and to be able to adjust insulin dosages and diet according to blood sugar findings, able to cope with unexpected stress, and to develop a positive approach to life. Effective diabetes management depends on the adherence of the child and family to the treatment regimen.

Empowering children and their families through education, motivation and support is therefore the cornerstone of good diabetes management. Siblings, the extended family, and school should be involved in the process. Following recommended treatments over a long period of time presents many difficulties for children and their families. The challenge for the paediatric diabetes care team and other health professionals is to provide enthusiastic, positive and comprehensive support, and to prepare young people and their families to cope positively and effectively with a lifetime of diabetes.

References


It appears that little progress has been made since the second edition of the St Vincent Declaration (SVD) in 1995. This provided clear guidelines on encouraging psychological well-being in people with diabetes. While many healthcare professionals intuitively would agree with the SVD recommendation, this may not be sufficient to actually improve the quality of psychological care.

Results from a number of recent studies highlight the importance of psycho-social factors in diabetes management. Research shows that psychological co-morbidity is prevalent in people with diabetes. As a result, well-being, self-care and glycaemic control are adversely affected. Depression is common in people with diabetes, and unfortunately under-diagnosed in many cases.

Recent studies, including the Diabetes Attitudes, Wishes and Needs (DAWN) Study, indicate that in general, psychological support is under-resourced and inadequate in both adults and children with diabetes. In this article, Frank Snoek and Elize van Ballegooie present evidence that the growing appreciation of the psychological implications of diabetes has not yet translated into a significant improvement of psycho-social care for people with diabetes.

Little progress has been made since the second edition of the St Vincent Declaration in 1995.

If these recommendations are not included in the national diabetes standards of care and reinforced by opinion leaders in the field of clinical diabetes, their influence on healthcare practice is further reduced.

What is in the guidelines? We reviewed the content with respect to psycho-social issues of various national diabetes
In psychology, co-morbidity refers to more than one mental disorder affecting a person at the same time.

A person with a major depressive disorder (depression) suffers from a depressed mood and/or a loss of interest or pleasure in daily activities for a prolonged period of time. This disorder is characterized by the presence of a number of symptoms, including significant weight loss or weight gain, insomnia or hypersomnia, feelings of worthlessness or excessive or inappropriate guilt, and recurrent thoughts of suicide.

Guidelines from 1998 to 2003. Articles in English on diabetes guidelines were retrieved from the websites of national diabetes and psychological associations, and using Internet search engines. E-mails were sent to representatives of national diabetes institutions, as well as psychological and psychiatric organizations.

Psychologists, psychiatrists and social workers are identified as the primary mental health professionals involved.

In total, 42 countries were screened for their national diabetes programmes and guidelines. Of these, 13 countries explicitly mention psycho-social problems. Elaborate information on these issues was found only in the guidelines of five countries: Australia, Germany, the Netherlands, Romania and the UK (including Wales, Scotland and Northern Ireland). Psychologists, psychiatrists and social workers are identified as the primary mental health professionals involved. The majority of the guidelines on psycho-social issues do not make age-specific recommendations.

In psychology, co-morbidity refers to more than one mental disorder affecting a person at the same time.

A person with a major depressive disorder (depression) suffers from a depressed mood and/or a loss of interest or pleasure in daily activities for a prolonged period of time. This disorder is characterized by the presence of a number of symptoms, including significant weight loss or weight gain, insomnia or hypersomnia, feelings of worthlessness or excessive or inappropriate guilt, and recurrent thoughts of suicide.

In total, 42 countries were screened for their national diabetes programmes and guidelines. Of these, 13 countries explicitly mention psycho-social problems. Elaborate information on these issues was found only in the guidelines of five countries: Australia, Germany, the Netherlands, Romania and the UK (including Wales, Scotland and Northern Ireland). Psychologists, psychiatrists and social workers are identified as the primary mental health professionals involved. The majority of the guidelines on psycho-social issues do not make age-specific recommendations.

Guidelines in Australia recommend that people with diabetes should be screened for a major depressive disorder.

Most of the diabetes guidelines recommend regular assessment of psychological functioning in people with diabetes at fixed points, for example when first diagnosed and during annual check-ups. Evaluation of psychological well-being can be carried out using standardized, validated questionnaires.

Given the high prevalence of depression in people with diabetes, the Australian Centre of Diabetes

The psychological problems mentioned in the diabetes guidelines are:

- depression
- eating disorders
- anxiety
- resistance to insulin therapy
- maladaptive coping behaviours
- cognitive and behavioural disorders
- sexual problems.
Strategies recommends that those with the condition should be screened and if necessary treated for a major depressive disorder (see Ruth Colagiuri’s article on page 31).

