# 'Pump school' – a structured education programme to empower children and young people using insulin pump therapy

*R Thompson**

## Abstract

**Background:** Caring for children and young people with diabetes is a complex process that must be firmly focused on the child or young person and their family and/or other carers, supported by the skills and experiences of a wide range of healthcare professionals. Continuous subcutaneous insulin infusion (CSII) is increasingly offered as a safe and effective alternative to multiple daily injections (MDI), yet its success depends on more than the technology itself. In partnership with families, the University College London Hospitals' diabetes team has developed a pathway that uses a series of pre-defined competencies, together with an innovative psycho-educational programme (Pump school), to promote engagement, motivation and flexible self-management, and facilitate successful transition to CSII.
**Method:** Mixed methods were applied for the development of the programme and its evaluation in terms of treatment regimen, $HbA_{1c}$ levels and rate of DKA between 2004–2008.
**Conclusion:** The programme is delivered in a clinic setting and has delivered promising improvements in self-management, psychological adjustment and long-term metabolic control. Its effectiveness is supported by significant improvements in clinical outcomes data, while acceptability to families is strongly supported by regular audit studies.

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## Key Words

Continuous subcutaneous insulin infusion (CSII); structured education; pump school; competencies; diabetes

## Introduction

Continuous subcutaneous insulin infusion (CSII) is increasingly being used as an alternative to multiple daily injections (MDI). CSII, which is also known as insulin pump therapy, is an external, programmable, battery-powered pump that incorporates a small reservoir of rapid-acting insulin (NovoRapid®, Humalog Lispro® or Apidra®). Insulin is administered continuously over 24 hours (basal insulin delivery) via a subcutaneous catheter, which is inserted manually every 2–3 days. Additional insulin is intermittently 'bolused' when carbohydrate is eaten or to correct high blood glucose levels, by pressing buttons on the pump device.

The CSII technique has gained increasing popularity among young people and their families living with diabetes; its safety and efficacy in children and adolescents is well established.[1–3] This treatment option is offered in most European countries and the USA.[4] However, in the UK population with type 1 diabetes, only approximately 1% of adults and 0.1% of children use insulin pumps.[4] There are therefore limited examples of good practice in pump initiation and delivery in UK paediatric centres.

## Authors

**R Thompson,** RSCN, BSc, MSc, Clinical Nurse Specialist – Diabetes Child & Adolescent Services, London, UK

***Correspondence to:**
R Thompson, Clinical Nurse Specialist – Diabetes Child & Adolescent Services, 6th Floor, Central, 250 Euston Road, London, NW1 2PQ, UK
e-mail: rebecca.thompson@uclh.nhs.uk

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## Pre-pump education

In 2004, the author received an educational support grant that enabled visits to diabetes centres in Yale, Connecticut (USA) and Uddevalla (Sweden), both of which are ack-nowledged as leading centres of excellence in pump therapy. Observed practice from these visits was integrated with an extensive systematic literature review,[5] from which a multi-disciplinary structured education pump pathway – specifically designed for a UK paediatric and adolescent clinic population – was created.

Our Pump school has been developed in partnership with families, with the objective being to facilitate and empower young people of all ages to manage their diabetes to the best of their abilities. The team offers each family a comprehensive multidisciplinary assessment prior to taking the first steps on the pump pathway. This pathway focuses on achieving a defined level of competency prior to commencing insulin pump therapy, using eight competency levels described by Kaufman *et al* (Table 1).[6] Taking this approach ensures that the psycho-educational programme is delivered in a flexible and developmentally appropriate manner, and identifies targets and goals that require input and support from the multidisciplinary team.

Assessing attitudes to self-injection is an important part of the pathway as,

| Competency | Characteristics | Level |
|---|---|---|
| Safety | Initial information, injections, blood testing, treatment for hypoglycaemia | 1 |
| Basics | Blood glucose targets, actions for levels out of target, glucagons, action of different types of insulin, diet and carbohydrates | 2 |
| Carbohydrate management | Determine quantity of carbohydrates in food, use of plan for carbohydrate intakes | 3 |
| Correction | How to correct blood glucose out of target | 4 |
| Daily changes | Decision making about changes in daily routine adjusting insulin and carbohydrate intake | 5 |
| Base dose adjustment | Making base dose adjustments, review blood glucose values to observe overall effects of treatments | 6 |
| Advanced diabetes management | Understand hormone pathways and food absorption; know about strategies to reduce complications | 7 |
| Maximised control, basal and bolus therapy | Independence in MDI/CSII to maximise control, flexibility and freedom | 8 |

**Table 1.** Competency Level Scale used with clients prior to commencing insulin pump therapy[6]

in contrast to expectations, needle fearfulness has been identified as a factor that is predictive of poor metabolic control.[7] It is likely that this fear is more complex than simply being a needle phobia, since children who were identified as being needle fearful were the only participants who consistently missed bolus doses on an insulin pump; several gave fewer than three bolus doses per week.[7] Prior to starting on an insulin pump, all young people – regardless of age – are expected to wear a demonstration pump which uses saline. In addition to evaluating how well a young person copes with being 'attached' 24 hours a day, this enables people to be observed for (or self-report) any anxiety that they have about cannula insertion. Younger children who are identified as being upset by this procedure then have several follow-up sessions with a play therapist, who use favourite soft toys with pretend pumps, story books incorporating diabetes, and introduce the idea of rewards (such as sticker charts). Children and young people are also offered psychological intervention, where they and their parents can further explore attitudes to needle fearfulness. Using solution-based therapy, incorporating approaches from narrative therapy, families focus on what worked in the past, describe a preferred future and use scaling to identify where they are in relation to this.[8] Their responses are used to think about how they can get to a point in the future where anxiety will not hamper them.

