A life without diabetes: One person's journey through total pancreas transplantation

Julia Hicks

This case study highlights some of the many challenges young people are faced with as a result of living with the condition and how living with diabetes-related complications resulted in one young person's decision to undergo total pancreas transplantation. It explores the enormity of such a decision-making process as well as acknowledging the importance of both medical and psychological support.

The UK has one of the highest rates of type 1 diabetes in the world, for reasons that are currently unknown. Type 1 diabetes affects approximately 31 500 children and young people (CYP) in the UK, and the incidence is increasing by about 4% each year, particularly in children under the age of 5 years, with a five-fold increase in this age group in the last 20 years (Diabetes UK, 2015; Juvenile Diabetes Research Foundation, 2016).

The emotional and physical impacts of living with a chronic condition are inevitably life-changing (Liberman et al, 2015). In addition to learning skills and medical therapies, diabetes requires time, energy and motivation to manage well (NICE, 2015). Good management is crucial, given that the number of children being diagnosed with type 1 diabetes under 5 years old is rapidly rising and will result in increasing cases of diabetes-related complications in the future (Tuomilehto, 2013). These complications are not only costly to the NHS but can also affect quality of life and may be debilitating, and even fatal, for some. The direct annual global cost of diabetes is more than US$827 billion (World Health Organization, 2016).

My experience

I was diagnosed with type 1 diabetes at the age of 11 years and achieved relatively stable glycaemic control throughout my childhood and adolescent years. At the time, the nationally recommended HbA_{1c} target for CYP with diabetes was 58 mmol/mol (7.5%) or below. In England and Wales, figures suggested that only 18.4% of CYP were achieving this target (Royal College of Paediatrics and Child Health, 2015). It is now recommended that CYP with type 1 diabetes aim for an HbA_{1c} of ≤48 mmol/mol (6.5%; NICE, 2015). The Diabetes Control and Complications Trial (DCCT) Research Group (1993) suggest that the onset of diabetes-related complications can be prevented or delayed by implementing intensive education and treatment in children and adolescents.

The complications

Exocrine insufficiency

Approximately 11 years after diagnosis, I began experiencing occasional episodes of steatorrhoea and vomiting. Gradual weight loss occurred and the frequency of hypoglycaemia increased.

In order to minimise the impact of a long-term condition on daily living, it is advocated that one should try to externalise it (Christie, 2013). The physical symptoms interfered with day-to-day life and my emotional wellbeing and confidence deteriorated. I restricted the quantities, types and timings of food in an attempt to limit the likelihood of triggering any undesirable gastrointestinal reaction. It has been suggested by Walsh (2006)

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Article points

1. Young people with type 1 diabetes are faced with many challenges.
2. The author's diabetes-related complications led her to consider total pancreas transplantation.
3. Two years on, she has seen an improvement in glycaemic control and reduced treatment burden; however, gastroparesis remains problematic and infrequent episodes of hypoglycaemia occur.
4. This procedure is not a "quick fix", and careful thought should occur before embarking on a journey where there may be many significant challenges to overcome.

Key words

- Complications
- Pancreas transplantation
- Psychological support

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that families need to find a way to gain perspective on an illness so that it does not take over a person's identity – this was extremely challenging when the cause was unknown, adding to my frustration and anxiety over the next 18 months.

My blood glucose levels were increasingly difficult to manage and fluctuations were prevalent following these episodes. At the time, I was on a multiple daily injection regimen and, although this was designed to be flexible (Sharef et al, 2015), the significant demands in relation to glucose excursions remained unmanageable.

In order to address this issue and improve glycaemic control, I researched, at length, the use of continuous subcutaneous insulin infusion (CSII) therapy. At the time, this was not as commonly used or widely available in the UK as it is today, but I was fortunate to be granted funding. CSII is an intensive form of management and is not necessarily appropriate for all individuals. However, the opportunities for dietary flexibility and variable insulin dosing that this therapy allowed (NICE, 2008) improved my glycaemic control and changed my life dramatically.

The cause of my steatorrhoea was extensively investigated and, eventually, a diagnosis of exocrine pancreatic insufficiency was given. Oral pancreatic enzymes were prescribed and some of the gastrointestinal symptoms improved.

Autonomic neuropathy – gastroparesis

A few months passed and, despite an initial improvement in the frequency of steatorrhoea, the vomiting increased. At first the episodes were infrequent, with minimal impact. As the frequency increased, however, blood glucose control began to pose a greater challenge. I sought the advice and opinions of medics, surgeons and dietitians, and, after 3 years of investigations (and in the absence of any other diabetes-related complications), gastroparesis was identified as the most likely cause. Many of the features of gastroparesis are similar to those of irritable bowel syndrome, making it challenging to diagnose (NICE, 2014).

Research and evidence to support the management of gastroparesis is limited and inconclusive (Camilleri et al, 2012; Parkman, 2015). Living with this condition is challenging and it has a significant effect on quality of life. In my case, the gastroparesis led to a major decline in self-esteem and a deterioration in health and wellbeing. My work and social relationships were affected, and isolation from social and family support networks was evident. The impact on life as a whole was profound.

