

# Reflection on 30 years as a PDSN

**D**iabetes is a 24/7 condition, with no holiday for the children and families we work with. After 30 years of working with children and young people with diabetes and their amazing families, it will be time for me to retire in the new year. I have had the pleasure of being section editor of this journal since 2006, and I will be handing over to Peter Doyle, Lead Diabetes Nurse for Children and Young People at Pennine Acute Hospitals NHS Trust. The following editorial is a personal reflection on the advancement of diabetes management over the years.

## Diet

Children and young people used to have the amount of carbohydrates counted in “black lines”, with 1 line being equivalent to 10 g of carbohydrate. The formula used was 10 g for every year of their life plus 100 g, to a maximum of 220 g for girls and 250 g for boys. These were then distributed through the day evenly into three meals with three smaller snacks. The British Diabetic Association (now Diabetes UK) had a carbohydrate reference book in which foods were classified as green, amber or red; food did not have the food labelling panels that we take for granted today. Staff and families learned the numbers for regularly eaten foods, and I can still quote how many lines are in certain foods. However, this was somewhat dismissed in the 1990s and replaced with the general healthy eating message and just a regular distribution of meals that were high in fibre, low in fat and with plenty of fruit and vegetables. Carbohydrate counting has been readopted more recently, partly due to its requirement for insulin pump therapy, but there has also been an increased understanding of the role of fat and protein in the management of diabetes.

Before the discovery of insulin, diabetes was managed using low-carbohydrate diets to help prolong life. There is now a movement on social media in favour of low-carbohydrate diets for the

management of type 1 diabetes. In this issue of the Journal, [Frances Hanson and Jennie Brown](#) discuss the latest research and advice if you have a family wanting to follow a low-carbohydrate diet.

## Insulin regimens

Over the years I have used a wide variety of insulin regimens, including free-mixing insulin into a syringe once or twice a day, fixed mixed insulin twice a day, insulin three times a day and multiple daily injections, along with pump therapy. In the era of fixed mixed insulin, it was not uncommon for my family to have a full range of mixtures, from 10% to 50%, in their fridge, and I would titrate between these different mixes as one size doesn't fit all. This basic understanding of insulin actions has served me well and I became an Independent Nurse Prescriber in 2005. In a recent National Paediatric Diabetes Audit spotlight report, there was a statistically significant difference in mean adjusted HbA<sub>1c</sub> in services where a nurse prescriber was employed (Royal College of Paediatrics and Child Health, 2019). I would wish, for the future, that all specialist nurses could see the need, and receive the support, to enable them to become Independent Nurse Prescribers.

## Education and empowerment

There are often accusations that children and young people's teams are paternalistic and that our relationship with our families creates dependence rather than independence. Education is the cornerstone to diabetes management and it should be age-appropriate. I believe that all children, young people and their families should receive consistent messages and education from their diabetes team. To put someone on a bolus advisor with no knowledge of what insulin:carbohydrate ratios or insulin sensitivity factors are, including how to calculate them, disempowers our families. I have presumed competence in all families I have encountered and foster a belief that it is their



**Helen Thornton**

Clinical Nurse Specialist in Paediatric and Adolescent Diabetes, St Helens and Knowsley Hospitals Trust, Merseyside

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In this  
issue:

### Low-carbohydrate diets for children and young people with type 1 diabetes: Unpicking the evidence

A detailed review of the current evidence regarding low-carbohydrate diets and the potential risks associated with their use, as well as advice on supporting and monitoring those patients who choose to follow this dietary approach.

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### The Poole Young People's Diabetes Service

This service, which targets users aged 15–23 years transitioning to adult care, has achieved improved HbA<sub>1c</sub> and greater engagement, with fewer missed clinic appointments and fewer diabetes-related hospital admissions. This article describes how the service was developed, how it operates today and how it is looking to evolve in the future.

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condition to be managed, not ours. All pump users should be able to self-inject in the event of pump failure, and we should ensure the team around the child can also manage diabetes, to enable inclusion. This includes not only extended family members but also schools and voluntary organisations.

However, I also strongly believe that children and young people can be given too much responsibility too early, and that this is detrimental to long-term outcomes. Education should be age-appropriate and delivered by appropriately trained staff. The Goals of Diabetes Education programme (Novo Nordisk, 2016) was originally developed in Denmark. I had the privilege to update this twice, along with a team of like-minded members of the multidisciplinary team, and to have it rolled out nationally. Within this issue, Jo Dalton and her team discuss [The Poole Young People's Diabetes Service](#) and how they have empowered young people in their daily lives with diabetes.

