Patient education and diabetes care: Part 1

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Today's diabetes world is fast-moving and exciting; knowledge is accumulating at an astonishing rate. To help understand the present, however, it sometimes helps to examine the past.

In this installment of *Tattersall's Tales*, Robert Tattersall gives part one of a two-part series tracing the history of patient education, highlighting the various struggles faced in the modification of knowledge provision and the quest for lifestyle change and self-management.

Even before the introduction of insulin in 1922/3, diabetes was unique in that the treatment – diet – had to be implemented by the person with the condition and progress charted by urine testing. Education was therefore a *sine qua non*. In the late 19th and early 20th century this meant giving general lifestyle advice, such as avoiding worry and taking moderate exercise. This was supplemented by a list (often incredibly detailed) of things that could, and a longer list of things that could not, be eaten. It was easy for authoritarian physicians to make people stick to their diet in an institution, although few went as far as the Italian Arnaldo Cantani (1837–1893) who reputedly locked patients in their rooms so that they could not get forbidden foods.

Where teaching should be carried out varied from country to country. As early as 1916 Joslin recommended centralisation, writing that:

> *"The labour entailed in educating a diabetic nurse in a hospital where diabetes is rarely treated is far more than that required to teach the patient. The patient has diabetes – not the nurse – and is consequently the one most interested . . . the management of diabetic patients in many large hospitals is an example of inefficiency. Instead of having the diabetic patients grouped together where the diets could be easily supervised, they are usually scattered throughout many wards."*

In Germany in the early 1900s there were several residential diabetes clinics, while Bohemian and Moravian spas, such as Carlsbad and Luhačovice, claimed that their waters had specific antidiabetes properties. Rich people with diabetes undoubtedly derived great benefit from a sojourn at one of these institutions. However, the German specialist Carl Von Noorden pointed out that drinking Carlsbad water at home did not work and that the essential element of a spa "cure" was not the water but removal of strain, long walks, a regulated diet and classes on diabetes management.

As far as I know, the only residential institution in England was the private Duff House sanitorium in Banff, Scotland (later moved to Ruthin Castle in North Wales), where from 1913 Dr E I (later Sir Edmund) Spriggs (1871–1949) organised sessions, which included a class by the diet nurse and a demonstration of urine testing by laboratory staff. Spriggs produced what was probably the first patient-orientated book in Britain, *The Patient's Manual of Diabetes*, which ran to 20 chapters including one on "special gardening". At the Medical Society of London in 1921 Spriggs suggested that every hospital should organise classes for in- and out-patients since "the expense would be trifling and the benefits great". It seems likely that this fell on deaf ears because most voluntary hospitals would have had neither the inclination nor finances to organise such classes.

Lifestyle change, to use an anachronistic term, needed the intelligent cooperation of the person with diabetes or his or her family, preferably both. Teaching also needed to be tailored since, as Strouse wrote in 1920, "There is no use in talking in the language of the laboratory to a patient who understands only the language of the kitchen. We must either teach him the new language or translate our Greek into understandable English". Considering that in the 1920s around 20% of the population of London were illiterate this would have posed major problems.

After insulin

Before 1920 there had been a few books specifically aimed at people with diabetes. Probably the best known was Joslin's *A Diabetic Manual for the Mutual use of Doctor and Patient*, first published in 1918. After the introduction of insulin the market expanded dramatically. In England in 1925, Robin Lawrence produced the first edition of *The Diabetic Life: Its Control by Diet and Insulin* and there were others by Conybeare, Leyton and Cammidge. Many of these books proved enduring best sellers. Lawrence's reached its 15th edition in 1944 and Joslin's its 8th in 1959.

There is little evidence about the organisation of education and care for the ordinary person with diabetes before World War II. What there is suggests those living in cities within easy reach of fabled institutions (e.g. Boston, London or Vienna) received good technical treatment; for others living in remote areas, what happened seems to have been a matter of chance.

