

Setting up a specialist paediatric diabetes sports service

Taffy Makaya, Anne Marie Frohock and Alistair Lumb

The importance of exercise in maintaining health and well-being in children and young people (CYP) with type 1 diabetes is well recognised. However, CYP and their families frequently report obstacles to engaging in sport and exercise, including managing the risk of severe hypoglycaemia, poor skills and precision performance secondary to hyperglycaemia, and difficulties in negotiating the nutritional requirements for optimising growth and sport. The Oxfordshire Children's Diabetes Service has set up a nationally-recognised multidisciplinary paediatric diabetes sports service to encourage and support CYP with type 1 diabetes who participate in sport. We explore the process and challenges involved in establishing the clinic and evaluate its outcomes.

Participation in exercise and sport is important in maintaining the health and well-being of children and young people (CYP) with type 1 diabetes (T1D) (National Institute for Health and Care Excellence, 2016; JDRE, 2018). Exercise in CYP with T1D is shown to have beneficial effects on physical and mental health: reduction in long-term cardiovascular disease risk, reduced insulin resistance, improved blood pressure and endothelial function, reduced glycated haemoglobin (HbA_{1c}) plus improved fitness and sense of well-being (Zoppini et al, 2003; Miculis et al, 2010; Quirk et al, 2014). Getting CYP in general – particularly adolescents – to engage in physical activity is challenging, and research has shown that CYP with T1D tend to be more sedentary and less active compared to their non-diabetic peers (Wilkie et al, 2017). It is recognised that managing T1D and exercise is challenging; CYP and their families report obstacles that prevent them from engaging in

sport (Pivovarov et al, 2015; Jabbour et al, 2016; Riddell et al, 2017). In addition to the barriers reported in the general population, surveys of CYP with T1D highlight a number of additional limitations:

- Fear of hypoglycaemia
- Worrying about under-performing when blood glucose (BG) readings are high
- Families/patients being unsure what to do with diabetes and no-one being available to give advice
- Families/CYP find it hard to have spontaneous fun/exercise due to a need for planning around diabetes.

CYP with T1D who take part in high-level and/or competitive sports may experience these concerns more frequently or severely. Such athletes train regularly – often for long periods at a time – take part in competitions and tournaments, and may travel away from home or family (Griffiths, 2018). All of these factors impact on their diabetes management strategies.

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Article points

1. Exercise is beneficial for children and young people (CYP) with type 1 diabetes (T1D).
2. The Oxfordshire Children's Diabetes Service set up a multidisciplinary paediatric diabetes sports service to encourage and support CYP with T1D participating in sport.
3. Participation in sports clinics resulted in changes in HbA_{1c} outcomes, reductions in hypoglycaemic episodes and high patient satisfaction.

Key words

- Clinic
- Exercise
- Hypoglycaemia
- Sport
- Type 1 diabetes

Author details

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Box 1. Objectives of the sports clinic.

- To establish a multidisciplinary clinic specifically to focus on the management of diabetes in children and young people who are competitive sports people
- To explore in depth the individual challenges faced by each child or young person
- To reduce overall occurrence of hypoglycaemic events in the child or young person
- To optimise blood glucose control during and after exercise – avoiding excessive hypo- or hyperglycaemia and aiming for an improved/stable HbA_{1c}
- To optimise sports performance
- To educate children and young people and their families on the effect of different types of exercise on blood glucose levels
- To provide nutritional advice tailored to each individual’s sporting and physiological requirements.

The Oxfordshire Paediatric Diabetes Service recognised that we have a number of CYP who are ‘elite sports-persons’ who perform competitively and often at regional or national level. Some reported that they were struggling with severe, frequent hypoglycaemia that was affecting their confidence in taking part in sport. A number also noted that their performance was ‘off’ when they experienced high BG levels. We wanted to offer these CYP encouragement and support in pursuing their sporting goals. They needed more than the standard exercise management advice offered during routine clinic appointments, indicating a gap in service provision and the potential need for a more dedicated service.

Planning and implementing a paediatric diabetes sports service


As part of team discussions, the Paediatric Diabetes Service identified members within the paediatric and adult diabetes services with an interest in diabetes sports management. Three individuals then formed a specialist multidisciplinary team (MDT):

- Alistair Lumb, an adult diabetologist with a keen interest in sport outside of work and experience in looking after adult sportspeople with diabetes
- Anne Marie Frohock, a paediatric dietitian and qualified yoga instructor with an interest in sports nutrition
- Taffy Makaya, a paediatric endocrinologist and keen runner with an interest in adolescent medicine.

