

# “Mighty oaks from little acorns grow”: The development of joint multidisciplinary clinics for children and young people with type 1 diabetes and coeliac disease

Gita Modgil, Christopher Knight, Clare Ewan

**In 2014, the authors introduced a joint multidisciplinary clinic consisting of the paediatric diabetes team, a gastroenterology clinician and specialist dietetic colleagues with knowledge and experience of both of these long-term conditions. These clinics have allowed the elimination of clinical care variability and equity factors, and have also reduced the frequency of speciality clinics visits for children and families, reducing costs, travel time and the need for parents to take time off work and for children to be away from the educational setting. They have amalgamated the investigations required for both conditions to minimise venesection and to reduce costs from multiple blood tests. The clinics have also created more hospital follow-up appointment spaces for children requiring specialist gastroenterology and dietetic expertise. Specific feedback was sought from parents, carers and children/young people during all phases of clinic development. This feedback was positive and has enabled the authors to not only continue but also further develop these clinics in line with the wishes of the families.**

The estimated prevalence of coeliac disease in people with type 1 diabetes in the UK ranges from 1.6% to 10%, with a systematic review demonstrating a pooled prevalence of 6% worldwide (Elfström et al, 2014). Children and young people (CYP) with type 1 diabetes are expected to attend routine diabetes clinics at least four times per year, and recent guidance from the British Society of Paediatric Gastroenterology, Hepatology and Nutrition states that children with coeliac disease should be seen at least annually (Murch et al, 2013). In the UK, there is wide variation in clinical care and equity of care for CYP with both conditions. In Somerset, our local cohort of children with these two long-term conditions is increasing. The prevalence is in keeping with national data; however, we are experiencing a larger cohort of children newly diagnosed with both conditions either simultaneously at presentation or in quick succession. We became increasingly aware that we were expecting

our families to attend multiple clinics per year for specialist advice regarding their conditions. Services for each condition were already well established in our hospital, but the combined/joined-up services had never been reviewed, and they relied upon professional communication that was not patient-centred.

In his work *Troilus and Criseyde*, Geoffrey Chaucer, known as the father of English literature, wrote: “...as an ook cometh of a litel spyr...” (a spyr being a sapling). He implied that great things may come from small beginnings. This is very much how we view the rise and development of our joint multidisciplinary clinic for CYP with type 1 diabetes and coeliac disease. The idea started small, discussed in conversation during one clinic setting about patients’ repeated attendance for multiple clinics. It has developed into a regular biannual clinic, certainly the first of its kind in the south-west of England and even, to our knowledge, in the UK as a whole. In this article, we describe the

**Citation:** Modgil G, Knight C, Ewan C (2016) “Mighty oaks from little acorns grow”: The development of joint multidisciplinary clinics for children and young people with type 1 diabetes and coeliac disease. *Diabetes Care for Children & Young People* 5: 71–4

## Article points

1. The estimated prevalence of coeliac disease in people with type 1 diabetes is as high as 10%.
2. Current equity of care for children and young people with both of these long-term conditions is variable.
3. Separate services are well established but rely upon professional communication and are not patient-centred.
4. Development of combined services has allowed elimination of clinical care variability, fewer clinic appointments for families and financial benefits for the authors’ Trust.

## Key words

- Coeliac disease
- Joint multidisciplinary clinics
- Patient-centred care
- Type 1 diabetes

## Authors

Gita Modgil is Consultant Paediatrician and Lead for Paediatric Diabetes; Christopher Knight is Consultant Paediatrician and Lead for Gastroenterology; Clare Ewan is Paediatric Specialist Dietitian, all at Musgrove Park Hospital, Taunton, Somerset.

### Page points

1. The authors set up a joint clinic for type 1 diabetes and coeliac disease, in which a diabetologist, gastroenterologist, dietitian and paediatric diabetes specialist nurse all see each patient together.
2. Clinics were set up with a booking pattern of 40 minutes per patient, and there are two to three clinics, each with six to eight families per clinic, per year.
3. In order to make the service as patient-centred as possible, anonymous feedback forms were given to all children or parents who attended the clinics, and alternative arrangements were made for those who did not like the new clinics.

#### Box 1. Feedback on the joint multidisciplinary clinic: Family preferences.

- 100% of families preferred being seen in the joint clinic. One child disagreed with their parent and a separate consultation was offered to them.
- 67% found the number of people in the room just right; 34% found the number of people too high. This latter group primarily comprised young people, and they were offered a separate, smaller consultation with individual team members after the joint consultation.
- 83% of families strongly agreed that they were happy to discuss both medical conditions in the presence of both the diabetes and the coeliac disease teams. The remainder of the families (17%) agreed with this sentiment.
- 67% of families agreed that there was plenty of time to discuss their diabetes care with the team.
- 67% of families agreed that there was plenty of time to discuss their coeliac disease care with the team.

development of this clinic and evaluate it according to feedback from its attendees.

