

AUSTRALIAN

VOLUME 9 • NUMBER 2 • JUNE 2006

Diabetes

The official publication of the Australian
Diabetes Educators Association

Educator



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ADEA updates

A Reality Check from those in the know

Motivational Interviewing

Intellectual disability and diabetes

A Reality Check From Those in the Know

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More than 1,000 Australian adults are diagnosed with Type 1 diabetes each year. Yet until recently there have been no educational materials produced specifically for newly diagnosed adults. Is this another “forgotten generation”?

A group of young people who had grown up with diabetes started Reality Check, an Australian organisation of young adults with Type 1 diabetes, in 1998. They were surprised to find that as many, if not more, people newly diagnosed with Type 1 diabetes in their 20s and 30s were approaching Reality Check for information and support. Reality Check founder Kate Gilbert says, “People were sharing stories with us, of being told their diagnosis beyond childhood was very rare and even ‘freakish’, and that their first few years of living with diabetes were full of confusion and fear.”

“After hearing the same story 20 times, I began to look into how rare the diagnosis of Type 1 diabetes in adulthood really was,” Kate continues. “Then we started looking into how we could help prevent the problems we were hearing about.”

A rocky start to a difficult journey

Reality Check was awarded funding from the federal government in 2003 to look at the information needs of newly diagnosed Australian adults with Type 1 diabetes. They found that 23% of the 33 diabetes centres involved with the National Association of Diabetes Centres (NADC), who participated in an initial survey, had no educational resources at all to give adults at diagnosis. A further 23% reported that they only had information written for and about children, to give to adult patients. These figures confirmed the anecdotal evidence that Reality Check had gathered and confirmed the fear that a large number of people were getting a very rocky start to their journey with a very complex and demanding chronic condition. Following are some of the comments we received from young adults regarding their later diagnosis of diabetes.

Lisa was diagnosed with Type 1 diabetes when she was 25 in 1997. She said, “I wasn’t given anything to take away and read after my stay in hospital, except for instructions from my doctor – insulin doses written on a scrap of paper. I am still very confused about how much insulin I should be giving myself. I would like to know what is the better way of control, GI Factor or carb counting? I am still very confused on that issue.”

Gary was 18 when he was diagnosed and feels he received a lot of good information but it was all of a “technical” nature. He explained: “It would have been good to get some real life feedback from people who were already diagnosed and how they were living with this illness.” Gary went on to seek out information from a variety of what he calls “non-traditional” sources; a family friend who was a chemist, for example. But he said he never found the practical information and advice he was eagerly searching for in those first couple of years. Thirteen years later he reflected that this lack of information made his first years with diabetes extremely difficult.

Ben had a similar experience, though his diagnosis was just five years ago at the age of 29. He says, “I was given very few resources by my endocrinologist, but the diabetes educator from Diabetes Australia gave me a bit more info. Most of the really useful stuff I had to source myself.”

Mark also shared his experience of diagnosis with Reality Check during the project: “I was diagnosed this year at the age of 38. I was not really given any information to read but I was referred to Diabetes Australia to see a diabetes educator. This was not possible for three days so I was referred to an educator at my local hospital.

“I was provided with an injector and insulin and some minor photocopied literature and told: ‘Good luck, you’ll be fine’. A couple of weeks later, I was sent a small book with more information about diabetes.

“I bought several books myself to learn as much as I could, and I hoped like all hell it was Type 2. Not to be, unfortunately.”



Kate Gilbert checks out the new resource.

Their own worst enemies

An event that will forever be in the annals of diabetes history involved a member of this oft-forgotten group. The patient that diabetes pioneer Dr Elliot Joslin first gave an insulin injection to was a nurse. It was August 7, 1922 and Elizabeth Mudge had only left her Boston apartment once that year, so debilitating was her condition and its necessary regime before the discovery of insulin. Elizabeth had been diagnosed with Type 1 diabetes five years earlier at the age of 37.¹

Many years of clever lobbying by parents and children has done wonders for the public awareness of Type 1 diabetes but combined with the decades of it being known as ‘juvenile diabetes’, it seems that the public – and an unfortunate number of GPs and other health professionals – have begun to assume that Type 1 diabetes only affects children.