This MDT held focus-group discussions with other members of the diabetes service to gather ideas on the challenges facing CYP doing lots of sport. The MDT also attended the inaugural UK JDRF Performance in Exercise and Knowledge Conference in 2015 (JDRF, 2015), which provided an opportunity to interact with experts within the field of T1D sports management. Learning opportunities included lectures on the physiology of exercise in T1D, the challenges of – and strategies for – management; and focus group discussions.

Identifying aims and objectives for the clinic

The paediatric diabetes sports clinic was developed with the aims of establishing a supportive



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Diabetes Sports Clinic Referral Guidelines

Please consider BEFORE offering a Diabetes Sports Clinic appointment to youngsters.

The Diabetes Sports clinic has limited capacity and therefore should ONLY be considered for youngsters who are:-

- Participating in multiple sports regularly
or
- Participating in a sport at high level (outside normal curriculum at school)
and
- Motivated to undertake extra BG monitoring around exercise
- Motivated to make insulin dose or carbohydrate adjustments
- Would benefit from specialist advice on how to manage diabetes around exercise

It is NOT for averagely active youngsters who are struggling with hypos during PE or when undertaking general activity.

Figure 1. Sports clinic referral guidelines

Calculating nutritional requirements in very active CYP with T1D can be very challenging (Iafusco, 2006). Paediatric diabetes healthcare professionals have to take into account the energy requirements needed for growth, basal metabolic rate and the increased demands associated with sport, training and exercise (Smart et al, 2018). Ensuring the right type and right amount of nutritional intake, for example avoiding ingestion of large quantities of fast-acting sugar to treat recurrent hypoglycaemia, can be particularly challenging for those trying to maintain their weight for weight category sports or build muscle bulk/strength for power-based sports.

Table 1. Example of an individualised care plan for a young person on multiple daily insulin injections.

Activity: Skating on weekdays			
Duration: 60 minutes	Before	During	After
Time of day: 6.45am			
Time from last meal: 0–90 minutes			
Carbohydrates	First breakfast: aim to consume at least 20 g	No extra carbs needed	GOLDEN HOUR second breakfast: aim to consume 80–90 g, eg cereal and milk AND milkshake
Insulin	No bolus for 20 g of carbs or less Consider giving insulin for higher carb levels	N/A	Give 30% less insulin: either use the exercise setting at –30% or calculate the carbs and then subtract 30% before entering the amount into the meter Do not correct highs
If activity is longer than 60 minutes, consider one of the following before bed: a pre-bed carbohydrate snack (10–30 g) containing fat and protein without bolus insulin OR reducing evening long-acting insulin by 10–20%			
Activity: Skating on Saturdays			
Duration: 2–3 hours	Before	During	After
Time of day: 6.45am			
Time from last meal: 0–90 minutes			
Carbohydrate	First breakfast: aim to consume at least 20 g	20 g per hour for final 2 hours Use dextrose tables/ Lucozade Sport/jelly sweets	GOLDEN HOUR: aim to consume 20 g carbs with protein, eg milkshake Lunch: aim for 80–100 g carbohydrate and protein
Insulin	No bolus for 20 g of carbs or less Consider giving insulin for higher carb levels	N/A	Snack: no insulin Lunch: give 30% less insulin – either use the exercise setting at –50% or calculate the carbs and then subtract half before entering the amount into the meter Consider giving half correction dose with lunch If high
If activity is longer than 60 minutes, consider one of the following before bed: a pre-bed carbohydrate snack (10–30 g) containing fat and protein with bolus insulin OR reducing evening long-acting insulin by 10–20%			

environment within which to nurture CYP's enthusiasm for sport and to empower families and CYP with T1D to become more independent and confident in managing the challenges of sport and diabetes. The specific objectives of the sports clinic are given in *Box 1*.