To begin with, my vomiting was cyclical and can be described as nothing more than physically and mentally exhausting. A combination of anti-emetic and pro-kinetic pharmacological therapies was trialled, without success. I embarked on an extremely restrictive low-residue, liquid dietary regimen (with the addition of nutritional supplementation) to minimise the symptoms and impact on my life, as recommended by Camilleri et al (2012).

Anaemia, vitamin deficiencies, fatigue and significant weight loss were identified and the level of concern from professionals increased. A symptom/management diary was advised. It took time to learn the triggers for vomiting and how to best manage them in order to stabilise blood glucose levels. My coping capabilities rapidly diminished and desperation set in.

There has been significant success using CSII for selective individuals with severe gastroparesis in experienced CSII centres (Sharma et al, 2011). In addition, continuous glucose monitoring was suggested as a therapy option by a company representative, and a 6-week trial of sensor-augmented pump therapy was offered free of charge.

Following the trial, it was evident that, although intensive effort was required, my glycaemic control was far better and glucose excursions less frequent. The ability to predict glucose trends and suspend insulin delivery in the instance of hypoglycaemia was invaluable and restored some confidence, reassurance and normality to life. At the time, sensor-augmented pump therapy was identified as an exceptional funded treatment and only available to those who met the required criteria due to the need to justify its expense. The challenge was financial, and I was determined to overcome it. I applied for funding and, after 12 months of letters, appeals and involvement from my MP, I was finally successful.

Diabetic macular oedema

There are many factors associated with the risk

of developing diabetes-related complications, including lifestyle choices, duration of diabetes, age at diagnosis, and cardiovascular risks such as hypertension and dyslipoproteinaemia. The DCCT Research Group (1993) reported that dyslipoproteinaemia is associated with microalbuminuria and retinopathy development, while Gallego et al (2008) demonstrated the role of blood pressure in development of diabetic retinopathy. Annual screening for complications is recommended for everyone with type 1 diabetes (NICE, 2015).

After 18 years of living with type 1 diabetes and attending annual retinal screening, I was diagnosed with diabetic macular oedema (DMO) – the leading cause of blindness among individuals with diabetes (Romero-Aroca, 2010). The DCCT Research Group (1993) reported that 27% of people with type 1 diabetes developed DMO within 9 years of diagnosis. Despite the absence of any renal or cardiovascular complications, and following a relatively short history of non-proliferative retinopathy, this was unexpected.

The treatment options available on the NHS were limited. Laser therapy was available at the time. It is used to destroy parts of the retina and the growth of abnormal vessels in order to prevent further vision loss. I was aware that, compared with laser therapy, vascular endothelial growth factor (VEGF) inhibitors demonstrated more positive outcomes for people with DMO (Royal College of Ophthalmologists, 2012; American Diabetes Association, 2016).

As advocated by Barry and Edgman-Levitan (2012), I received advice and support throughout the decision-making process from family and ophthalmologists, which led us to apply for exceptional treatment funding for the anti-VEGF drug ranibizumab. This pharmaceutical option was not available through the NHS at the time, but it is now licensed for the treatment of DMO (NICE, 2013). It was anticipated that monthly intravitreal injections for 12–24 months would be necessary to improve oedema and vision. A number of weeks later, the application was approved. Although an anxious time, my relief that there was a chance to rectify my sight was overwhelming, and the fear of intravitreal injections was insignificant by comparison.

After a few treatments, the oedema settled and my vision improved. Although I was grateful for the opportunity to receive this treatment, it was time consuming. I often needed to take time from work (occasionally an entire day) and relied heavily on both psychological and practical support from friends and family in order to uphold this commitment.

A decision to be made

Eighteen years after my diagnosis of diabetes, the challenges and pressures of living with the complications were proving too much to manage. Hypoglycaemia, weight loss, fatigue, malnutrition and the psychological impact of living with several chronic conditions were taking their toll. I had continued to work full time, but I was physically and emotionally drained. A negative impact on personal relationships was evident and my social confidence and self-esteem were low.

After discussion with my local endocrinologist, a referral was made for me to discuss my situation with a regional team specialising in islet cell and whole pancreas transplantation. The consultation provided an opportunity to ask questions and gather information about the treatment options.

Ultimately, frequent and severe hypoglycaemia was the basis for my decision to pursue a whole organ transplant rather than islet cell transplantation. Research underpinned that the likelihood of achieving insulin independence was higher with a whole organ transplant, with the additional benefit of improvement to exocrine function (Robertson et al, 2003).

I met with a transplant specialist team to discuss the possibility of a pancreas alone transplant (PAT). In the absence of any kidney disease, this was the preferred and professionally recommended treatment option, most suitable in my circumstances. I met with the team twice and spent the next couple of years deliberating over the risks and benefits.

