Visit to the Joslin Diabetes Center: What I learnt

In 2017, Gayle Richards was awarded a grant from the Winston Churchill Memorial Trust, which awards Travel Fellowships that give individuals the opportunity to travel to other countries to observe, learn and research aspects of care. Learning can then be brought back to the UK. Part 1 and part 2 of her story are available online. In part 3, Gayle outlines her experience observing the practice at the world-renowned Joslin Diabetes Center in the US.

n the second part of my educational trip funded by the Winston Churchill Travel Fellowship, I visited the world-famous Joslin Diabetes Center in Boston, MA, USA. Throughout my career as a DSN, the Joslin Center has been a perceived as a leader in many aspects of diabetes care: research, education and clinical care.

My specific intention in visiting was to meet John Zrebiec who, together with Daniel Cox and Linda Godfried, has developed and delivered the Blood Glucose Awareness Training (BGAT) intervention in the US. I was keen to learn how BGAT can help individuals with type 1 diabetes manage problematic hypoglycaemia.

The Joslin Center was founded in 1898 by Elliott P Joslin, and is affiliated with Harvard Medical School. Elliott Joslin is seen as the pioneer of education to promote self-management for people with diabetes and, especially, for promoting the role of the nurse in this. He said, "A well trained nurse is of more value than the patient's doctors", and he created a fund to support the role of the "wandering nurse", who would go wherever patients needed them, whether this was their home, workplace, school or diabetes camps. Even before the discovery and use of insulin, Joslin developed an inpatient education programme, as his motto was "those who know the most live the longest". The entrance to the Joslin Center has a photograph of one of these early Nurse Educators.

To visit the Joslin Center, it is necessary to apply to join the Visitor Program. This involves a payment, references and a health check (with proof of vaccinations). An individual programme tailored to my request was set up. This focused on shadowing Certified Diabetes Educator clinics and education groups, in addition to meeting with members of the Behavioral Health team (including John Zrebiec himself).

The Joslin Center is housed over four floors in the area of Boston, where many of the large health institutions are based. It has over 600 staff, most of whom are research scientists. In the past, patients were admitted to a ward area, including for education programmes. Now, however, only outpatients are seen. The centre also has its own eye institute, where retinal screening and laser treatment are carried out. There is also a separate



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Photograph of one of the early Nurse Educators of the Joslin Center.

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unit for children and young adults. Over 21 000 people a year are seen at the centre, of whom around 40% have type 1 diabetes. There are ten Certified Diabetes Educators seeing patients in clinics and group programmes. These educators are registered nurses, registered dietitians and exercise physiologists.

Education programmes comprise the DO IT (Diabetes Outpatient Intensive treatment) programme, which is a 4-day intensive education course, one-to-one and in groups, delivered by a multidisciplinary team; and the Why WAIT (Weight Achievement and Intensive Treatment) programme, which is a 12-week weight reduction and diabetes management course. Unfortunately, I was not able to see these programmes running during my visit. However, whilst there I was able to attend group education sessions on continuous glucose monitoring (CGM), gestational diabetes and insulin pump initiation, and to sit in on clinics with registered nurses and dietitians.

My overall impression was that technology is seen as an important part of managing diabetes, perhaps more so than in the UK. CGM and insulin pumps were used by nearly all the visitors with diabetes (type 1 and 2) that I met. The Nurse Educator clinics were just beginning to use the Medtronic Minimed 670G "closed-loop" system, which had recently been launched. It was really exciting to see this new technology in usual clinical practice, and also to hear about some of the challenges with this system.

The funding of healthcare in the US is incredibly complicated. Insulin pumps and CGM are often funded through insurance, but choice is limited in the more basic insurance plans. The registered nurses did not need to get involved in finance details, as this was dealt with by finance managers within the centre.

Two examples of the implications of insurance-based systems were evident to me whilst there. The group education session for women with gestational diabetes involved teaching them to do home blood glucose monitoring. As they all had different insurers, they had been issued with different blood glucose meters. Medicare, the government-funded health insurance programme, funds education for people with diabetes. In

attempts to reduce costs, funding for education at Joslin at diagnosis has been reduced from 10 hours to 2.5 hours. Pumps can be funded by insurance plans but there is no obligation for the user to attend education programmes or see healthcare professionals. In one of the Nurse Educator clinics, a man attended for education concerning an upgrade of his pump. He had not seen a healthcare professional for many years, and many issues familiar to UK clinics emerged. He was not testing his glucose levels or changing his cannulae/infusion sets as recommended, and he had had admissions with diabetic ketoacidosis. It was reassuring to know that the same issues arise on both sides of the Atlantic.

