Relative **values**

The vital role played by the family in helping to manage an individual's diabetes has been highlighted, thanks to a new project based at Oxford University. **Helen Lloyd** recorded interviews with relatives of people with diabetes for the oral history website, Diabetes Stories, and tells *Balance* about what she discovered

The idea of recording interviews with family members came from people with diabetes whom I interviewed for Diabetes Stories, a website funded by the Wellcome Trust as a contribution to the history of medicine (as featured in Nov/Dec 2005 *Balance*). People would often say that they 'could not have survived' without the help of a relative and I felt that, if this were literally true, the role of the family should form an important part of the history of diabetes care.

Launched in 2005, the site originally only contained 50 interviews with people who had diabetes themselves. A year later, in 2006, we received a grant to record a further 50 interviews with those who cared for people with diabetes during the 20th century, with an equal number of healthcare professionals and family members.

Emma, left, with her mother and sister, shortly after diagnosis in 1988

Two-sided story

For the original project I recorded a 26-year-old woman, Emma, who was diagnosed with diabetes at the age of 10 (pictured above). She told me how calm her parents had been at the time of diagnosis and throughout her childhood, in contrast to other parents who gave anxious advice to their children every time they left the house.

After the interview, her mother made me a cup of coffee and told me a very different story, so I decided to record her for the family members' project. She described how "the doctor came to talk to us both, and to say that Emma had diabetes, and I just burst into tears. I felt absolutely bereft. It was the most dreadful feeling. I didn't really know a great deal about diabetes, but it just seemed to be the most awful thing that could have happened to her."

Now, many years later, she realises that her reactions were "absolutely ridiculous… there are so many other things that she could have had that would have been far worse".

Some of the most moving accounts are from people remembering how they had to cope with a relative's diabetes when they were children. One young man, Tom (pictured right), describes coping with his sister's serious hypos: "she was moving and she was conscious, but she couldn't get words out. That really sort of worried and kind of upset me". A young woman recalls that when she was four or five she heard what she thought was a monster growling in the kitchen, only to discover that it was her mother, Bena (pictured right), having a hypo. Both these interviewees felt there was a need for more information and support to be given to children in their situation.

Family affair

Many family members felt that they were better at spotting signs of low blood glucose levels than doctors or nurses or even the person with diabetes. A few actually saved the life of a relative they found unconscious, but many more provided encouragement to stick to a healthy diet, which may have been life-saving in a less dramatic way.

One Asian interviewee, Shanaz (pictured right), recalls that, after her father was diagnosed with diabetes in 1960, her mother learnt to cook boiled potatoes and sprouts for him, because there were no Asian diet sheets available.

However, by the time her two older sisters were diagnosed with diabetes 40 years later, they received plenty of advice on following a healthy Asian diet. In the case of one sister, her husband and children all decided ▷

As a child, Tom, left, recalls being "worried" and "upset" about his sister's diabetes

Bena and her daughter, 1982

Shanaz (sitting on her father's knee) and family, 1969

A history of diabetes: Joan and Clive

Joan was diagnosed with diabetes when she was four, in May 1945. Her father was working away from home and her mother found it hard to cope with Joan's bed-wetting and rapid weight loss, before the local doctor made the diagnosis. Joan and her husband, Clive, still have an urgent note sent by the doctor to her mother, instructing her to go to hospital: "You must take your child to Addenbrookes without a moment's delay…Take her ration book, identity card, et cetera, but waste no time".

In the 1940s many people could still remember the time before insulin became available (in 1923), when children would die from diabetes. After Joan's diagnosis, her mother's former employers wrote to say "we do hope and pray that she may be spared to you".

Accounts on the Diabetes Stories website suggest that the circumstances surrounding diagnosis affect the way in which diabetes is regarded by the person themselves and their family members for many years afterwards. Joan's mother continued to be anxious about her throughout her life. When Clive began courting Joan around 1960, he remembers that "we had to be home at a certain time, because meals at a certain time were an absolute must…her mother was very careful of controlling her diabetes – or perhaps that was an attempt to keep her out of my clutches!"