Yet, 50% of people with Type 1 diabetes, like Elizabeth Mudge, first develop the condition in adulthood.²

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This group of people has remained for a long time largely invisible. They are so busy trying to find the information and support they need in the midst of a full life, sometimes also coping with a confused diagnosis, that fixing the systemic problems and information gaps they encountered remains far from their minds. After all, they were often also told repeatedly their diagnosis was incredibly rare, and they were alone.

Paul wrote to Reality Check with delight when he learnt of the work underway with newly diagnosed adults, saying: “This is a problem area that the medical establishment has utterly ignored. However, I do have to say that us mid-aged people are our own worst enemies. We are diagnosed at the time of our life when we are wrapped up in work, family etc etc and there is not much time left over for anything else!”

Developing a Starter Kit for adults with Type 1 diabetes

Research into information needs identified a clear need for a comprehensive educational resource. An inventory consulting both diabetes health professionals and people with diabetes identified some useful resources but nothing that was comprehensive. Both groups confirmed a Starter Kit for adults with Type 1 diabetes was needed.

The first step in the project was to consult with diabetes educators about their experiences of educating newly diagnosed adults about Type 1 diabetes. All NADCs were invited to contribute, and 33 centres across Australia identified 19 broad topics as being necessary in a Starter Kit. The most frequently reported essential topics were counselling or mental health advice, alcohol and drugs, legal and employment issues and pregnancy.

People who had been diagnosed with Type 1 diabetes as adults then contributed what information they felt they needed. 70 people detailed for Reality Check what information they had been given at diagnosis, as well as useful resources that they had found on their own. The most frequently reported essential topics were: dietary advice, an introduction to

other adults with Type 1 diabetes, personal stories from others with diabetes and insulin adjustment advice.

Information was written or sourced to cover almost all topics identified by both groups. It was of interest to see a different assessment of information needs from the perspectives of diabetes educators and people with diabetes. Table 1 shows a comparison of all topics identified by both groups.

A draft resource was compiled and 32 people who had been diagnosed with Type 1 diabetes within the last three years reviewed it and completed a comprehensive survey. At this early stage 83% reported that the draft resource was ‘better’ or ‘much better’ than what they had been given through their own initial education after diagnosis.

Extensive development of the resource followed and a second draft was reviewed by 20 diabetes centres around Australia, including both metropolitan and regional areas, to ensure the clinical accuracy of the information.

Table 1: Information needs of adults at diagnosis with Type 1 diabetes

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Identified by diabetes centres (n=33)		Identified by people diagnosed with Type 1 diabetes as adults (n = 70)	
Counseling/Mental Health advice	58%	Food (inc recipes, GI Factor)	26%
Alcohol & Drugs	50%	Introduction to website for young adults with diabetes	23%
Legal / employment issues	50%	Stories from others with diabetes	17%
Pregnancy	33%	Insulin adjustment	13%
Meet others my age	33%	Sport and exercise	11%
Online/email-able	25%	Alcohol	6%
Sex	25%	Cause of diabetes	6%
Difference between Type 1 & Type 2	17%	Meet others my age	6%
General info about diabetes must be targeted to age group	17%	Information for and how to tell family and friends	4%
Travel	17%	Research being done into cure etc	4%
Monthly hormonal changes	8%	Reaction times of insulin	3%
Others are diagnosed as adults	8%	Told that others are diagnosed as adults too	3%
Cause of diabetes	8%	Pregnancy	3%
Sport and exercise	8%	Sick days	3%
24 hour support line	8%	Effects of stress	3%
Weight/diet	8%	Difference between Type 1 & Type 2 diabetes	1%
Complications	8%	Monthly hormonal changes effect on blood glucose levels	1%
Evaluating online health information	8%	Useful books and websites	1%
Introduction to a Diabetes Team	8%	Insulin delivery options	1%
		A Blood Glucose metre provided	1%

The Starter Kit fills the gap

Reality Check published 'A Starter Kit for Adults with Type 1 Diabetes' in October 2004 and 50 diabetes centres immediately began using it in their practice. The information in the Starter Kit was also published as a mini-website, which has been visited by more than 4,000 people.

