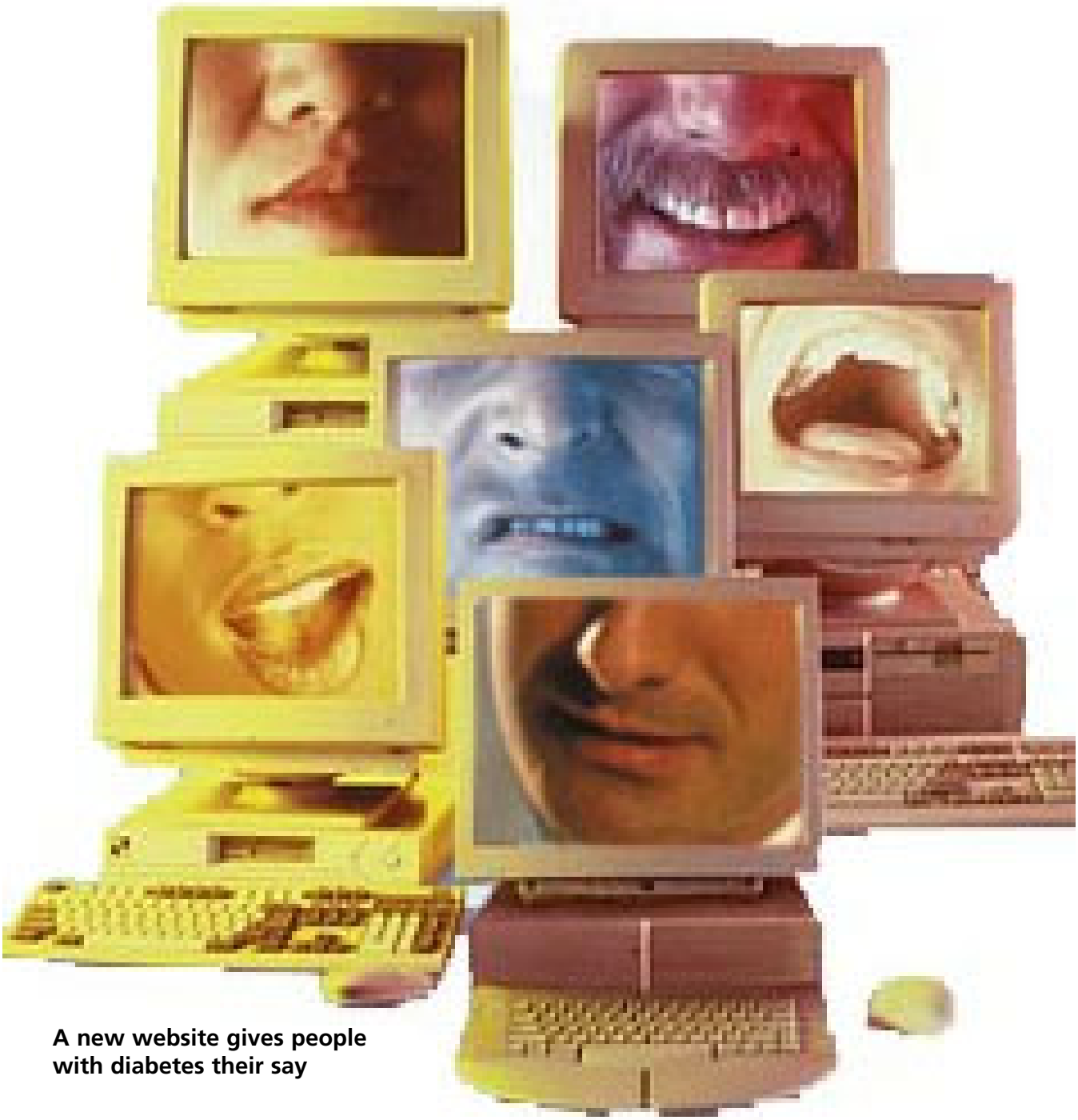

A new website gives people with diabetes their say

Speaking with hindsight

Thanks to a new website, people can now find out how diabetes care has developed through the twentieth century by hearing people with the condition tell their own stories. Here, **Helen Lloyd**, who recorded all the life histories, explains the inspiration behind the website and tells some of the remarkable stories that can be heard on it

Photography: Photo Library

This autumn sees the launch of www.diabetes-stories.co.uk – a new website on which 50 people who were diagnosed with diabetes in the twentieth century recount their life-stories.

As reported in Sept/Oct *Balance* (page 22), the project is based at the Oxford Centre for Diabetes, Endocrinology and Metabolism and funded by the Wellcome Trust, as a contribution to the history of medicine. The website is intended not only for professional historians, but for all those with an interest in diabetes.

The idea came from Professor David Matthews from the Oxford centre. He had been fascinated by the memories of some of his older patients and wanted them to be recorded for posterity. He felt that while medical journals have documented scientific advances, they have rarely recorded the patient's viewpoint – and this is a particularly serious omission in the case of diabetes, which depends so much on patients managing it themselves.