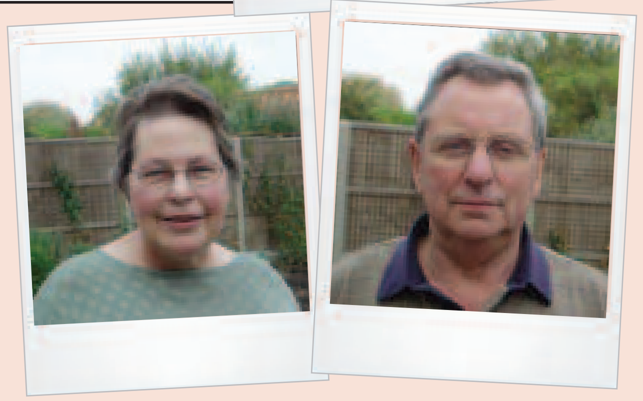
In many ways, her mother's anxiety proved unfounded, because Joan looked radiantly healthy when she was interviewed at the age of 66. However, both Joan and Clive attribute the three miscarriages she had after her first child to diabetes. At the time of the second miscarriage in 1977, Clive remembers that the maternity hospital did not liaise well with the diabetes department and so failed to notice the signs of low blood sugar before she became unconscious. "Had she been at home, it wouldn't have happened," he says, "because I was so used to living with her by then that I could look at her and see when things were going low. She didn't have the usual symptoms of sweating, she'd just go vague, and go very white around the nose. That was about the only symptom, but I did get quite good at picking that up."

Clive also thinks he has acquired expertise in coping with his wife's moods: "If there was a mood swing, I would want to know why". He has always made sure she eats regularly and takes supplies when they go out, but he thinks that his most significant contribution to managing her diabetes has been his moral support: "That's probably the most important thing – being prepared to listen, and not fly in a huff and walk out."

At the time of interview, they had been married for 45 years and both talked positively about the role that diabetes had played in their relationship. Joan thinks that having diabetes has given her more understanding of other people's problems, and Clive believes that coping with diabetes has strengthened their marriage. Had he known what he was taking on "I'd still do the same thing again tomorrow," he says. ☐




From left: Joan as a toddler, Joan aged 17, and Joan and Clive tying the knot in 1962



Clive and Joan (with their baby in 1963, right, and below in 2007), talk positively about the role diabetes has played in their relationship

to change their diet: "They now oven-grill and use non-stick pans. You hardly see any fat in the house now and they don't add extra salt to their food. They've bought a running machine. They've all lost weight – it's not just her – and basically they're motivating each other".

Different strokes

Not all family members had this degree of involvement. One husband said his wife's diabetes "didn't register to a very great extent" for more than 20 years, partly because he was busy at work, and partly because, with any illness, "people tend to find it boring". In another interview, a wife complained that after 50 years of marriage she had lost interest in cooking and resented how much time she had to give to the timing and content of meals.

In most cases the website avoids the word carer because many family members did not want to be regarded as the carer of their loved one; but those who had taken on an official full-time role, with a Carer's Allowance, accepted the term. They bewailed the fact that governments fail to finance, and doctors fail to recognise, their crucial role in the management of diabetes.

However, this crucial role is fully recorded in our oral history of diabetes and will certainly be recognised by all who visit the website. ☐

Further information

The new version of the website – www.diabetes-stories.co.uk – will be launched officially at the Diabetes UK Annual Professional Conference on 13 March 2009.The website is based at the Oxford Centre for Diabetes Endocrinolgy and Metabolism. It was funded by a Wellcome Trust grant to Professor David Matthews. Special thanks to Dr. Nathan Hill (website design) and Sue Beatty (diabetes research nurse).