



# Past caring

The life stories of 50 people who were involved in diabetes care during the 20th century have been recorded for an oral history website based at Oxford University. **Helen Lloyd**, who recorded the life stories, writes about the changes to which they bear witness



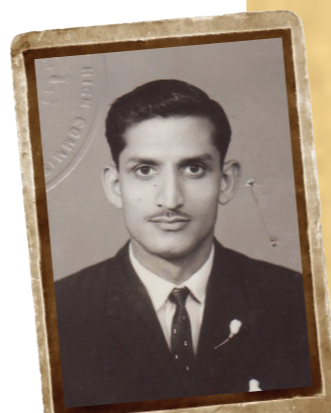
Manchester University Medical Students Representative Council 1945-46. Joe Needoff is seated in the front row, centre

**C**ontrast the stories of two GPs who practised in the second half of the 20th century within a few miles of each other. Dr Joe Needoff worked as a GP in the Black Country from 1951 until he retired in 1989, at the age of 67. He says that throughout that time he never saw a young person with diabetes. Only a few, mainly elderly,

patients had diabetes, and he remembers that in the early days they would bring a urine sample for testing, which he would mix with a reagent in a test tube, boil over a gas flame and watch for a change of colour.

There was no nurse to help him, so, when he needed a chaperone, he would call on his wife, who lived on the premises, or request help from a female patient in the waiting room. There were usually plenty of people in there, as there was no appointments system. He had no diabetic clinic by the time he retired because “we simply didn’t need one” – there had been no big increase in numbers.

About 12 miles away, in inner-city Birmingham, Dr Ali Zafar practised as a GP from 1975 until his retirement in 2006. At the same time, he worked first as clinical assistant and then hospital practitioner in the diabetes clinic at Heartlands Hospital. When he had trained in India in the 1960s, there had



Top, Ali Zafar’s 1969 passport photograph, and, above, Ali enjoying retirement in 2007

been no high incidence of diabetes, and his training had been far more concerned with TB and malaria. After he became a GP in this country, with 60 per cent of his patients from the Indian sub-continent, he noticed that the number of people he diagnosed with diabetes was increasing rapidly – particularly after 1980.

At the time he was interviewed in 2007, when he was still working part time, he said that the increase felt like “an explosion”. He was offering random testing to some patients and feared that if he offered it to all, a “very, very high number” would turn out to have impaired glucose tolerance. He sees very overweight children and speculates that this may be due to an attitude that has endured from life in rural India or Pakistan, when weight was equated with strength and a greater ability to plough a field or carry water. His practice has had its own diabetic clinic for several years.

We will add the life stories of both these men to our website (see ‘Further information’, page 27) by the end of this year. On the website already are 50 interviews with patients diagnosed between 1927 and 1997, to which we will add 50 interviews with those who have cared for patients, including family members, doctors, nurses, dietitians and one podiatrist. Website users who have audio speakers will be able to listen to the complete interviews, unedited. There are also transcripts, written summaries, audio extracts, photos, an interactive database, and facilities to search for words, phrases and topics.

It may seem an odd choice to include an interview with Dr Needoff, who had little experience of diabetes, on a website devoted to the history of diabetes care. However, many of the patients already on the website relate encounters with GPs who had a similar lack of experience. Our aim was to represent the whole range of care already described on the website from the patients’ point of view. Though some patients were treated by diabetes specialists, many were treated by healthcare professionals of all kinds who had little specialist knowledge, but were still required to treat people with diabetes: their experiences are an important part of the historical record.

One of the aims of oral history is to record stories that would otherwise go unrecorded, so we decided not to include many people whose work had already been well documented. However, since a few of the

patients on the website were treated by pioneers such as RD Lawrence, we felt our website should also include a few of those pioneers. Although much of what they have achieved is recorded in their own publications, these extended interviews provide insights that are not available elsewhere.