He invited suggestions for suitable interviewees from medical staff at Oxford, at Worcestershire Royal Hospital, Leicester Royal Infirmary, and Selly Oak Hospital in Birmingham. Also, Diabetes UK suggested some people with very early diagnoses, including a woman from Essex who was diagnosed in 1927 and is still fit and well at the age of 86. The person featured with the most recent diagnosis is an Oxford patient diagnosed in 1997. But all the interviewees talk about their lives right up to the present, so the website gives a full history of the experiences of patients across nearly 80 years.

The interviewees represent experiences of Type 1 and Type 2 diabetes, and come from a range of backgrounds. They talk not only about changes in diet and medical treatment, but in the attitudes to diabetes of medical staff and of people in the outside world. Together, they chart changes in the National Health Service and in society's attitudes to illness. In some cases they also touch on a broader social history, since they are encouraged to talk about their whole lives to avoid giving the – often false – impression that their lives have been dominated by diabetes.

Some interviewees bring experiences from other countries. For example, a 73-year-old man from St Kitts in the Caribbean, who has had diabetes for 40 years, reminisces about a childhood spent in the fields, chewing sugar cane. An Asian woman, who was expelled from Uganda by the dictator Idi Amin, recalls that she measured her glucose levels by the number of ants attracted to her urine around the hole in the ground that served as her family's toilet.

The website makes it possible to listen to the complete audio recordings, since it is often more compelling to hear the original accents and intonations than to read a written account. Only the most dedicated researcher will listen right through all the life-stories; but digital technology, combined with full transcripts and summaries, enables website users to find the sections of the interviews most relevant to their concerns.

The hope is that the website will be of interest not only to historians, but to student doctors and nurses, and to people with diabetes and their friends and families. A patient who is afraid of kidney dialysis will be able to listen to someone who already has experience of it. A student nurse writing an essay on the effects of diabetes on the family will find a wealth of material from different viewpoints.

Two very moving interviews have been recorded with mothers ▷

While journals have documented scientific advances, they have rarely recorded the patient's viewpoint

Were it not for insulin, they would not be here to tell their stories

with diabetes whose own young daughters have developed diabetes in recent years. Both wept when their daughters' diagnoses were confirmed, and yet both are very positive about their own experience of diabetes.

Perhaps the interviewees have been affected by the knowledge that, were it not for insulin and other medical advances, they would not be here to tell their stories. Some say that they have tried to make the most of life because they thought time might be short – only to discover that they have lived longer than many friends without diabetes.

Several feel that they are healthier than they would have been without diabetes, because of having such a strong motive to keep fit. Others talk frankly about their struggles and failure to keep to a healthy lifestyle. Yet even people who have had a hard life use one oft-repeated phrase: "I've been very lucky." □

Further information
Visit www.diabetes-stories.co.uk

Erika's story

Erika Harding was born in Vienna in 1931. She came from a well-to-do family of jewellers but, when she was about three, her parents separated and her father, who was Jewish, eventually came to England.

When Hitler's troops invaded Austria in 1938, Erika and her mother were in danger, even though her mother was not Jewish.

She recalls that some "thugs" turned them out of their flat and threatened her mother with a truncheon. In 1939, they fled to Switzerland, and then came by boat to England shortly before war was declared. Erika remembers clearly that she wasn't sea-sick, so when she looks now at the photo of the thin, hollow-eyed little girl on

Erika Harding, here photographed in 1939 and today, tells her story on the new website www.diabetes-stories.co.uk

the boat, she's sure that she had already begun to be ill with diabetes.

Her mother got a job as a resident domestic help with a history professor in Oxford. Erika went to live in a refugee hostel in Surrey, with her father and his new wife, who knew nothing about children and assumed that Erika was pretending to be ill.

In 1940, her father and stepmother were interned as "enemy aliens" on the Isle of Man, and her mother gave up her domestic work to join Erika at the hostel. At first, her mother was too distracted to notice that her daughter was ill. It was not until Erika returned from a children's party, claiming to have drunk 24 glasses of milk, that she was taken to the doctor. She was whisked straight into hospital and went into a coma that night.

Insulin injections saved her life and her mother was taught how to administer them. (Erika did not inject herself until she was ten, when an air-raid prevented her mother from getting back to the hostel in time.) The hospital gave instructions on testing her urine with Benedict's solution over a flame, and she remembers that the liquid often shot out of the test tube.

She was also put on what was then known as the Weighed Diabetic Diet, also known as the 'Line-Ration' Scheme, which involved the exact weighing and measuring of proteins and carbohydrates.

In wartime, those with diabetes were given extra protein rations but only a pound of cubed sugar per year, to be used if their blood glucose dropped.

She says her mother was not warned by the hospital about hypoglycaemia and so was completely taken aback when she found her daughter lying on the floor of her bedroom, after doing a series of energetic handstands.

Erika carried crumbling lumps of sugar around in her pocket for years, and now thanks God for glucose tablets! During her teens, she began to abandon the very strict regime advocated by the hospital: "It was still considered sinful to eat sugar," she says. "I mean diabetics just didn't, you know, but this diabetic did a bit."
