

Turn back time



A new website launched in September presents the life-stories of 50 people diagnosed with diabetes between 1927 and 1997, told in their own voices. **Helen Lloyd**, who recorded the life-stories, writes about the changes to which they bear witness.

For future researchers our collection of 50 life-stories will cover a crucial period in the history of diabetes, from 1927 to the present day. Some older interviewees recall stories of relatives with diabetes who died before the advent of insulin, while some younger interviewees look forward to a possible cure. In between comes the realisation that, even with insulin, people with diabetes face many obstacles to leading a normal daily life; and it is their moving, and sometimes humorous, struggles to overcome these obstacles that are recorded in our collection.

CD copies of the recordings have been placed in two archives, at the British Library Sound Archive and at the Oxford Centre for Diabetes, Endocrinology & Metabolism (OCDEM), but the complete unedited recordings can also be heard on our website (see page 32 for details). Only the most dedicated researcher will listen to 50 interviews, lasting

between one and two hours each; so the website divides them into short numbered tracks – with summaries, transcripts, and various search tools to enable researchers to find extracts on a particular subject. There is a wealth of material on changes in insulin, blood testing, diet and exercise and on the gradual recognition of the patient's expertise. References to less obvious matters include the encouragement of teenagers to smoke by parents wishing to compensate for sweet deprivation; the reluctance of teachers to use the cane on diabetic children, and the role children played in managing their mothers' diabetes. There are also photos of old equipment, diet sheets, letters and family portraits provided by the interviewees.

The idea of recording an oral history of diabetes came from David Matthews, Professor of Diabetic Medicine at OCDEM. When he heard patients recall glass syringes, blunt needles, or test tubes heated

The people who don't want sugar

THE HISTORY of healing is packed with drama, suspense and surprise. Sometimes the rewards for success are great. Sometimes they turn sour.

The way in which insulin was discovered, which has prolonged the lives of millions of sufferers from diabetes, contained all these intriguing elements.

Tonight's dramatised documentary *Comets Among the Stars* tells the story of the Canadian country doctor, Frederick Banting, and his assistant Charles Best for the recognition of the value of insulin in 1921. What diabetes is, how insulin keeps it under control, and how it is explained here by Science Editor Peter Dinkley.

Diabetes is a disease in which the sugar level in the blood rises uncontrollably. Insulin, a hormone manufactured by cells lining the pancreas, brings it under control.

8.20pm **Comets** on the Sky

over the kitchen stove, he regretted that there was no permanent record of their experiences and discussed with me how such a record could be made. I had managed several oral history projects and collected nearly 300 life-stories, but had no specialist knowledge of diabetes. However, we decided that my lack of medical qualifications would be an advantage – giving to the interviewees the confidence of knowing that they were the experts on their own lives, and perhaps enabling them to talk more freely about their encounters with health professionals and about their failures to follow medical advice. This was borne out by the number of interviewees who said this was the first time they had confessed to fabricating urine or blood test results.

Suggestions for potential interviewees came from staff at OCDEM, Worcestershire Royal Hospital, Leicester Royal Infirmary, Selly Oak Hospital in Birmingham and Diabetes UK. Some 50 were selected to represent a variety of ages, backgrounds, experiences, and types of diabetes. (Priority was given to earlier decades of diagnosis, so there are more Type 1 interviewees than Type 2.)

It was hard to find people from ethnic minorities willing to be interviewed, despite the prevalence of diabetes in some groups. Those we did record offered a variety of explanations for the shame attached to diabetes, including its association with impotence; the need for people from farming backgrounds to be strong; Hindu belief in reincarnation, and hostility to pork insulin among Muslims and many people from the Caribbean. A 'shame' word-search would also find examples from white interviewees, and provide an interesting subject for research.

The aim of oral history is to record lives that might otherwise go unrecorded. Our collection includes 10 people from ethnic minorities and many from working-class backgrounds, but also middle-class professionals who have never before had the opportunity to tell their stories.

During 100 preliminary telephone conversations with potential interviewees, almost all said it was the first time they had talked about 'what it's really like' to have diabetes. They had often given their 'histories' to medical staff and answered questionnaires for various studies, but these had all been to fulfil someone else's agenda. Our aim was to allow them to set the agenda themselves – to

structure the interview and digress if they wished, since what we might regard as a digression, they might consider particularly significant. We cannot know what the interests of future historians will be, so it seemed important to allow the interviews to range widely. The interviewees each gave up half a day to make a recording on mini-disc in their own home.