It is strongly recommended that diabetes care teams should be multi-disciplinary, including a mental health specialist with an interest in the field. In the case of diabetes negatively affecting the psychological well-being of relatives, psychological care should not focus solely on the person with the condition.

The International Society for Paediatric and Adolescent Diabetes recommends that overt psychological problems or psychiatric disorders in young people or family members should receive support from the diabetes care team and expert attention from a social worker, psychologist or psychiatrist trained in child and family therapy.

Call for action
The importance of the psycho-social problems related to diabetes is clearly recognized. However, little progress has been made in translating this awareness into clinical practice. Only a few countries have specific recommendations which guide health-care professionals in counselling people with diabetes and their families. Given the magnitude and impact of psycho-social problems in people with diabetes, focus on this issue in national guidelines is urgently needed. In this context, attention should also be paid to the practical barriers to adequate psychological care, such as that represented by the lack of psychologists who are specialists in diabetes.

Existing guidelines, such as those developed in Germany, the Netherlands, Romania, Australia and the UK, can serve as a model for other countries. To further stimulate this process, IDF, in collaboration with the DAWN Programme, is currently working on a global guideline on psycho-social issues related to diabetes, and will include such issues in its own global guideline in 2005.

Frank J Snoek and Elize M van Ballegooie
Frank J Snoek is Professor of medical psychology at the Vrije Universiteit Medical Centre in Amsterdam, the Netherlands.

Elize M van Ballegooie is a Bachelor in psychology and is involved in the DAWN Programme.

References
Integrating psycho-social issues into national diabetes programmes

Ruth Colagiuri

It is widely agreed that people with diabetes can lead a ‘normal’ life. Like people who do not have the condition, people with diabetes can function fully in family, workplace, and community settings. However, it is also accepted that diabetes self-care is complex and demanding. Being obliged to balance food intake and exercise against medication, self-administer injections, and self-test blood for glucose levels is not ‘normal’. The demands of diabetes self-management can impact negatively on the psychological status of people with the condition. In this article, Ruth Colagiuri argues that psycho-social problems should be acknowledged as a complication of diabetes. The author suggests that psychological problems should be identified and managed in the same way physical diabetes-related health is managed.

People with diabetes or those who have a close personal relationship with a person with diabetes know how strongly the condition impacts on every-day life. Studies demonstrate that people with diabetes have significantly more psychological problems than the background population. Rates of depression have been seen in people with diabetes which are 2-4 times higher than those in the general population.1,2

In the recent Diabetes Attitudes, Wishes and Needs (DAWN) Study, which surveyed over 5000 people with diabetes in 13 countries, people with diabetes reported poor well-being, anxiety and stress.3

The psychological complications

It has been established that psycho-social issues are a clearly identifiable factor which impacts significantly on people with diabetes, and influences their ability to manage their condition. As with the physical complications of diabetes, people with the condition face different types and degrees of psychological problems.

Adaptational problems

It would be almost abnormal for a person not to experience some difficulties adjusting to life with diabetes...
diabetes. These common problems should be managed with the collaboration of a primary care physician (general practitioner – family physician), a diabetes nurse or a specialist diabetes doctor with training in counselling skills.

It would be abnormal for a person not to experience some difficulties adjusting to life with diabetes.

**Psychological problems**
These may be more complex and may include mild to severe anxieties, depression, and severe coping difficulties. Specialized behavioural therapies may be required from a psychologist – preferably one who has received some training in diabetes-related problems.

**Psychiatric problems**
These are complex and transcend behavioural issues. Although they are unlikely to be caused by diabetes, psychiatric problems may complicate and impact negatively on diabetes management and outcomes. These will require medical and behavioural assessment and treatment.

**Key intervention points**
The psychological problems should be assessed and managed at the primary point of contact between the person with diabetes and the health system – with the primary care physician or diabetes nurse. If these problems are complex, the person should be referred for further assessment and management to a health professional with specialized psychology skills, or to a psychiatry service.

The Australian National Diabetes Strategy and Implementation Plan identified key intervention points for diabetes:

- no diabetes
- pre-diabetes
- undiagnosed diabetes
- known diabetes
  - at diagnosis
  - established uncomplicated diabetes
  - diabetes with complications.