The nursing team also considers other caregivers who support the child each day, and their training requirements. Between the ages of 5 and 16 years, children spend about 15 000 hours at school,[9] during which time school personnel are primarily involved in supporting them with the demands of diabetes. School staff are invited to join the pump school, but the diabetes nursing team offers to visit the school (together with a parent) prior to each live pump start. This visit provides education and hands-on training, which aims to increase school staff confidence levels, followed by discussion and agreement around individual responsibilities of the parents, teachers, learning support assistants and the young person. For children who are unable to give their own additional boluses, staff members are taught how to use the pump calculator, to determine how much insulin is needed for a correction bolus and/or a food bolus at meal and snack times during the school day. The school is then left with a medical management plan containing written instructions and flow charts, signed by the school, parents and a member of the diabetes team.

## Pump school curriculum

Adequate education, both when commencing pump therapy and during the first couple of years following initiation, is critical. The key to success is to ensure that children and families develop practical strategies to perform day-to-day tasks themselves. Kaufman and colleagues[6] analysed the relationship between a child's developmental stage and initiating pump therapy, concluding that skills emerge first, followed by knowledge and attitudes. A pre-school child can report their diagnosis and minimally recognise and report hypoglycaemia. A child of 6–8 years of age can perform a finger-prick blood test, state the basics of a nutrition plan and rudimentarily understand hypoglycaemia and hyperglycaemia. By the time a child is 8–10 years of age, he or she should be able to master some of the technical skills, such as how to

unhook the pump and activate a bolus with direction. As children gain some of the cognitive skills that enable them to manage aspects of pump therapy with more independence, they can begin to determine how to balance activity. By 10–12 years of age, a child can be expected to have the technical and cognitive skills to be safe within the school environment. Their knowledge level enables them to start carbohydrate counting and to know how to correct blood glucose levels out of target range. Young adolescents (12–15 years of age) have the cognitive ability to adjust insulin, food and exercise, and to correct abnormal glycaemic patterns. Older adolescents have the knowledge and skills to determine what factors affect basal rates and bolus doses, programme in changes independently and use sick-day protocols without assistance. Although it must be noted that individual differences will affect development and it cannot be assumed that all children will fit neatly into these categories.

Young people and parents complete agreed and negotiated homework tasks as they move along the pathway. On reaching the targets identified in level 5 of the competency scale,[6] groups of two or three age-matched young people are invited to attend Pump school. They receive a written programme, which helps to orientate children and their parents to the session and encourages their participation, by asking them to bring examples of personal experiences with them. Siblings and other interested carers (e.g. nursery/school staff, grandparents) are also invited to attend the 2-day Pump school.

The first day of Pump school consists of basic pump skills training, provided by different members of the team (consultant, dietitian and clinical nurse specialist) and covering:

- Differences between insulin delivery in MDI and CSII
- Importance of glycaemic control and glycosylated haemoglobin ($HbA_{1c}$) in relation to long-term complications
- How to calculate insulin requirements
- Selecting a catheter (also covering needle and catheter length, and approaches to aid the insertion)
- Rewinding and filling the reservoirs
- Blood glucose monitoring
- Suspending and disconnecting the pump
- Basic functions of the pump.

| | 2004 | 2005 | 2006 | 2007 |
|---|---|---|---|---|
| **Twice-daily insulin** | 9.8 ± 0.2 | 9.4 ± 0.2 | 9.7 ± 0.3 | 9.5 ± 0.4 |
| **MDI** | 9.7 ± 0.2 | 9.2 ± 0.2 | 9.2 ± 0.2 | 9.7 ± 0.2 |
| **CSII** | 8.6 ± 0.3 | 7.6 ± 0.2 | 7.4 ± 0.2 | 7.7 ± 0.1 |
| **Total number of samples each year** | 247 | 269 | 342 | 370 |

MDI: multiple daily injections; CSII: Continuous subcutaneous insulin infusion.

**Table 2.** Mode of insulin therapy used and its relationship to $HbA_{1c}$ level

A successful strategy has been for parents to insert the catheter into themselves and wear the pump to see how it feels. Subsequently, they insert (or support the young person to insert) a catheter and attach it to a pump delivering saline, in order to practice safe usage for the next seven days.

After this period, young people and families return for the second training day to learn advanced features including:

- Recognition and treatment of hypoglycaemia
- Recognition and treatment of hyperglycaemia
- When to give subcutaneous insulin via a pen device
- Illness management and ketones
- Effect of activity
- Advanced functions of the pump
- Troubleshooting and alarms.