Clinic set-up

The specialist MDT produced specific referral criteria for the sports clinic, see *Figure 1*. The clinic accepts new referrals up to age 17 years. They produced a pre-clinic letter asking family

members to collect information on BG levels, type of sport/training schedule, hypoglycaemic events, meals and snacks, etc, for several weeks prior to the appointment. The child/young person and their family were given a 40-minute consultation with the MDT during which the individual challenges faced by each child/young person were explored in depth. During this consultation, the MDT completed an individualised care plan with recommendations for insulin dosage before, during and after participation in sport. The CYP's carbohydrate

Table 1 (continued). Example of an individualised care plan for a young person on multiple daily insulin injections.

Activity blood glucose (BG) check			
Blood glucose	Before	During	After
<4 mmol/L	Treat hypoglycaemia before starting <i>You will be more likely to hypo during exercise, so check BG more frequently</i>	Treat hypoglycaemia and recheck BG has stabilised before continuing	Treat hypoglycaemia
<5.5 mmol/L	10 g carbohydrate more than plan	10 g carbohydrate more than plan	Check BG regularly and continue with plan
5–10 mmol/L	Continue with plan	Continue with plan	Continue with plan
10–14 mmol/L	Delay carbohydrate by 20–30 minutes	Delay carbohydrate by 20–30 minutes	Continue with plan +: – Anaerobic exercise: consider half the usual correction dose. – Aerobic exercise: consider 25% of the usual correction dose
>14 mmol/L	Check for ketones and manage high BG before starting activity	Check for ketones and manage high BG before continuing activity	Check for ketones and manage high BG
Ketones	Before	During	After
<0.6 mmol/L	– Anaerobic exercise: consider half the usual correction dose – Aerobic exercise: hydrate well, delay carbohydrate intake by 20–30 minutes, start activity. Check BG frequently	– Anaerobic exercise: consider half the usual correction dose – Aerobic exercise: consider 25% of the usual correction dose	– Anaerobic exercise: consider half the usual correction dose – Aerobic exercise: hydrate well, delay carbohydrate intake by 20–30 minutes, start activity. Check BG frequently
>0.6 mmol/L	DO NOT EXERCISE. Follow correction doses for ketones	DO NOT EXERCISE. Follow correction doses for ketones	DO NOT EXERCISE. Follow correction doses for ketones
Estimated nutritional requirements (calculated based on the energy requirements for growth and exercise)			
Assuming 5 figure skating sessions, 2 dance sessions, 1 body-conditioning session and 3 hours of other exercise per week:			
Daily energy requirements	3,071 kcal/day		
Daily carbohydrate	418 g/day		
Daily protein	64 g/day		
Daily fluid	1,800 ml/day		

and/or protein intake was tailored to their specific needs, see *Table 1* for an example. Copies of the sports clinic letters and plans were sent to the parents and CYP, their GP and the patient's diabetes specialist nurse for information. The families were supplied with Anne Marie's email address as well, in case they needed additional support or the clarification of plans. The MDT piloted the first diabetes sports clinic in 2014 and received very positive feedback and led to the establishment of a regular clinic.

In addition to establishing a regular clinic, the MDT developed family information leaflets for children on multiple daily insulin injections and on insulin pumps, focusing on how they can manage exercise/sport (available at www.ouh.nhs.uk/childrens-diabetes/information/default.aspx).

Family-centred education days were established. These were targeted at sharing information with parents/carers and CYP on the physiology of exercise in T1D. Motivational speakers gave

presentations at these events. The team also shared information with their peers and colleagues at national and regional training days, such as British Society for Paediatric Endocrinology and Diabetes, JDRF Discovery and National CYP Diabetes Network days.

Monitoring outcomes

Attendance and satisfaction

Over the initial 2.5-year period, a total of 20 appointments were offered for the specialist diabetes sports clinic. The attendance rate was 90%, as two individuals did not attend their appointments. The 18 families and CYP with T1D who were seen were sent questionnaires with a covering letter and self-addressed return envelope to gather feedback about their experiences. The questionnaire form was anonymised to encourage free and open responses. There were seven questions, see *Box 2*. The first six questions offered a choice of five responses from 'very satisfied/strongly agreed' to 'very dissatisfied/strongly disagreed'. The last question had a 'yes' or 'no' response. There was also space for free text comments.