Professor Trisha Dunning, Director of Endocrinology and Diabetes Nursing Research at St Vincent's Hospital says, "We use Reality Check's Starter Kit at St Vincent's in Melbourne. I would recommend it mostly because it was compiled by people with diabetes and was also assessed before it was distributed."

It was essential that the development of the Starter Kit involved, and was made relevant to, people living outside of major cities. Ann Robinson, diabetes educator at The Townsville Hospital, tells us:

"My experience is that once an adult is diagnosed and they have listened to the docs, the educator, the dietitian and their head is spinning with information, there is something special about the content of Reality Check's Starter Kit."

"It is written in a voice that says we have experienced what you are experiencing. Plus the content is reliable, so I have no hesitation about all my patients having access to the Starter Kit. We can't wait until we can get our hands on the reprinted Starter Kit."

Abbott Diabetes Care has supported Reality Check to re-print the Starter Kit in 2006. It is available free of charge to all health professionals who work with adults with Type 1 diabetes during the initial period after their diagnosis.

It seems appropriate to conclude with the voice of a person with Type 1 diabetes, to highlight the feedback Reality Check now receives from people soon after their diagnosis. Cate wrote recently:

"I've just been diagnosed with Type 1 – two weeks ago. It's all a bit overwhelming. I have found myself a lot of information, but it's all written in

complex terminology and hard to get through, but I checked out the Starter Kit online and it was really straight forward. The Starter Kit is a good starting place for me, I think. Thanks very much."

References

1. Feudtner, C., Bittersweet. Diabetes, Insulin, and the Transformation of Illness. 2003. The University of North Carolina Press.
2. Colagiuri, S. et al, National Diabetes Strategy and Implementation Plan, Diabetes Australia, 1998, p. 70.

A Starter Kit for Adults with Type 1 Diabetes can be previewed and ordered online by visiting www.realitycheck.org.au/starterkit.

Orders can also be placed by phoning Donna Kealey, Marketing Coordinator Abbott Diabetes Care on 03 9843 7116 or donna.kealey@abbott.com.

Other enquiries can be directed to Kate Gilbert, founder of Reality Check Young Adults with Diabetes Inc. and managing author of the Starter Kit by email to kate@realitycheck.org.au.

ADEA Clinical Placement Program – Update

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The impetus behind the development of the ADEA Clinical Placement Program lay in the concerns of many rural and remote diabetes educators as to the limited opportunities available to them to enhance their knowledge and skills regarding insulin administration. Based largely on data from the recent ADEA needs assessment of rural and remote diabetes educators, this new ADEA program has set out to address many of these concerns.

The main aims of the program are to provide opportunities to develop knowledge and skills in insulin initiation and stabilisation through newly created learning partnerships between individual rural and remote diabetes educators and Credentialed Diabetes Educators in larger centres. Strategies involve one-week clinical placements, followed by a three-month period of frequent contact by phone or email. A business partnership between ADEA and sanofi-aventis has provided funding support.

The pilot program comprises

placements from Western Australia (linking Pam Grierson from Carnarvon with Fremantle Hospital) and New South Wales (linking Kerry Porter from Bathurst with Westmead Hospital). Preparation for the recently conducted clinical placements involved extensive negotiation between all parties and agreement on individual learning contracts. Evaluation of these clinical placements is currently underway. The evaluation criteria have been based on the expectations of ADEA for this project, the expressed needs of the individual placement educators

and the experiences of the preceptors and managers of the placement diabetes centres.

Both Kerry and Pam are currently maintaining contact with the placement hospitals as they proceed through the three month period of consolidation of the work they began during the one week placement. The final extensive evaluation, which will assess the feasibility of many aspects of this pilot program, will inform the development of a new ADEA program that can be utilised in a variety of settings within rural Australia.