Required action and tasks are recommended which correspond with these intervention points. For example, at diagnosis, provision is recommended for:

- clinical care according to guidelines
- education in self-care
- information about recommendations for clinical care.

Currently, at policy and planning level, the physical and psycho-social management of diabetes are separated. However, these intervention points could be employed by national diabetes programmes and action plans in order to incorporate the identification and treatment of psychological problems into existing initiatives and services for people with diabetes.
For example, the evidence grows stronger for stress as a risk factor for diabetes; it may be reasonable to consider this in primary prevention initiatives aimed at high-risk individuals. Furthermore, although the physical impact of diabetes is widely reported, the psychological burden is relatively unrecognized. The National Diabetes Programmes Toolbox urges the inclusion in community awareness programmes and advocacy efforts of psychological issues among the complications and disease burden of diabetes. This can be done with little effort and at no additional cost.

Although the physical impact of diabetes is widely reported, the psychological burden is relatively unrecognized.

In the management of known diabetes, a number of simple validated tools are available for the identification of psychological problems. These require no more time to apply than does measuring blood pressure. With minimal training and support from a psychologist, any health professional could apply these at diagnosis. Any of the key intervention points along the continuum of diabetes care can be used to determine the need for treatment and the type of assistance required.

These tools could also be used at annual screening for complications and at any time of significant change in the person’s diabetes status. This is particularly important at the onset or worsening of complications, when the person with diabetes may be forced to make major adjustments in order to accommodate limitations in function and lifestyle as a result of physical disability.

A holistic approach to care
In diabetes care, the health workforce should be skilled in the provision of services which address the psycho-social needs of people with diabetes. The collection of data in order to monitor the burden of diabetes complications, whether for the individual or regionally, should include information on the nature and extent of psychological problems.

Psycho-social issues represent a significant complication of diabetes. This should be recognized and addressed alongside clinical care and education. Relatively simple assessment, counselling and behavioural therapies are available which could be used by most health-care professionals with a little additional training and support from a psychologist. These are not routinely employed in diabetes care. However, from a policy and planning perspective, integration of psycho-social care in diabetes is entirely possible within the framework of a national diabetes programme.

A role for diabetes organizations
In order to bring about the changes which are required to ensure the appropriate attention to the psychological issues, it is important that the national diabetes organizations take seriously their role as advocates for people with the condition. This requires the development of lobbying strategies to effectively campaign for the inclusion of this aspect of diabetes care in national diabetes programmes.

Ruth Colagiuri

Ruth Colagiuri is the Director of Health Policy and Management of the Australian Centre for Diabetes Strategies at the Prince of Wales Hospital, Randwick, Sydney, Australia.

Dr Colagiuri is a Senior Lecturer at the University of New South Wales, Australia, and Vice President of Diabetes Australia.

References
The establishment of a practice which puts the person at the centre of care will require a change in the attitudes and beliefs of health professionals, and people with diabetes. A service which places the person with diabetes at the centre of care will undoubtedly demand the adoption of this philosophy by the organizations responsible for the delivery of diabetes care, as well as those networks serving the interests of people with diabetes, both locally and nationally. In this article, Arun Baksi highlights the various important components that comprise 'patient-centred' practice, and draws attention to the changes required within health-care organizations.

The health professional should collaborate with people with diabetes to identify their anxieties and fears.

In the management of chronic diseases, the promotion of self-management must be the principal objective. This is particularly applicable to diabetes. For the health carer, supporting self-management consists of the provision of information and skills to people with diabetes. The information given has to be relevant, and appropriately timed. An emphasis should be placed on effective communication, ensuring that the information offered has been fully understood.

In terms of disease management, it is important for the health professionals to take positive steps to establish a rapport with the person with diabetes. A recently diagnosed person with diabetes needs a level of...
confidence in order to take a series of decisions regarding the management of his or her condition. In order for this person to gain confidence, reassurance should be offered by the health carers. In the early weeks following a diagnosis, the amount of information imparted and skills developed will vary considerably according to the person's psychosocial state and ability to understand.

During the weeks that follow, the majority of people with diabetes usually begin to feel better. As a result of the initial information given and medication prescribed, their condition is stabilized. In the UK, a multi-disciplinary team will be involved with the subsequent management of a person's diabetes. Since details of ongoing diabetes education are rarely recorded, members of the team are usually uncertain as to the extent of the person's diabetes knowledge.

There does not appear to be a mechanism to assess the diabetes knowledge or skills of people with the condition. Often, the assessment is left to chance. No national or international agreement exists to indicate the knowledge and skills which are needed in order to empower people with diabetes to effectively self-manage their condition.