### The acorn: The origins and objectives of the joint clinic

Our objectives were to optimise the quality of the service our CYP and families receive with regard to both diabetes and coeliac disease, whilst also improving access and convenience for them. We were aware of the large number of clinic appointments families need to attend and, therefore, wanted to streamline our service provision to cover both diabetes and coeliac disease in one visit. We also wanted to optimise our support for CYP and families who receive a diagnosis of diabetes and coeliac disease concurrently, as they need much more support and can find the dietary alterations required for coeliac disease more challenging if they also have to adapt to the management of diabetes. Whilst implementing this, our objective was to make this change as patient-centred as possible, so it was important to prospectively collect feedback from CYP and parents, and to use this to fine-tune our service delivery.

We identified a cohort of CYP who had diagnoses of both type 1 diabetes and coeliac disease through medical records and through our departmental colleagues, including all members of the diabetes team and dietitians. We set up a clinic with a booking pattern of 40 minutes per patient, longer than the usual 30-minute pattern. We were conscious that a large number of staff would make the consultation more impersonal and less interactive, so we kept the number of staff involved to a minimum: a consultant paediatric diabetologist, a consultant paediatric gastroenterologist, a paediatric specialist dietitian and a paediatric

diabetes specialist nurse, with access to clinical psychology if required. We aimed to start the consultation with discussion about the management of coeliac disease whilst the members of the diabetes team collated information regarding diabetes control, with the second half of the consultation dedicated to the latter aspect of care. We ensured that CYP and parents had access to all relevant sources of information for the two conditions, both in paper format and online. After the consultation, we asked them to provide us with their view of the service by completing the feedback form.

### The sapling: Development of the combined clinic

After a pilot formulation, we developed an evaluation form for CYP and parents to fill in. It aimed to capture the experience of each family in relation to their attendance at the joint multidisciplinary diabetes and coeliac disease clinic, over the period of 2014–15. There were two to three clinics per year, with six to eight families per clinic. All questions were answered outside the clinic setting and were anonymised, with free text sections incorporated into individually rated statements regarding the service. The forms could be completed by either the parent or the child/young person. Questionnaires captured views on clinic setting, allocated timings, healthcare professionals present and confidentiality of discussing both medical conditions together. Results of this evaluation and a sample of comments from the free text sections are shown in *Boxes 1* and *2*.

### The oak: The current clinic picture and research opportunities

Does this combined clinic actually result in

improved outcomes? There is certainly evidence in the literature to demonstrate that the introduction of paediatric coeliac clinics leads to increased self-empowerment to manage the condition via specialist knowledge and access to Coeliac UK (the national support group) information (Whyte et al, 2011). In the longer term, we continue to collect data regarding the various aspects of care for our CYP, including diabetes control, growth and adherence to a gluten-free diet. Qualitative benefits are described in *Box 3*. We have clearly demonstrated a reduction in the number of blood tests that each child undergoes (by agreeing and combining tests with routine annual review bloods), resulting not only in a saving for the Trust in terms of laboratory testing but also in fewer blood tests for the child. We also continue to create financial savings for the Trust with improved access to paediatric gastroenterology and dietetics due to the combined services. It is difficult to capture financial improvement data *per se* for families, but parents have highlighted the reduced travel and parking costs and the lesser impact upon work and education due to reduced need to attend multiple clinics. The attendance rate for these combined clinics is consistently near 100%.

An additional benefit of these combined clinics is the consistency of information discussed and given, as well as the opportunity for further specialist learning for the diabetes team regarding the intricacies of coeliac disease management by an allied specialist team. The impact of two chronic conditions upon day-to-day management and upon wellbeing was well recognised.

The combined clinic has also allowed us to focus our research efforts in this area. As an example, we examined our practice in human leukocyte antigen (HLA) genotyping at diagnosis of type 1 diabetes, concluding that, in line with other recently published evidence, this was an unnecessary cost as well as being distressing for children and parents. Our results demonstrated that HLA typing has a low specificity for coeliac disease in children with type 1 diabetes (Cordingley et al, 2016). Similar results were found by Elias et al (2015) in the Netherlands, where 86% of 110 children with type 1 diabetes were HLA-positive despite the fact that only seven had diagnosed coeliac disease, and by Mitchell et al (2016) in Scotland, where 94% of the 176 children with type 1

**Box 2. Additional free text comments from children and young people and their families.**

- “You all do a very good job, as you are aware through [child]’s results, as taught by yourselves. Well done! [Child] will be happier too with less hospital appointments.”
- “Joint meetings much better, less appointments make things easier.”
- “He felt there were too many adults in the room but fantastic clinic, I hope it continues!”
- “I’m happy to have both appointments combined but my child would prefer them both separate.”