### Evolution of equipment and technology

When I started working in diabetes, blood glucose was monitored with BM reagent strips. They were expensive, and meters were not readily available to all families, who had to buy them. A large drop of blood was put on the strip and, after a minute, wiped with cotton wool. The developing colours would then be read against a bottle a minute later. The colour range available on the bottle matched to blood glucose levels of 1, 3, 5, 7, 9, 11, 17, 21, 28 and 44 mmol/L. Some families would split the strips in half with a razor blade to make them go further and reduce the amount of blood required. I would test for colour-blindness at diabetes diagnosis and had our local children's group purchase meters for those who were colour-blind. The meter market flourished, and the companies soon cottoned on to the fact that if they provided diabetes nurses with free meters then we would recommend these strips to be prescribed by the GPs. This was way before the time of area prescribing committees, and we had a major influence on what our families received then, and still do so daily in our current practice.

Bolus advisors were incorporated into meters and apps as technology advanced. They enabled people without a pump to get more bolus advice. Like all devices, however, they require users to

understand how to programme them in order to utilise them fully.

We were an early adopter of downloading blood glucose data, as we tested beta versions of a programme for one company. Downloads enable more information to help manage diabetes, and we are developing a greater expectation of time in range as an indicator of diabetes control, rather than HbA<sub>1c</sub>. More families are remote-monitoring their young people with approved and non-approved devices they have purchased from the internet. This technology needs to be used sensibly, and over-reliance could become detrimental in the event of a non-approved device not alarming as expected or the psychological impact on an adolescent of feeling stalked by their families.

The launch of blood ketone monitoring enabled children and young people to be managed safely at home when unwell. Thinking back, the trigger for admission was large amount of ketones in the urine, vomiting and difficulty in breathing. Hardly an exact science, or indeed very safe, as it was easy for families to misjudge. We also managed some very sick children with diabetic ketoacidosis on the children's ward rather than in a high-dependency setting.

Pen devices became available not long after I started, although patients still had to purchase pen needles. One needle, one injection did not happen due to the cost, and pen needles were reused until blunt. It had been a revolution to have plastic insulin syringes, and when one company made them with half-unit increments paediatric staff rejoiced! Each company had their own devices that only fitted their insulin (*Figure 1*), and again they provided devices to specialist teams free of charge, enabling the ongoing use of their insulin. Dose accuracy on these early models was debatable and there was no rapid-acting insulin, so short-acting insulin was often used as a bolus, with basal insulin being injected with a syringe at night.

The evolution of insulin pumps then occurred, and with them a whole new learning curve. I embraced this technology, and we were early adopters of pump therapy in our region via individual funding requests. As a team, we rapidly moved into doing our own pump starts and initiated pump clinics. Pumps are evolving rapidly and teams need to stay up to date and proficient

with multiple pump devices. The ability to navigate menus over the telephone when troubleshooting with families is paramount to patient safety, as is robust structured education on initiation of pump treatment.

Continuous glucose monitoring (CGM) and flash monitoring have moved diabetes care on again, but the cost of this technology often has to be supplied by families. Flash monitoring is now available on prescription, but within the area I work CGM still requires an individual funding request and often multiple, time-consuming submissions for success.

[Adam Dawes](#) explores the use of insulin pumps, past, present and future, in this issue. With the advent of closed-loop technology, diabetes teams will have more to learn as the systems become more automated, but we also need to be aware of the families who choose not to wait for approved technology and create DIY closed-loop systems. Diabetes UK (2019) has recently released a [statement for healthcare professionals](#), which I urge you all to read and consider your professional responsibilities, especially when delegating care to school staff.

### Concluding remarks

I would like to thank all those amazing families who have taught me so much over the years. With

the knowledge I gained from them I was able to help other families. I also thank all the multidisciplinary team members throughout the world who have influenced my practice over the years. ■

Diabetes UK (2019) *Do it yourself (DIY) closed loop for people with type 1 diabetes (position statement)*. DUK, London. Available at: <https://bit.ly/2kM7lYk> (accessed 16.09.19)

Novo Nordisk (2016) *Goals of diabetes education: A structured educational programme for children and young people with type 1 diabetes. Healthcare professional guide*. Novo Nordisk UK, Crawley. Available at: <http://bit.ly/1UtFi4n> (accessed 16.09.19)

Royal College of Paediatrics and Child Health (2019) *NPDA spotlight audit report: The workforce in paediatric diabetes units 2017–18*. RCPCH, London. Available at: <https://bit.ly/2koJyuY> (accessed 16.09.19)

### Helen Thornton

Su Down, the Publisher and the Journal's editors, past and present, would like to extend our heartfelt thanks to Helen Thornton for all her help with the *Journal of Diabetes Nursing*.

For nearly 15 years Helen has steered the regular paediatrics sections for the Journal, commissioning and reviewing a host of articles and comments, as well as writing engaging and thought-provoking editorials.

We wish her a very happy and well-earned retirement. We are also delighted to join her in welcoming Peter Doyle as our new Paediatrics Editor.



In this issue:

### The use of insulin pumps in children and young people: Past, present and future

A review of insulin pump therapy in the paediatric population, discussing which patient groups it is most likely to benefit and when it should be initiated, as well as the role of pumps in closed-loop systems.

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Figure 1. A collection of insulin injection devices, old and new, used by the author over the years.