Diabetes education should be delivered in repeated cycles; in order for the person with diabetes to process and apply diabetes information, the same ground must be covered a number of times. This process requires months. A structured diabetes education programme for all people with the condition should be established in the clinical units which deliver diabetes care. A process of recording and monitoring is vital in order to enable assessment of the effectiveness of the education programmes.

**Individual care plan**

A partial solution to the issues concerning diabetes education programmes lies in developing individual care plans. These are contributed by people with diabetes, and all members of a multi-disciplinary team of health carers. Each consultation begins with the identification of problems, and the need for care as perceived by the person with diabetes. There should then be a discussion about the issues raised. In this way, an explanation can be offered of the options available, and agreement reached on a set of actions, including the need for more in-depth diabetes education.

After this, the issues as perceived by the health professionals can be discussed. The discussion should then be recorded on paper or electronic format, including agreed targets and time lines, in a client-held record. This will enable access by health professionals at any location to information about previous diabetes knowledge, thereby ensuring seamless care for the person with the condition. At the same time, a useful audit tool is provided for diabetes care and education. The implementation document of the English National Service Framework for diabetes recommends the adoption of this approach.

**Choice**

It is implicit that self-management enables people with diabetes to make choices regarding the treatments they are offered. The various options, with the advantages and disadvantages for each, should be explained and discussed. The person with diabetes should remain at the core of all decisions related to their health.
The importance of lifestyle
Therapeutic regimens should be tailored to the lifestyles of the people involved. The enormous number of treatments available allows health professionals to do this. People with diabetes should receive information on the function of particular drugs, and the adjustment of dosages according to daily activity. This is particularly important in the case of treatment with insulin. The lifestyles of people with or without diabetes are dynamic and subject to varying levels of physical activity and dietary intake. The increasing prescription of pre-mixed insulins which are taken once or twice a day suggests that health professionals do not always recognize the importance of lifestyles. A single injection of a pre-mixed insulins will inevitably restrict a person to twelve hours of insulin activity. This rules out any significant change in physical activity or diet during those hours.

Patient-centred health organizations
In the UK, it is now the policy of the government to ensure that people with diabetes are represented in most health-care bodies related to their care. This requirement raises many issues. An uninformed person cannot be expected to become an effective member of any health organization. If they are to argue their case as equal members with health professionals, such people should receive training in the relevant aspects of the health service, and have a decent grasp of medical terminology and evidence. The members of such bodies should not be chosen by organizations; they should be elected by peer groups of people with diabetes. The Isle of Wight diabetes service delivers intensive training programmes for people with diabetes. At the conclusion of each course, the participants are examined by external health professionals. Experience from these courses has demonstrated that despite the diversity among the participants of educational, social, and occupational backgrounds, the majority are able to qualify as ‘experts’ in diabetes. Some are able to deliver diabetes education and actively participate in the various health-care bodies dealing with diabetes. These people with diabetes have become an important resource for the health service. Additionally, they now constitute a significant proportion of the local diabetes network.

Experts hold the key
The creation of ‘expert patients’ will help health organizations in deciding policies pertaining to the delivery of care in chronic diseases. With the adoption of training programmes by national diabetes organizations, more informed people with diabetes will be able to become effective health campaigners and members of health-care bodies. Undoubtedly, the ‘expert’ people with diabetes are an important resource to health professionals in the delivery of effective diabetes care.

Arun K Baksi
Arun K Baksi is Honorary consultant physician and founder of the Arun Baksi Diabetes Centre, Isle of Wight Healthcare NHS Trust, St. Mary’s Hospital, Newport, Isle of Wight, UK. He was the founder Editor of Practical Diabetes International, and is now its honorary consulting editor.

Acknowledgement
The author is grateful to Ma’en Al-Mrayat and Patricia Wilson for their constructive criticism and suggestions in the preparation of this paper.
In order to address depression among people with diabetes, the frequency and gravity of this problem must be recognized by the citizens of the region, the health-care providers, and their governments. A commitment is required to implement strategies and actions to improve the recognition and treatment of depression and other psychological problems faced by people with diabetes. Only in this manner can the quality of life of people with diabetes and depression be improved.

In order to address depression among people with diabetes, the frequency and gravity of this problem must be recognized by the citizens of the region, the health-care providers, and their governments. A commitment is required to implement strategies and actions to improve the recognition and treatment of depression and other psychological problems faced by people with diabetes. Only in this manner can the quality of life of people with diabetes and depression be improved.