Fourteen forms were returned, representing a 78% response rate. Of the responses:

- 86% of families were 'very satisfied' or 'satisfied' with the pre-clinic information (including details of the information that would be useful for them to collect prior to coming to the appointment)
- 100% of families were 'very satisfied' or 'satisfied' with the length of the clinic appointment (40 minutes), the knowledge of the MDT, and found the discussion in clinic useful
- 93% of families 'strongly agreed' or 'agreed' that they were able to make improvements to their child's care using the information provided in the diabetes sports clinic. The remaining 7% 'neither agreed nor disagreed'.
- 100% of families were very likely or likely to recommend the clinic to family or friends who had CYP with T1D.
- 93% of families believed that they would benefit from a follow-up appointment.

The free text responses were very positive, see *Box 3*. The feedback received was used to inform future plans for changes to the service.

Box 2. Feedback questionnaire sent following attendance at the sports clinic

1. Were you happy with the pre-clinic information you received? (This included a letter with details of the information that would be useful for you to collect prior to coming to the appointment.)
2. Your appointment at the Sports Clinic was 40 minutes long. Did you feel this was enough time for your consultation?
3. Did you feel that the knowledge of the Sports Clinic team was adequate?
4. Did you find the discussion during the Sports Clinic useful?
5. With the information you received in the Sports Clinic, were you able to make some improvements to your child's diabetes care around sport/exercise?
6. How likely are you to recommend the Sports Clinic to your family or friends with type 1 diabetes?
7. Do you think you would benefit from a further/follow-up Sports Clinic appointment at some point in the future?

Box 3. Free text comments provided by families

- We would like to thank everyone for their time and support at the Sports Clinic. We were able to go for our football tour with more confidence and having the Dexcom has been invaluable.
- A really useful session – not just because of the contact of the meeting but because it was extremely motivating for our son and because the discussion took a very holistic approach. THANK YOU VERY MUCH!
- Very useful to discuss the specifics of my daughter's sporting activities as well as general knowledge.
- Thank you!
- It was great to be reassured that we are doing everything correct. ***** always comes out of the appointments very positive, which is great. Some of the explanations helped me to understand why each session is different!

Blood glucose control

We compared the number of hypoglycaemic episodes – blood glucose <4 mmol/L, as measured by finger prick meters – in patients in the 3 months before and after attending their diabetes sports clinic appointment. (In our service, continuous glucose sensor values <4 mmol/L have to be confirmed by a finger prick check.) Data were retrieved from Diasend® downloads, and paired data were available for 16 of the 18 patients who attended the sports clinic. There was a reduction in hypoglycaemic episodes in 10 of the 16 patients (63%), see *Figure 2*. Hypoglycaemic episodes were seen more frequently in patients taking part in endurance sports/activities.

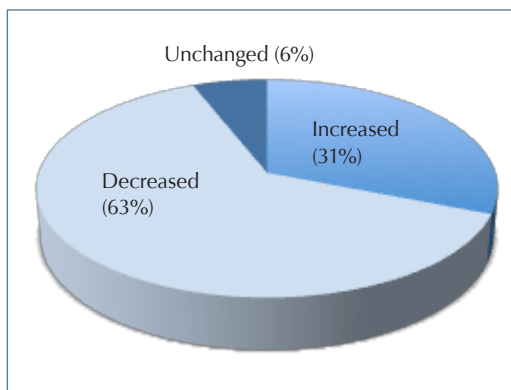


Figure 2. Effects on hypoglycaemic episodes in the 3 months following the diabetes sports clinic appointment

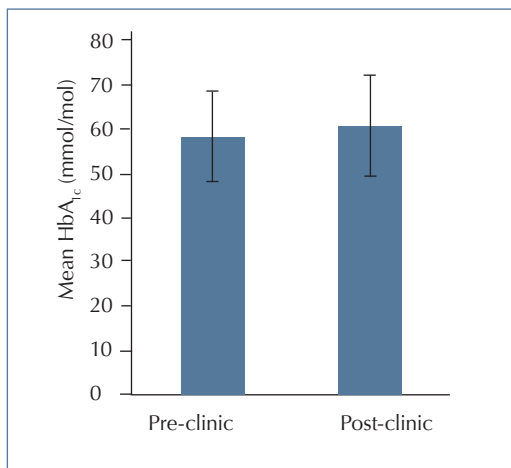


Figure 3. Mean HbA_{1c} (\pm SD) 3 months before and after the clinic appointment (n=17)

Average HbA_{1c} prior to the clinic appointment was compared to the HbA_{1c} in the 3–4 months after the clinic appointment for the 17 patients we had data for, see *Figure 2* and *Figure 3*. The results showed that, despite the reduction in hypoglycaemic episodes there was no significant rise in HbA_{1c} for the group, with an average pre-clinic HbA_{1c} of 58.3 mmol/mol (7.5%) and post-clinic HbA_{1c} of 60.9 mmol/mol (7.7%).