Elliott Joslin was instrumental in developing the role of diabetes nurses - now known as Certified Diabetes Educators - and I was keen to see how this role differed from that of DSNs in the UK. Much of the work that I witnessed in group education and one-to-one clinics seemed identical to that seen in the UK. The qualification of Certified Diabetes Educator can be held by any health professional and, in my limited experience, the dietitian and nurse clinics appeared to be identical. Both gave advice about pump settings and so on. Patients usually attend for a medical and education appointment either on the same day or close together. However, I was surprised that most of the decisions about pump therapy were made by the physician. Sometimes this caused conflict where the nurse/dietitian did not agree with the decisions made. One example was a patient who was attending for a pump start, as scheduled by the physician, but who did not really understand what using a pump would involve and had not undergone any training in carbohydrate counting.

The Nurse Educators did not have case loads as we would understand in the UK. Appointments were scheduled by clinic co-ordinators and there did not appear to be a focus on continuity of care. Nurses were only rarely involved at diagnosis of type 1 diabetes. Initial care would often be carried out in primary care or other medical centres. People could then chose to attend the Joslin Center if their insurance plan covered this, or if they chose to pay. Sometimes they would only attend once or intermittently, making follow-up difficult.

They would travel for some distance to attend, potentially from anywhere in the US but usually from the East Coast.

The Nurse Educators took emergency phone calls in very similar ways to the UK. These calls included giving advice for inpatients at the linked Brigham and Women's Hospital. Inpatient diabetes was supported by Nurse Practitioners, and they would seek telephone advice about management from the Nurse Educators. They could also prescribe.

The Behavioral Health team

The second part of my visit was with the Behavioral Health team at Joslin. This team is made up of John Zrebiec, Marilin Ritholz and a Medical Social Worker. The team see people with diabetes who have been referred to them by primary care teams or by other health professionals at Joslin. They run specific programmes and have input into the education programmes (DO IT and Why WAIT). They also conduct research into the psychological aspects of living with diabetes.

I was able to spend time with John and Marilyn, who were both very generous with their time. Marilyn has published work on many aspects of care, including having difficult medical conversations and the attitudes of people with diabetes to technology. Given the prevalence of technology in the clinics that I observed, this was of interest to me. Her work stressed the importance of assessing anxiety levels before starting new technology. Her participants described starting insulin pump therapy as like being diagnosed again, and they expressed concerns about coping with the frustration of learning new regimens, etc., and body image. Active participation in self-care, realistic expectations of pump use, and emotional recall of the diabetes diagnosis were associated with better glycaemic control. Marilyn found that it helps to have good decision-making and maths/logistic skills, and to be flexible, emotionally stable and open to new experiences (Ritholz et al, 2007).

Marilyn has also looked at patients' views of CGM. In a qualitative study, effective use of CGM was associated with coping skills, retrospective review of data and support from a significant other (Ritholz et al, 2010).

The time I spent with John Zrebiec was to explore my interest in the BGAT intervention. John worked with Daniel Cox at the University of Virginia to develop a training programme to help people with diabetes to accurately detect blood glucose levels using physical, mental and mood cues (Cox et al, 2006). Initially, this work included both high and low blood glucose levels, but more recently the focus has been on the recognition and prevention of hypoglycaemia, particularly in individuals with reduced hypoglycaemia awareness.

Over time, the education programme has evolved, but now fewer people are attending such programmes. The Joslin Behavioral Health team feel that this is due to many factors, including reductions in what insurance will cover, less time to attend appointments and the increase in use of CGM. John has continued to work with people with diabetes (and their carers/partners) on a one-to-one basis, and was able to describe how, using the principles of BGAT, they have achieved improved awareness of hypoglycaemia. From the sessions I spent with John, I was able to explore many aspects of the impact of impaired hypoglycaemia awareness. I also learnt many practical tips and exercises, which I have been able to incorporate into my clinical practice back in North Devon.

Cox DJ, Gonder-Frederick L, Ritterband L et al (2006) Blood Glucose Awareness Training: what is it, where is it, and where is it going? Diabetes Spectrum 19: 43–9

Ritholz MD, Smaldone A, Lee J et al (2007) Perceptions of psychosocial factors and the insulin pump. *Diabetes Care* **30**: 549–54

Ritholz MD, Atakov-Castillo A, Beste M et al (2010) Psychosocial factors associated with use of continuous glucose monitoring. Diabet Med 27: 1060–5

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