Relatively few studies have examined the psycho-social impact of diabetes. The Diabetes Attitudes, Wishes and Needs (DAWN) Programme addressed this issue in a study involving people with diabetes from 13 countries. A key finding was that depression was much more common in people with diabetes than in those without the condition, and was associated with impaired self-management and quality of life. Other studies confirm that depression often impairs metabolic control in people with the condition.

Although the countries of Latin America and the Caribbean were not involved in the DAWN Study, its conclusions apply to diabetes care in the region. In this article, Juan José Gagliardino looks at the application of the DAWN conclusions in a Latin American and Caribbean context.

The DAWN approach provides not only a measure of the frequency and severity of the problem, but also offers efficient tools for the diagnosis of psycho-social alterations. These could be of great value in improving the diagnosis and treatment of depression.
Achieving optimum care

DAWN in Latin America
Implementation of the DAWN activities in Latin America and the Caribbean will require a number of measures.

Sharing information
The dissemination of the results of the DAWN Study among opinion leaders, health professionals, people with diabetes, and governmental and non-governmental organizations in the region is essential for improving psycho-social care.

Screening for depression
Screening should be implemented for psychological problems in people with diabetes in the region. For this purpose, our group has prepared a questionnaire based on the WHO-5 Well-being Index. This will be distributed among different groups in Argentina and in other countries in the region.

Evaluating care
The WHO-5 questions should be applied to the measures used for the evaluation of the quality of care of people with diabetes. This would have a strong impact: psychological indicators of the quality of care received by people with diabetes in the region would be incorporated.

A multi-disciplinary approach
The postgraduate training programmes for general practitioners should incorporate the DAWN approach for the diagnosis and treatment of psychological alterations in people with diabetes. This measure could be applied as a pilot programme in a number of countries. The programme would then be evaluated with a view to wider implementation across the region.

A multi-disciplinary approach to diabetes care is required.

Implementation of the lessons from DAWN regarding the diagnosis and treatment of psychological alterations in people with diabetes should be learned at undergraduate level in the schools of medicine. This would allow the medical students to become familiar with the DAWN approach early in their education.

The WHO-5 Well-being Index (World Health Organization, 1998) measures psychological well-being. The Index recommends that people receiving primary care should participate in a screening process for psychological disorders. This is done by completing the WHO-5 questionnaire. It is recommended that people who score positively for depression should be examined in order to confirm a diagnosis of depression or to rule out normal distress or the physical causes of depression. Translations of the Index exist in: Albanian, Arab, Bulgarian, Dutch, English, Finnish, French, German, Hebrew, Hungarian, Icelandic, Japanese, Lithuanian, Norwegian, Persian (Farsi), Romanian, Russian, Spanish, Swedish, Turkish.
Teaching the lessons from DAWN would give medical students an understanding of the psychological barriers to effective treatment.

These last two measures will prepare a cadre of health professionals competent in the assessment of psychological problems in the care and treatment of people with diabetes. They will possess advanced training in the diagnosis and treatment of psychological problems, and counselling.

Continuous assessment
Implementation of the above-mentioned DAWN measures in Latin America will require continuous evaluation of the results obtained.

The region of Latin America and the Caribbean is heterogeneous in terms of ethnicity, culture and traditions, levels of literacy, health systems and socio-economic conditions.

Consequently, the task of implementing DAWN activities will not be a simple one. However, this is too large and important a problem to ignore. We must begin the implementation of these activities in a step-wise manner, in concert with the health professionals and diabetes educators of the region.

Building on previous knowledge
A number of factors could favour the effective implementation of the DAWN measures. These include the experience gained through the implementation of multi-centre studies with the participation of a number of countries – the *programa latinoamericano de educación a pacientes diabéticos no insulinodependientes* (PEDNID-LA) and the Qualidiab programme.

The implementation of the DAWN activities will offer people with diabetes in the region an opportunity to enhance their quality of life.

The proximity of the 12th meeting of the Latin American Diabetes Association is also important. This will take place in São Paulo, Brazil in September 2004. The event, which brings together people with diabetes and health carers from the region, would be a good opportunity for the official launch of the DAWN Programme in Latin America.

An opportunity for people with diabetes
The implementation of the DAWN activities will offer people with diabetes in the region an opportunity to improve the management of their condition and enhance their quality of life. While this will not be easy, the effort required is clearly justified by the potential benefits to health and quality of life for people with diabetes in the region.

