



**Chronic
Illness
Alliance**

**Report from Therapeutic Patient Education Conference
(inc. Diabetes Attitudes Wishes Needs (DAWN) meeting)**

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**Conference held in Florence, Italy.
27 to 30 April 2006**

I would like to acknowledge:

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- **Westbay HARP Diabetes System Redesign Project for their assistance with the poster presented at the conference, and**
- **National Health and Medical Research Council Health Advisory Committee for assistance with the poster presented at the conference.**

Please note: this is a selection of the papers presented at the conference. The descriptions of the papers are from my own notes and may not do justice to the full papers or to the meanings of the authors. If people are interested in finding out more details they should contact me for the program, authors and abstract details.

Aims of the conference

- Inspire multidisciplinary dialogue about how to increase the impact of patient-centred therapeutic educational efforts throughout the world
- Promote global best practice-sharing about how to put DAWN into action
- Clarify future priorities for concerted global advocacy and action for better care that is focused on the person with the disease
- Help build awareness globally and nationally of the importance of addressing the social and psychological barriers to effective diabetes and other chronic disease management

The take-home messages from this conference were:

- Diabetes requires social and emotional care
- Better health outcomes are achieved when psychosocial factors are acknowledged and managed
- It is unrealistic to rely on one single self-management or education strategy
- Better outcomes are achieved from multiple and multidisciplinary approaches
- Health care professionals receive a lot of education; have access to tools and do not necessarily implement them

Opening address by Jean Philippe Assal

As founders of the DAWN initiative, Assal and his colleagues aim to change the way diabetes is cared for. Assal considers that education programs are too monotonous and repetitive. They require far more work and improvement.

This presentation looked at the role of the humanities in improving health care professionals' understanding of suffering and to escape the bio-medical model. He argued that the arts put suffering in a context of people's lives, allowing health care professionals to expand their repertoire of caring.

Michael Weiss (USA consumer)

Michael spoke about the psychosocial impact of T1D. He expressed the view that he had had more than his 'fair share of problems with diabetes', including coping with peripheral neuropathies. He had feelings of anger and resentment for many years though he had only belatedly been willing to acknowledge those feelings. No health professional had ever asked him how he felt about having diabetes.

He was recently diagnosed with colon cancer and he pointed out that in making decisions about treatment for his cancer he was largely guided by the oncologist, and that the decisions were more clear-cut. There were also far more offers of emotional support during his ca treatment and concern shown for his emotional state. For him, the emotional issues of having diabetes were more problematical because he always feels responsible and always feels that he could do more to help himself. This level of guilt was compounded in people with T2D who felt responsible for having developed the disease in the first place.

Dr Josian Bensing, (Netherlands).**Effective communication as a vehicle for improving health and quality of life for people with chronic illness.**

Who is responsible for opening the discussion on adherence to lifestyle changes? The doctor or the patient? If one answers ‘both’ then it is likely that nothing will happen. Doctors rarely introduce the discussion on adherence and neither do patients.

Doctors will suggest that taking insulin is no big deal, while patients will consider it life-changing; patients are more likely to concentrate on life-style and take the initiative to talk about it. They need to know and to understand and to feel known and understood.

Key messages:

No ‘stupid’ patient questions.

Only ‘stupid’ health care professionals (her words, not mine).

A level of respect creates the environment for respect and will stimulate self-management.

Kari Rosenfeld (USA).**The importance of advocacy by people with diabetes.**

Advocacy by the person with diabetes or their families leads to empowerment of the person as well as peer-leadership. Kari has a 14 yr old with T1D, who has worked to raise awareness of needs of young people with diabetes. An example of Kari’s daughter’s advocacy can be seen on the following website: www.unitefordiabetes.org

Youth can become change agents; people with diabetes and their families are important resource to create better understanding and can be advocates to promote better care etc.

Anja Nielsen, (Denmark)**Advocacy of young people.**

Anja is a young woman who has T1D and has participated in diabetes camps and become a camp counsellor. Using this experience she has participated in government policy discussions in Denmark to improve the image of young people with diabetes and address some of the issues of discrimination.

Sherrie Kaplan, (USA)**Engaging with people with diabetes to assist them self-manage.**

Shared decision-making is the most desirable process where patients and health professionals agree to a specific action. As a routine process, this is still some way off and currently patients are given information and then expected to plan their lives around it. There is a fear amongst health professionals that if people are part of shared decision making they will become ‘difficult’; while other professionals believe that some patients are not educated enough to make their own decisions. However the more reliant on health professionals to make decisions for them the poorer the health outcomes.

“Advanced patienthood” = training people to be patients who make formal decisions; this can be done as part of the clinical visit.

Sue Craddock UK

(One of three speakers making the point that health professionals learn skills that they do not necessarily know how to implement properly.)

Craddock, a consultant nurse had dealt with the frustration of people returning to see her as though she had taught them nothing in previous visits. She applied ‘learning for life’ which involved learning to listen to people and people listening to themselves.

After this she set out to evaluate if she and her team had in fact developed better communication skills and found out that they had not!

Part of the lifestyle and behaviour change required in diabetes care in fact rests with health care professionals. They need to learn behaviour change, not just the patients. Developed a 2 day training package: first day involves videoing communication skills; second day involves patient-centredness training where the patient is empowered to have their say.

Frank Snoek, (Netherlands):

Tools and systems to promote patient-centred care.