The implications of being heard on a website were explained to those unfamiliar with the internet, and a CD or cassette copy was sent to each interviewee, to check that they were happy with it. Some accounts of sexual dysfunction were recorded separately and are

presented in transcript only, in a way that prevents identification. While it's a limitation to have these accounts separated from whole life-stories, we felt that the compensations provided by public access to 50 original recordings are considerable. Researchers can check generalisations against the original data: for example, it would be

possible to select extracts to suggest that patients have become more honest with doctors or dieticians since they were treated in a less authoritarian manner, but access to the complete data would give several examples of good relationships from the earliest decades.

Where criticisms are made, all the interviewees seemed instinctively to disguise the identity of those criticised. Where a doctor, nurse or podiatrist is named, it is always to pay tribute. We feared that staff who suggested potential interviewees might only offer success stories, but in fact both staff and patients took very seriously the responsibility of providing a full historical record, including failures as well as successes. Predictably enough, the most frequent complaint is of seeing a different doctor at each visit to a hospital clinic. The staff most praised are those whom the patient perceives as treating them 'as a person': the details of what this means over many decades will make fascinating listening for any healthcare professional.

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What diabetes is, and how it is managed, is packed with drama, suspense and surprise. Sometimes the rewards for success are great. Sometimes they turn sour.

The way in which insulin was discovered, which has prolonged the lives of millions of sufferers from diabetes, continued all

and his assistant Charles Best for recognition of the value of insulin in 1921. What diabetes is, and how insulin keeps it in check, is explained here by TVTimes Science Editor Peter Fairley.

Diabetes is a disease in which the sugar level in the blood rises

body—which secretes insulin to help digestion. In people with diabetes, the cells are damaged or destroyed, although no one yet knows why. Without insulin, the body builds up sugar in the blood, and it is excreted out of him in the urine, causing a coma which can lead to death. Using two dogs, Best showed how this disease is controlled by injecting insulin from a healthy pancreas.

10.0 News at Ten

10.30 Survival

Edge of the Abyss

BY COLIN WILLOCK

They stick up 13,000 feet into the wild highlands of Ethiopia, jagged peaks and precipices perhaps any other landscape. The Simien Mountains have been called a lost world. Now, like so many other places, the time in which it can be seen is its grandeur, may be gone. CAMERAS: JOHN BUXTON; EDITOR: JOHN BUXTON; PRODUCER: ANGELA BUXTON

Feature

Allan's story



Allan Jones was born in Pontypridd in 1938, the son of a miner whose sister had died of a "drinking disease" before insulin became available. When Allan became ill at the aged of 7, in 1945, they called out a local doctor several times, who recommended bed-rest and keeping warm.



One evening, when he had severe stomach pains, they traced the doctor to the nearby drinking club and were given a diagnosis of double pneumonia, to be treated with hot sweet drinks. Fortunately, an aunt insisted that they ignore this diagnosis and get a taxi to Cardiff Royal Infirmary, where Allan was immediately given insulin. He remembers his mother telling him that the hospital consultant, Professor Watkins, asked a line of medical students to attempt a diagnosis, and not

one was able to diagnose diabetes.

He spent a few weeks in hospital and his main memory is of being continually hungry. He can't recall being put on a strict diet when he came out, apart from a ban on cake, biscuits and sweets, and he assumed that both that ban and the injections would be temporary. He thinks the insulin he was given at first was "single strength" and he remembers often being sleepy at school. It was three years before the creation of the National Health Service and when he had to return to the infirmary with "a couple of comas", the taxis placed a large burden on the family finances. He remembers that they couldn't afford cotton wool and that needles were re-used until "virtually blunt".

His mother did his injections until he was about ten, but otherwise she was too busy looking after six children to make sure he tested his urine, and he remembers that "if I was full of sugar, I'd just go and drink a lot and wee a lot, and nobody took much notice".

When he left school at 15, he got a job as a messenger boy on the railways, and shortly afterwards paid a visit to a local hospital for ingrown toenails. He was dismayed when they took a urine test and kept him in for 26 weeks to stabilise him: "I was having so little to eat, I was starving, and they never ever suggested giving more insulin and giving more to eat."

For promotion at work he had to pass a medical, and he was so afraid of failing it that he took with him a sample of his brother's urine. He passed with flying colours and worked happily on the railways for 30 years: "the doctor's dead and gone now, probably, so I won't get him into any trouble."

Further information

To hear the rest of Allan's story, or those of many others with diabetes who contributed to the project, visit the oral history website at www.diabetes-stories.co.uk