Juan José Gagliardino
Juan José Gagliardino is Director of the Centre for Experimental and Applied Endocrinology, La Plata, Argentina – a PAHO/WHO Collaborating Centre for Diabetes. He is Chairman of Physiology in the School of Medicine, La Plata University, La Plata, Argentina.

Further Reading
Please find below a list of IDF publications. Once completed, you can return it by fax at +32-2-5385114 or by e-mail to merry@idf.org. These publications can also be ordered via our online bookshop at www.idf.org/bookshop. All prices are in EUR and are exclusive of postage and packaging. Shipping costs will be calculated based on weight and destination. The total cost will be communicated to you upon receipt of your order. Thank you.

### Publications

<table>
<thead>
<tr>
<th>Publication</th>
<th>Language</th>
<th>Quantity</th>
<th>Price (EUR)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes and Kidney Disease: Time to Act (2003, 90 pp)</td>
<td>EN</td>
<td>25.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes and Cardiovascular Disease: Time to Act (2001, 90 pp)</td>
<td>EN, FR, ES*</td>
<td>25.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes and Obesity: Time to Act (2004, 60 pp)</td>
<td>EN</td>
<td>35.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes and Kidney Disease: Time to Act (2003, 65 pp)</td>
<td>EN, FR, ES*</td>
<td>35.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost-effective Approaches to Diabetes Care and Prevention (2003, 36 pp)</td>
<td>EN</td>
<td>15.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global Strategic Plan to Raise Awareness of Diabetes (2003, 20 pp)</td>
<td>EN</td>
<td>free</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes Atlas second edition (2003, 360 pp)</td>
<td>EN</td>
<td>30.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes Atlas second edition Executive Summary (2003, 56 pp)</td>
<td>EN, FR, ES *</td>
<td>30.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes Atlas second edition + Executive Summary</td>
<td>EN</td>
<td>110.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes Voice (Special Issues):</td>
<td>EN, FR, ES *</td>
<td>12.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevention (2003, 56 pp)</td>
<td>EN, FR, ES *</td>
<td>12.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney Issue (2003, 44 pp)</td>
<td>EN, FR, ES *</td>
<td>12.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>International Standards for Diabetes Education (2003, 24 pp)</td>
<td>EN</td>
<td>free</td>
<td></td>
<td></td>
</tr>
<tr>
<td>International Curriculum for Diabetes Health Professional Education (2002, 112 pp)</td>
<td>EN</td>
<td>free</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Putting People at the Centre of Care (2004, 44 pp)</td>
<td>EN, FR, ES *</td>
<td>12.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevention (2003, 56 pp)</td>
<td>EN, FR, ES *</td>
<td>12.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney Issue (2003, 44 pp)</td>
<td>EN, FR, ES *</td>
<td>12.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>International Consensus on the Diabetic Foot (1999, 96 pp)</td>
<td>EN</td>
<td>5.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD-ROM (2003)</td>
<td>EN</td>
<td>15.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Booklet + CD-ROM</td>
<td>EN</td>
<td>18.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Please circle language of your choice

### Your Contact Details

- **MS**
- **MR**
- **DR**
- **PROF**

**Family Name(s):**

**First Name(s):**

**Organization / Company:**

**Address:**

**Postal Code:**

**Country:**

**Phone:**

**Fax:**

**E-mail:**

**VAT:**

**Occupation:**

Do you have diabetes? □ Yes □ No

### Payment Details

- I will pay by credit card, to be billed in euros.
  - Please charge to my card:
    - □ American Express
    - □ Mastercard
    - □ Visa
  - Name of cardholder:
    - My card number is: ________________
  - Expiry Date: ________________
  - Signature on card: __________________

- I will pay by direct bank transfer to the IDF account no (IBAN: BE36-6451-4103-2981; BIC: JVBABE22)
  - at: Bank J Van Breda & Co, Vlaanderenstraat 53
  - B-9000 Gent, Brussels, Belgium. Please indicate as reference: PUBS ORDER
  - VAT: BE433.674.328

Please return this form to: INTERNATIONAL DIABETES FEDERATION

Executive Office • Avenue Emile de Mot 19 • 1000 Brussels • Belgium • Phone: +32-2-5385511 • Fax: +32-2-5385114

www.idf.org/bookshop
Enhancing health communication: the German experience

Susan Woods-Büggeln

The recent euphoria surrounding the positive effects of preventative measures with people with impaired glucose tolerance or manifest Type 2 diabetes is rarely reflected in the experience of the health-care professionals working with people with diabetes. Despite efforts to advise and inform, there is very little lasting change in health-care behaviour.