Professor Harry Keen was the first healthcare professional to be recorded for our website, at the end of 2006. He was then aged 81, but still working part time in the Unit for Metabolic Medicine at Guy’s Hospital and also helping out at the surgery of his GP son. When Harry Keen began his medical training at St Mary’s Hospital, London, in 1943, insulin had been available in the UK for 20 years and the complications of long-term diabetes were beginning to emerge.

He remembers that those who trained him were reluctant to talk about these complications: “The doctor, I think, felt that this was a dreadful thing to be happening, and that they should be celebrating the successes of insulin, rather than bemoaning this new and awful hazard that was beginning to appear.” It was felt that there was little point in warning patients about the possibilities of blindness or kidney failure, since little could be done. “It wasn’t till later,” he says, “when it was clearly recognised that the level of control which you imposed on the diabetes made an enormous difference to outcome...that people could argue it is worthwhile [to warn people] because people will then pay more attention to their control.”

## Women in diabetes

Later in the interview, Harry Keen says that in his opinion “the appearance of the diabetes specialist nurse was the most important thing for the person with diabetes since the discovery of insulin”.

Another interviewee, Mary MacKinnon, describes one of the earliest courses to train specialist nurses, in Birmingham in 1983. But nearly 30 years before that, in Leicester in 1954, Joan Wilson was



Diabetes pioneer Professor Harry Keen, seen here as a 22-year-old medical student in 1947



Joan Wilson in 1948, six years before she became a specialist diabetic health visitor



Hard at work in the children's ward, second floor of the London Hospital – now the Royal London Hospital – in 1943

appointed a specialist diabetic health visitor, with full nursing qualifications. I interviewed her at the end of 2006, just before she died, and she said that when her title eventually changed to diabetes specialist nurse (DSN), her job remained unchanged. She visited many patients in their own homes and, in the days before mobile phones, they would phone her at all hours on her home line. Her husband became adept at giving necessary reassurance until he could contact her.

Joan Wilson was appointed by another Joan – Dr Joan Walker, who retired in 1967 and died in 1995, but is still remembered with admiration by several interviewees whose reminiscences may be located

by typing her name into the site's search facility. She did the first British population-based survey of diabetes in Ibstock, near Leicester, in 1957. During the Second World War, she ran the diabetic service in Leicester, as an assistant physician, but when the male consultants returned from the war, she was displaced and deprived of access to hospital beds. She made the best of this situation and created a scheme that integrated outpatients with home-based care and involved GPs and specialist health visitors – decades before this became mainstream practice.

While for most of the 20th century consultants were mainly men, dietitians were mainly women. One of our interviewees, Patricia Torrens, trained as a dietitian in Edinburgh from 1940 to 1943 (when even cabbage had to be carefully weighed for patients with diabetes). She remembers that some male caterers coming out of the Forces into the hospital service after the war were highly suspicious of the new profession of dietitian. The dietitians had either trained in nursing or domestic science or, in



Patricia Torrens, third from the right, with Edinburgh medical students, 1942

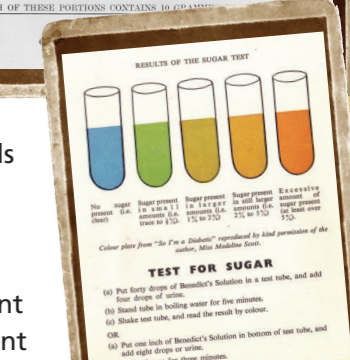
some cases, had a science degree. As many had no knowledge of mass catering, the male caterers thought they were very full of theory, with little practical experience, "which to some extent was right". She later went on to be an adviser to the Department of Health from 1971 to 1984.

### Exceeding expectations

The interviewees talk about every aspect of their professional lives, including relationships with colleagues, reactions to changes in technology and treatment, and the day-to-day impact of changes in the health service. In this, the NHS's 60th anniversary year, it is worth noting that all interviewees show a commitment to free healthcare. This may surprise website users from the USA, who currently account for around 60 per cent of hits on the site.