Future plans for service growth

Response from patients and families and the local NHS foundation trust has been encouraging. As a result, improvements have been made to the service. The number of clinics has been increased from two to four a year, doubling capacity. This means that the MDT now has the capacity to offer

follow-up appointments to review progress, and to accept out-of-area referrals from the Thames Valley Network, which has generated extra income.

Despite improvements, there are ongoing challenges faced by the service. The MDT has been approached by other healthcare professionals from the region who would like to join us and sit in during clinics as a learning opportunity, but this has not been possible so far due to limited space. There are also issues around the provision of funding to cover staff education and training. Staff members have made adjustments to their job plans to account for this new service. Negotiating this in the absence of substantial extra income can be challenging, which is why it is important to have the support of the extended team.

Discussion

It is important within clinical practice to identify areas of need or areas for potential growth. The Paediatric Diabetes Service and MDT has recognised the importance of empowering families and CYP with T1D who are actively engaged in high levels of sport and training by providing targeted education in a number of areas, such as:

- The effects of different forms of exercise, such as aerobic *versus* anaerobic exercise, resistance *versus* cardiovascular workouts, endurance *versus* high-intensity workouts, on the body of the CYP with T1D and his/her BG readings
- Strategies for preventing sports-related hypoglycaemia
- Preventing/minimising high BG, which can have a negative impact on concentration, coordination and decision-making – all critical skills when taking part in sport at a high level
- Balancing the nutritional and metabolic requirements of growth, diabetes and exercise.

This level of input and education is difficult to provide within a general diabetes clinic setting. By establishing a separate sports clinic, the MDT is able to focus on sport and provide specific teaching and expertise to meet the needs of participating CYPs and their families. There have been very positive results from this initiative, including excellent user uptake, reduction in hypoglycaemic episodes, and increased confidence

in self-management of diabetes around sport and exercise. These results led to the Oxfordshire Diabetes Sports Service receiving a commendation award at the 2016 National Quality in Care Awards, in the category for Diabetes Team Initiative of the Year.

Conclusion

Sport and exercise in CYP T1D have recognised benefits but several barriers exist. A service gap for a dedicated paediatric diabetes sports service was identified and a specialist, MDT approach to managing sports and diabetes instigated that has resulted in improved outcome measures. This clinic can serve as a reference for other centres setting up a similar, specialist service.

Establishing a new service can be time-consuming and logistically challenging; however, with dedication and commitment it is possible. It is important to have a clear plan, aims and a strategy for implementing the proposed service. It is also recommended practice to audit work and actively seek feedback. The authors believe in sharing practice and ideas to encourage the growth of services within other teams. ■

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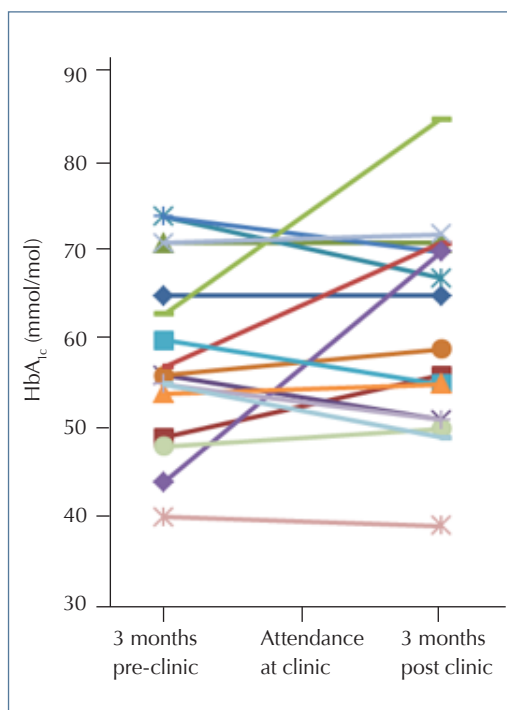


Figure 4. Individual variation in HbA_{1c} before and after participation in the sports clinic

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