Many health-care professionals report feelings of frustration and anger. They often describe the people in their care as 'difficult'. Many carers show symptoms of provider burn-out; their initial attempts to help are replaced by resignation and emotional distance. In order to understand this phenomenon, Susan Woods-Büggeln takes a close look at the process of communication between health professionals and people with Type 2 diabetes.

The first avenue of treatment upon diagnosis of Type 2 diabetes is weight reduction and increased physical exercise. This involves behavioural change at a level which is likely to interfere with a person's lifestyle. This person is commonly of middle age and their decisions are likely to be influenced by a number of psycho-social characteristics.

Interrupting behavioural pathways
People of this age are likely to have been behaving the way they do for several years, if not decades. Their behavioural choices are based on decisions which were made a long time ago, and have been well practised. People of middle age who do not repeat lifestyle patterns, such as relationships, living arrangements, and work would be unusual and may have some psycho-social problems.

Based on this observation, the conviction that people of middle age

May 2004 | Volume 49 | Special Issue
Achieving optimum care

Achieving optimum care

Age are able and willing to change central areas of their lifestyle is empirically unfounded. Stable behavioural change involves a highly complex psychological process. Spontaneous behavioural impulses such as eating fast food while out shopping are consciously interrupted and replaced by other behaviours – buying, preparing and eating healthy food before going shopping. This can often mean a loss of positive consequences, such as taste or convenience.

The conviction that people of middle age can easily change their lifestyle is unfounded.

Stable social network

Most people do not exist in a social vacuum; our behaviour is constantly reinforced by the reactions of friends, colleagues and family members. Expected behaviour will elicit largely predictable responses; unusual behaviour may provoke irritation. In order to achieve effective, stable change, a person requires the ability not only to tolerate a long-term loss of positive consequences, but to do this despite resistance from their social environment. This involves a certain level of social competence.

A lack of symptoms

One of the precursors of behavioural change is the perception of a discrepancy between the way things are and the way they should be. Another is the belief that this discrepancy is subjectively important. In people with Type 2 diabetes, the symptoms are not apparent or are barely noticeable. This is either because they appear very gradually or because they may well be attributed to other phenomena.

Falling levels of energy and libido, and a gradual loss of the ability to enjoy life are often attributed to the general process of ageing, including social changes such as retiring, than to an undiagnosed illness.

Informational deficit

When tablets no longer suffice, a change to insulin therapy may be the only sensible route in the opinion of the health-care professional. However, for the person involved, this recommendation can be a reminder that their condition is chronic and may be interpreted as a sign that the person’s diabetes is getting worse. The person with diabetes may mistakenly believe that those who inject insulin have more complications than those who take only tablets. Thus, the medical recommendation may provoke feelings of fear and sadness.

People with diabetes often feel anger and frustration at not having been ‘healed’, despite following the previous recommendations. It is also common for people to passively avoid further communication; the person agrees to insulin therapy but does not actually follow the recommendation.

Co-morbidity

At the time of diagnosis, a large proportion of people with Type 2 diabetes have some form of macro-vascular condition. Heart disease is psychologically very threatening. In comparison, raised blood sugar levels do not appear as threatening, particularly as this represents only one of a row of laboratory parameters, such as levels of cholesterol, triglycerides,
and blood pressure, which are higher or lower than they should be.

People are offered numerous therapy recommendations for various medical conditions. The recommendations which are subjectively more closely associated with acute life-threatening complications and which are easier to implement are more likely to be given priority.

**Traditional role expectations**
The treatment of Type 2 diabetes takes place within the framework of a relationship that has so far been defined by the rules of acute medicine. In the traditional ‘patient-provider’ model, the person with diabetes:
- shows symptoms
- implements treatment over a restricted time period
- displays a positive emotional response as symptoms abate.

The health-care professional:
- makes a diagnosis
- offers a treatment recommendation
- displays a positive emotional response as the person with diabetes shows gratitude.

In this model, the aim of treatment is to save or heal; success is defined by a lack of symptoms. After successful treatment, ‘patient’ and ‘provider’ happily go their separate ways.