**Box 3. Benefits of holding combined clinics.**

- Elimination of clinical care variability and inequality.
- Reduction in clinic frequency for children with dual long-term conditions.
- Reductions in time and cost of parental travel.
- Reductions in time away from children’s education and parents’ work.
- Amalgamation of blood tests allows minimal venesection and reduced laboratory costs.
- Increased clinic capacity for children requiring specialist gastroenterology/dietetic advice.
- Creates opportunities for focussed areas of research.

diabetes were HLA-positive, of whom only 11 had diagnosed coeliac disease. Testing was complicated in our practice, requiring additional forms and external laboratory support. Parents perceived negative HLA results as valuable; however, positive results were difficult to understand and resulted in escalated anxiety and increased clinic visit duration because of the need for in-depth explanation. There were also financial implications, with HLA typing costing £38 per test, whereas coeliac serology only costs £8 per test. As we have approximately 30 children diagnosed with type 1 diabetes each year, stopping HLA testing saves approximately £1140 per year. In line with other larger studies, we have ceased HLA typing, as a high proportion of children with type 1 diabetes are HLA-DQ2/DQ8-positive.

**The woodland: Hopes for further combined clinics**

This is a simple initiative brought about by thinking outside the “NHS box” and looking differently at the patient’s journey and the expectations that we impose, often inadvertently, on families with

**Page points**

1. As a result of these clinics, children and their families have benefited by having fewer appointments and blood tests, reduced time and cost of travel and less time spent away from work/education.
2. The Trust has also benefited from cost savings due to laboratory testing, as well as a high rate of attendance at the clinics and opportunities for further specialist learning.
3. The clinics also led the authors to re-evaluate their practice in genotype testing for coeliac disease at diabetes diagnosis, concluding that it was an unnecessary cost in addition to being distressing for children and parents.

**“Our initiative could easily be replicated in other district general hospitals and the concept could be extended to children with other multiple chronic conditions.”**

**Box 4. The opinion of a parent.**

*“I think it’s a very good thing that both diabetes and coeliac clinics are held together and I fully support this initiative. I would always attend both clinics with [my child] anyway but to keep the two clinics together would be beneficial for [my child]. It ensures that both her conditions are looked at together at the same time.*

*Having clinics closer to home works better too. The less appointments in the year are better – there is less impact on mine and my husband’s work commitments – we both work and sometimes it is hard to change shift times to attend multiple clinics. There is less impact upon [my child’s] schooling too as she has to miss less lessons, with less disruption upon her education. There is a big reduction in travel costs, petrol, car wear-and-tear and parking costs.*

*The number of people in the clinic room was fine and [my child] and I were happy to discuss both conditions in the presence of both teams. There was plenty of time to discuss both conditions. The team all do a good job – as they are aware through [my child’s] results and their teaching. Well done – [my child] will be happier with less hospital appointments! I think these joint clinics should be promoted to other units too.”*

multiple chronic conditions. It was devised to make life for families and CYP with two chronic conditions easier by making simple adjustments to our routine practice and working habits. It did not involve extra costs, funding or additional IT packages (the core team members were already in place), just simple adjustment of our clinic arrangements with a pure patient focus. We have been able to adapt our current local services with minimal change to working patterns for our team members and with maximum impact upon our CYP and families. There is no other service like this for children with type 1 diabetes and coeliac disease in the south-west region or even, as far as we are aware, in any other part of the country. The initial service has been extremely successful, and families are fully supportive of it continuing after its 2-year pilot.

In addition to positive feedback from parents (Box 4), our joint clinics were mentioned as a point of good practice in our recent National Diabetes Peer Review in September 2014 and were also highlighted as such to our Trust Executive Board. We are proud to have been commended in the National Quality in Care Diabetes Awards 2015 under the category of best initiative for CYP and emerging adults. The judges “really liked that patients were being consulted and each patient was assessed as an individual and not just part of a programme. It deserves praise for putting the patient at the centre of the initiative.”

**Summary**

Our initiative could easily be replicated in other district general hospitals and the concept could be extended to children with other multiple chronic

conditions. Indeed, our paediatric colleagues in other speciality areas are reviewing their cohort of children to create similar combined clinics for children with long-term conditions. We have shared our work and successful feedback at our regional South West Paediatric Diabetes Network meeting, with positive response. A number of clinical leads have gone back to review their own practice and services, and several units are initiating their own combined clinics. We hope this may extend beyond the south-west region and allow further growth of “mighty oaks” nationally. ■

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