Over the past year, we have received 870,000 hits from around the world and expect more, once we have added the interviews with family members and healthcare professionals. Such widespread interest exceeds the expectations of Professor David Matthews, whose idea it was to record this oral history, and of the Wellcome Trust, which funded us and chose our work as a 'Research Highlight' – an honour usually reserved for a scientific breakthrough.

Peter Watkins gives an excellent summary of the period covered by the interviews with healthcare professionals in his essay 'Evolution of diabetes care over half a century' (*Clinical Medicine* 2007; 7: 109–113). His account of improvements in treatment and equipment inspires a wish to know more about what it was like to live through such major changes. The answer is to be found at [www.diabetes-stories.co.uk](http://www.diabetes-stories.co.uk)



Top, counting the carbs 1956 style – each pictured portion of food contains 10g. Above, Benedict's Solution urine-testing chart, in use from 1937 to the early 1950s

### Further information

The oral history website, [www.diabetes-stories.co.uk](http://www.diabetes-stories.co.uk), is based at the Oxford Centre for Diabetes, Endocrinology & Metabolism, and funded by the Wellcome Trust. The interviews with healthcare professionals and family members will be added to the website during autumn 2008. The website will be launched officially at the Diabetes UK Annual Professional Conference in March 2009.



### Husne Ara's story

Husne Ara was born in Bangladesh in 1953 and became interested in diabetes as a child, after her father was diagnosed and she did his injections for him. She recalls that in Bangladesh any illness was considered serious and disabling and that "every little job has to be done for them".

She came to England to get married in 1970, at the age of 17, and after bringing up her children she got a job in 1990 as a diabetes link

worker for the Royal London Hospital, working with the Bangladeshi population in Tower Hamlets.

She was trained by a diabetes specialist nurse (DSN) and then acted as advocate for patients, while also explaining their treatment to them. She spent most of her time accompanying DSNs on home visits, making follow-up phone calls and, sometimes, follow-up visits alone.

After a diabetes centre opened in 1993, she became more involved in outpatients' clinics and home visits were gradually reduced until they ceased. She thinks it is better for patients to attend clinics because it combats the idea that they are disabled and they derive encouragement from meeting others with the same condition.

When she began her job, many patients could not read, so she used symbols – for example, a sun or moon to indicate morning or evening dosage. As food labelling became more common, she helped

them to interpret the labels. Shopping is mainly done by men, and older Bengali women rarely go outside, so she suggests to women that they exercise by going up and down their staircase or their balcony.

Much of her job has involved educating colleagues about cultural issues. When a dietitian asked her to discourage the use of ghee, Husne Ara explained that Bangladeshi people do not use it, as they are fish-eaters, and ghee is not used to cook fish. When another dietitian expressed amazement that patients ate two plates of rice per meal, Husne Ara explained that in Bangladesh it had been a cheap form of carbohydrate that made people feel full. She suggested that the amount should only be reduced slowly to give their bodies time to adjust.

Leaflets in Bengali were of little use to patients who spoke the Sylheti dialect or who could not read; so in 1994, she made a video in Bengali, Sylheti and English, and she now translates English DVDs. Having

run group education sessions since 1995, she has recently led structured education sessions, similar to DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed), increasingly conducting them at GPs' surgeries. She includes information about fasting during Ramadan and also educates non-Muslim colleagues in what Ramadan involves. In 2006, she was appointed diabetes lay educator.

A year before I interviewed her, she herself was diagnosed with diabetes, which, she says, has given her greater understanding of the condition because "I am actually on the same road as those people I see every day". Previously, she had lectured a patient about diet, but now she understands "how difficult it will be for that person to resist two plates of rice, every time they're going to eat dinner. And I think by understanding that, my job is actually easier, now, than it was a year ago."

Top, Husne Ara in 1971, aged 18, a year after arriving in England, and, above, in 2007, a year after being appointed diabetes lay educator