More self-help tools as well as electronic access to information are available now. Use of these tools needs to be integrated into the healthcare delivery process. At the same time there is a need to integrate psychosocial care into clinical care and to undertake psychosocial assessment. This requires validated tools. MIND is an example of this (Monitoring Individual Needs in People with Diabetes) The aim is to increase the recognition of psychosocial issues. MIND is part of a new DAWN project which includes an Australian arm.

There are tools and systems to promote patient-centred care. These include

- Delivery redesign
- Chronic care model (not acute care)
- Decision support
- Information systems
- Self-management
- Changing health professionals’ attitudes and patient behaviour.

Meta analyses demonstrate that even if one of these elements is introduced then there is an improvement of care. Patients also need to be involved in developing these tools. Health technology now offers opportunities to develop cost-effective resources.

All these three presentations made the point that Health Care Professionals have a lot of learnings which are not effectively implemented.

M Morris, (UK).**When Education Alone is Not Enough: psychologically based program for people with type 1 diabetes.**

The aim of this program was to equip people with T1D with skills. Study was designed to determine whether psychological input would assist people to make better use of education and information. Eighty eight individuals took part; were all self-selected and ready to change. Thirty five per cent of the participants kept diaries and gave them to researchers at end of the project. Topics included stress management, management of negative thoughts, assertiveness training. Qualitative analysis of the diaries was undertaken and showed that before the program people were feeling much more negative about the program and afterwards were more positive about it. Also showed that the psychological support allowed them to make better use of the education and information they received. The diaries demonstrated that the shared experience was a vital component to people improving their management. The researchers would like to follow up this study with a RCT.

F Amati, Italy**Enhancing daily physical activity**

Research demonstrates that people with diabetes are likely to abandon physical activity regimes after about six months. To motivate people to maintain their exercise routines the researcher created a one day motivational workshop. People were administered tests to explore their individual risks and motivations. They attended both individual and group sessions and adopted exercise regimes they felt they could maintain, rather than those they were told they needed. Tests administered after one year demonstrated that 38.8% had become more active.

To determine the effects of a structure education program on illness beliefs, quality of life, and physical activity in newly diagnosed T2D.

DESMOND program-theories behind this program:

- a common sense model
- social learning theory (Bandura 1980)
- heuristic systematic model (Chaiken 1987)

226 people newly diagnosed with T2D attended a DESMOND program in various parts of the UK and completed surveys about beliefs, quality of life and physical exercise. As they completed the program tests showed that they improved in all measures. This study concluded that DESMOND improves in these areas and predicts improved glycaemic control.

M Piana Italy.**Narrative Approach to Education and Care of People with Chronic Disease.**

The narrative approach examines the complex reality of each person subjective experience. It adds to the quantitative aspects of research. This approach looks at each person's means of gaining awareness through education i.e. each person has a subjective response to their illness. When health professionals understand the subjective experience of an illness they are better able to treat it. These researchers

are using the narrative tool with young people with T1D who attend a residential camp learn about living with diabetes and write about their experiences. In this manner learn about the deeper meanings young people attach to having diabetes.

M Funnell (USA)

Empowerment Approach to Group Teaching..

Patients need to be informed and empowered in order to actively participate in decision-making. While education is an important first step there is also need for educators to address psychosocial issues. Also need to address individual needs within the groups where education takes place. This research relates to 6X 2 hour sessions which were determined by the participants' questions and interests. Created a situation of self-directed behaviour change by affirming participants' ability to develop a program that reflected their needs. This approach also worked in cultural groups because it respected different cultural needs.

Qualitative analysis based on Charmaz' work and using NVivo software. Interpretive analysis showed that on diagnosis people had a feeling of insecurity related to their perception of their changing selves. People adapt self-control strategies which may then evolve to empowerment. People needed to feel safe before they could start to feel empowered.

C Atsalos (Australia)

Facilitation of Healthy Lifestyle Changes

A two year program for people who have acknowledged not adopting healthy lifestyle changes. Group consisted of 9 women and 2 men. Longitudinal collection of data (over 2 years), by interview and focus groups. Data analysed by hermeneutic phenomenology. Group commenced with light-hearted atmosphere, encouraged to avoid judgemental words such as 'should' and 'must'. Many people were of an age where they had not thought of themselves and their own needs for some time; had little sense of self-worth. They were encouraged to think about the things they wanted to do, and to develop feelings of self-worth. When this happened were more likely to exercise esp. walk. Program gave them space to admit their own inadequacies, and experiment with own ways of caring for themselves. Suggests advice alone is not enough. Atsalos says that having done this project she no longer talks very much in consultations with people with diabetes. They know they should diet and exercise, so now she just asks them what they would like to do and waits for the answer.

(Peter Nowak, Austria).

Art of empowerment: doctor-patient interaction.

Patient is the primary producer of health a quality of life. Doctor is the gateway to professional knowledge. The doctor/patient communication is the product of their meeting. Health literacy is important facet of this meeting.

Doctor's role in the meeting: Doctor has power and knowledge but not trained to communicate.

Patient needs to get control over their own situation in this interaction. Control relates to what information to supply to doctor; what information to receive; making decisions and the amount of interaction.

Literature review shows there are no meta-analyses of the findings re doctor/patient interaction.

First general results after a synthesis of 6 studies demonstrates that in order to empower people doctor needs to ask for a narrative; give the patient the right to interrupt; not to interrupt the patient; give short explanations and to use the same metaphors the patient uses.