In England before World War II it was usual to start insulin in a nursing home or hospital, depending on the individual's means. In either venue the initial "stabilisation" took 2 or 3 weeks and included education of variable quality. A patient who first attended King's College Hospital in 1932 aged 10 remembered that she was kept in for 3 weeks and that her mother was only allowed to visit once a week on Sundays. The opportunity for continuing education was theoretically at outpatient follow-up visits. This was fine if the patient went privately; Beatrice Reid has described highly educational and motivating visits to RD Lawrence in Harley Street (http://tinyurl.com/BeatriceReid). However, in England most were followed-up in ordinary general medical clinics which were pretty awful.

Gladys Wauchope (1889–1966), who herself developed diabetes in 1926, remembered that at the London Hospital in 1920, the session lasted from 1 to 7pm. Large numbers of patients attended, most of whom had come for "Rep Mist" [repeat the mixture] (Wauchope, 1963a). She started a diabetic clinic in Sussex in 1934 and soon found that up to a hundred patients would attend in 2½ hours to be seen by two or three doctors. Laconically, she comments that, "one acquires a knack of working fast without appearing to hurry" (Wauchope, 1963b).

In 1948, at the inception of the National Health Service, there were 22 diabetes clinics in London, three in Birmingham and three in Glasgow. What is striking is that most were only held on one half day each week. In 1951 Robin Lawrence suggested the setting up of special centres for diabetes in London and the south east of England (Lawrence, 1951). The rationale was that "most general consultants (and their house physicians!) feel that they are ill equipped to deal with diabetics in general wards or afterwards as outpatients. Diabetics themselves crowd to any centre where their problems can be helped or solved". Lawrence suggested that:

> *"In a small centre with some 300 diabetics, the doctor needs one sister trained in diets and insulin and able to teach, a nurse to help her, and a cooperative house-physician. The same team should see the outpatients at their regular visits, at least three or four times a year … the prime essential is a continuity of personal supervision for months and years. The patients need this, and it pays economically."*

The failure of education

What was first articulated in the 1950s was that any random sample of people with diabetes were invariably lacking in basic knowledge. For example, in 1952 Samuel Beaser (1910–2006) questioned 128 people attending the Boston Diabetes Fair and found that "all were distinctly deficient in knowledge of their disease" (Beaser, 1956). He thought it was a common impression that "both old and new patients are equally in need of education and at least *yearly re-education* [my italics]". Responsibility lay with both administrative and professional staff with the understanding "that patient education is a vital facet of the minimum standards of medical care in their institution".

It seems likely that this fell on deaf ears. Don Etzwiler (1927–2003) remembered that in the late 1950s, while attending paediatric endocrine clinics at the University of Minnesota, "I became grossly aware that many young patients there were having difficulties with their diabetes, not because of the intrinsic nature of the illness, but rather from a lack of basic knowledge concerning its management" (Etzwiler, 1962).

Another problem was that children with diabetes were often overprotected and lacking in self-confidence. One solution was camps during the summer holidays. The first was set up in 1925 by Dr Leonard Wendt of Detroit and by 1952 – the year in which the British Diabetic Association set up its first – there were 18 in North America (Marble, 1952).

The philosophy of these camps varied. Some regarded the recreational aspects as most important and thought urine and blood testing should be kept to a minimum. Others thought they afforded an opportunity to regulate diabetes control and educate the child in self-care. It also gave their harassed parents some respite. Some children had such unsatisfactory home conditions that residential hostels, such as that set up by the London County Council at Hutton in 1939 (later moved to Palingswick House, Hammersmith), could be life-saving in teaching management and self-reliance (Henderson, 1949). Such facilities were uncommon for adults; ordinary convalescent homes did not cater for people with diabetes because "the risk of coma is too dismaying for the matron and the thought of special diets too upsetting for the cooks" (*Lancet*, 1950).

In summary, what passed for patient education up to the 1960s was the Gradgrind model of "filling empty pitchers with imperial gallons of facts" (Dickens, 1854). Like Gradgrind's pupils, patients were expected to be passive and were not encouraged to participate in their own treatment or even to ask questions. The Zeitgeist was that "authority was everything; you disobeyed any form of it, from a schoolmaster to a doctor, at your peril. You didn't even think about it" (Luard, 2000). This changed in the 1970s but did not have the desired effects on glycaemic control for reasons which I will explore in the next article.

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