Despite the oversimplification, it is this type of role expectation that may cause irritation and mutual disappointment in the care of people with a chronic medical condition. In people with Type 2 diabetes, care involves permanent intrusions into a person’s life. The health-care professional cannot heal; and the person with diabetes often manages to integrate only a portion of the recommendations into their life. Irritation and mutual disappointment may result if both parties cling to the traditional model of acute health care. This may cause poor communication, and avoidance of the central issues.

**A dysfunctional model**
In the care of people with Type 2 diabetes, health-care providers are labouring under assumptions about health-behaviour change and motivational processes which are dysfunctional: not only are these assumptions ineffective, they alienate the very person who is the focus of care.

Commonly, the health professionals are also unable at a behavioural level to marry their humanistic convictions with their medical aims. Often, they are able to communicate empathically with people with diabetes until they begin to talk about therapy. These health-care professionals are usually caring, highly motivated people whose aim is to empower those with diabetes...
to manage their condition. However, health professionals are often frustrated and puzzled by their own lack of success in communicating effectively with the people they wish to help.

**Practical steps**

To address the particular problems faced by health-care professionals in working with people with Type 2 diabetes, an interactive workshop (Novo Akademie) was founded by Hansruedi Stahl of Novo Nordisk Europe together with an expert advisory board. Over two days, the participants, including diabetologists, diabetes specialist nurses, and general practitioners work with specialists from the fields of diabetology, psychology, and communication on the practical problems they encounter in their work. In order to understand the treatment barriers from the point of view of the person who is the target of the recommendations, the results of the DAWN (Diabetes Attitudes, Wishes and Needs) Study are presented and the particular psycho-social situation of people with diabetes is analyzed.

Particularly difficult situations are analyzed in role-play activities. Only after undergoing a process of emotional change, the participants can practise more effective communication strategies. These activities include elements common to most role-play work, which are necessary to prepare for this emotional change. These include the following:

**Empathy**

By acting out the role of the person with diabetes in their own difficult case scenario, the health-care professional is able to share with this person some of their emotional experiences and feelings. Through observation, the other group members learn to empathize with people with diabetes.

**Group support**

The other participants attempt different approaches in order to communicate with the person with diabetes. Supported by this group approach, the health-care professionals are often relieved of individual feelings of inadequacy. This process is likely to reduce negative self-appraisal and resulting anger.

**Reflection**

The course allows the participants an opportunity to question their existing dysfunctional assumptions regarding motivation and health-behaviour change, and facilitates the generation of more realistic alternatives.

**Practice**

More effective communication strategies are developed and practised. The health carers increase their behavioural repertoire in order to manage difficult situations. This may reduce negative emotions and allow for a more creative, relaxed approach.

The elements listed above are likely to be associated with a reduction in the emotional barriers to effective treatment on the part of the health-care providers.

The NovoAkademie offers workshops for diabetes health professionals throughout the year as part of the DAWN Programme of Novo Nordisk Europe. Advanced seminars for previous participants are now being developed. While the feedback is very positive, evaluation of the long-term effects is necessary.

Susan Woods-Büggeln

Susan Woods-Büggeln is a clinical psychologist who is both qualified in Germany as a Psychotherapist and in the United Kingdom as a Chartered Clinical Psychologist (British Psychological Society). She works in the Diabetes Department of Bethanien Hospital and at a Diabetologist Specialist Outpatient Clinic in Hamburg, Germany. She is Vice Chairperson of the Psychology and Behavioural Medicine Working Group of the German Diabetes Association.

Acknowledgement

Thanks are extended to communications specialist, Hansruedi Stahl, Business Development Director, Central Europe, Novo Nordisk. Hansruedi Stahl founded the NovoAkademie and is responsible for running the centre and organising the workshops in collaboration with the expert advisory board.
Acceptance of advertisements in Diabetes Voice should not be construed as an endorsement by the International Diabetes Federation (IDF). The IDF does not test advertised products and, therefore, cannot ensure their safety and efficacy. Acceptance of advertising does not imply that the IDF has conducted an independent scientific review to validate product safety and efficacy of advertising claims. Opinions expressed in articles by contributors do not necessarily represent the views of the IDF.
I wish...

...I hadn’t been scared of insulin injections, because they have made me feel much better.

Novo Nordisk is a focused healthcare company and a world leader in diabetes care. We believe that significant improvements in diabetes care will occur not only through better medical treatment but also through greater awareness of diabetes. In addition to increasing our efforts to identify better treatments, we are therefore taking an integrated approach to diabetes care. We will work actively to promote collaboration between all parties in the healthcare system in order to achieve our common goal: To defeat diabetes.

www.novonordisk.com