PAT requires lifelong immunosuppression to prevent rejection of the graft and recurrence of the autoimmune process (Rangel, 2012; Gruessner and Gruessner, 2013). The immunosuppressive medication has side effects and the procedure itself has significant morbidity risk and a small risk of mortality (Robertson, 2003). Each individual

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case is assessed for suitability. Individual patient circumstances are taken into consideration and are scrutinised to ensure strict criteria and guidance for undergoing transplantation are met. My application for transplantation was made on the basis of severe and frequent hypoglycaemia, which was having a cascading, detrimental effect to many aspects of my life, including my ability to work effectively (Lin et al, 2010). A relationship between repeated severe hypoglycaemia and spatial memory performance has been identified (Hershey et al, 2005). In a later study, Perantie et al (2008) had similar findings; however, the effect was more pronounced in children with early-onset diabetes and those with longer diabetes duration. The overriding factor for me was that my quality of life had declined to such an extent that it was impacting on my ability to function effectively both physically and emotionally; my life fulfilment was inadequate.

Life without diabetes

Pancreatic transplantation is a specialist area and it is recommended by the American Diabetes Association to be performed in tertiary care centres that are adequately equipped to manage the complex medical and psychosocial needs of transplant recipients over the long term (Robertson et al, 2003).

Following several hours of open abdominal surgery, a nasogastric tube, jejunostomy, urinary catheter and wound drain had all been inserted, and the realisation of the journey ahead dawned on me. The need for exogenous insulin had been eliminated and a state of insulin independence achieved. However, further surgery was necessary the next day in order to try to identify the cause of rapidly deteriorating blood pressure and haemoglobin levels. As has been reported in several cases (Lehmann et al, 2015), a bleed was identified and repaired. I returned to the high-dependency unit of the transplant ward, where I remained for 2 weeks. During this time, I was educated about caring for a pancreas transplant. Members of the multidisciplinary transplant team visited daily to deliver role-specific advice and education, including advice on dietary restrictions, caution around meal preparation, travel, illness management, pharmacological information, physical exercise and physiotherapy.

Despite lengthy consultations with professionals, discussions with patients with previous experience and reading around the subject, I was not fully prepared for what the next 4 months would entail. Twice-daily self-monitoring of blood glucose, blood pressure, heart rate and temperature was advised for the first 12 months. I was initially required to take oral medication every 2 hours during the day – a total of 63 tablets. This number gradually reduced and the frequency declined to twice daily once a "steady state" had been established. Despite the constant nausea, vomiting and pain, awareness that the medication was vital for graft survival (Rangel, 2012) was crucial in maintaining adherence.

After discharge from hospital, I was cared for by my family at home. The follow-up commitments were made clear prior to the surgery and were an essential component of the ongoing care package. I was required to travel to my local transplant centre (approximately 50 miles from home) three times a week for blood tests to ensure the functionality of the pancreas. This was not only designed to provide means of a clinical review, but to help me understand and provide patient empowerment.

Several hospital admissions for electrolyte imbalances occurred over the following 4 months, and the time spent in hospital was disproportionate and not conducive to daily living. The decision was taken to change from a bladder-drained pancreas transplant to an enteric conversion (Gruessner and Gruessner, 2013).

Although the immunosuppressive medication was well tolerated and has maintained graft function as intended, after 18 months it was believed to have caused a degree of toxicity, resulting in stage 3 chronic kidney disease (Tan et al, 2008).

Twenty-four months after the transplant, my schedule of intravitreal injections has been reduced to every 3 months. Despite improvement in glycaemic control and a reduction in glucose variability, gastroparesis remains problematic and, subsequently, infrequent episodes of hypoglycaemia occur. Evidence suggests that enhanced glycaemic control may have a positive impact and result in some improvement to gastric emptying and symptoms of gastroparesis; however, outcomes are variable (Morrison et al, 2015).

Conclusion

Diabetes is a chronic condition requiring intensive

management and commitment in order to minimise the risk of developing associated complications. Genetics and the duration of the condition may also have a role to play. The physical and psychological impact of living with diabetes-related complications is challenging and life-altering; recognition and utilisation of the support and services available is crucial in coping.

Specialist healthcare professionals have a profound role in delivering education and empowering children and young people to understand and manage their condition, allowing them to be involved and helping them to make informed choices. It is crucial for individuals to be aware that a life without diabetes does not always necessitate a life without complications. The concept of a pancreas transplant may appeal to some; to others it may not. The treatment option is by no means a "quick fix" and careful thought and consideration should most definitely occur before embarking on a journey where there may be many significant challenges to overcome along the way.

The initial decision-making process requires time in order to develop a clear understanding of the risks involved in this life-altering procedure. Access to specialist teams and appropriate advice is fundamental in this process. Liaising with others who have experience (both positive and negative) is also helpful in understanding the process and the implications and possible consequences of the procedure. Determination, commitment both before and after, and a sound, well-established support network is crucial and should not be underestimated. ■

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