## Post-pump education

Insulin is initiated at the start of the second training day. Blood glucose levels are checked throughout the day and initial changes to the basal rate are made. Young people are instructed how frequently to test their blood glucose levels, and have access to 24-hour nursing/medical telephone cover during this time.

Healthcare providers need to be aware of the wide variation in time required for parents to feel comfortable – and then competent – in using CSII to manage their child's diabetes. Families are contacted at least once daily for the first two weeks, to allow a period of adjustment and consolidation of knowledge. Conversations around blood glucose trends, insulin alteration and problem solving have been useful in supporting families to determine dose adjustment. Families are encouraged to lead these conversations and make suggestions of changes that they think are necessary.

We also offer annual education days for all young people on insulin pumps, which provide a range of information and additional education as well as peer support.

The Pump school curriculum and its delivery have been developed over a 5-year period. Feedback from structured questionnaires and regular audits[10] has enabled the team to incorporate comments and ideas from children, young people and families into the current Pump school format. Seventy children and young people have commenced insulin pump therapy, 55 of whom have attended the Pump school.

Quarterly measures of glycaemic control (using $HbA_{1c}$ levels), which are

| | % of patients |
|---|---|
| **Twice-daily insulin (n=6)** | 19.4% |
| **MDI (n=59)** | 23.7% |
| **CSII (n=39)** | 65.9% |

**Table 3.** Percentage of patients hitting target $HbA_{1c}$ levels (<7.5%) by mode of insulin therapy (January–March 2008)

collected in the diabetes clinic, demonstrate the benefits of using CSII therapy. Analysis of data from 2007 (99 CYP, BD n=15; MDI n=45; CSII n=39) showed $HbA_{1c}$ levels to be significantly lower in the CSII group ($p<0.001$) compared with children on other insulin regimens. In addition, children on the pumps used lower dosages of insulin ($p=0.01$) than children on other regimens. Improved $HbA_{1c}$ levels seen in the CSII group were also sustained over time (Table 2), and 65.9% of young people on insulin pumps hit target $HbA_{1c}$ values (<7.5%; Table 3) and experienced fewer episodes of severe hypoglycaemia.

Research into CSII identifies the potential increased risk of developing diabetic ketoacidosis (DKA), with DKA rates in the literature varying from 2.7–9 episodes per 100 patient years.[11–14] In contrast, our internal audits show our current rate of DKA to be 0.04 episodes per 100 patient years.

The team responds to individual learning needs using telephone, e-mail and clinic appointments. Annual reviews invite families to focus on how moving to CSII supports the use of strengths, abilities and res-ources in self-management (including how to recognise trends in blood glucose levels and how these relate to the management of basal and bolus insulin dosages). Families who have participated in the Pump school increasingly demonstrate the ability to alter insulin independently and safely, with appropriate evaluation following blood glucose monitoring.

## Conclusions

As a clinical team we are aware of how young people and families are demonstrating more proactive self-management, increased responsibility for self-care choices, greater contributions to clinical decision making and setting the focus at follow-up clinic appointments, identifying solutions to deal with challenges that they might face.

The pump school is an innovative and effective patient-centred approach to care. The structured educational programme that we have developed appears to empower children, young people and families who use insulin pump therapy. The effectiveness of this programme is supported by significant improvements in clinical outcome data, and its acceptability to families is strongly supported by regular audit studies.

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## Conflict of interest statement

None

## References

1. Berghaeuser MA, Kapellen T, Heidtmann B, *et al.* Continuous subcutaneous insulin infusion in toddlers starting at diagnosis of type 1 diabetes mellitus. A multicentre analysis of 104 patients from 63 centres in Germany and Austria. 2008. *Pediatr Diabetes* doi:10.1111/j.1399-5448.2008.00416.x.
2. Kaufman FR, Halvorson M, Carpenter S, *et al.* Insulin pump therapy in young children with diabetes. *Diabetes Spectrum* 2001; **14:** 84–89.
3. Pickup J, Mattock M, Kerry S. Glycaemic control with continuous subcutaneous insulin infusion compared with intensive insulin injections in patients with type 1 diabetes: meta-analysis of randomised controlled trials. *BMJ* 2002; **324:** 705–708.
4. Department of Health. Insulin Pump Services – Report of the Insulin pump working group. 2007. London: DoH.
5. Thompson, R. The relationship between education, support and the success of CSII initiation in children, young people and their families: A review. 2005 City University.
6. Kaufman FR, Halvorson M, Miller D, *et al.* Insulin pump therapy in type 1 pediatric patients: now and into the year 2000. *Diabetes Metab Res Rev* 1999; **15:** 338–352.
7. Maniatis AK, Toig SR, Klingensmith GJ, *et al.* Life with continuous subcutaneous insulin infusion (CSII) therapy: child and parental perspectives and predictors of control. *Pediatr Diabetes* 2001; **2:** 51–57.
8. Christie D. Dancing with diabetes: brief therapy conversations with children, young people and families living with diabetes. *European Diabetes Nursing* 2008; **5:** 28–32.
9. Llahana S, Poulton BC, Coates V. The paediatric diabetes specialist nurse and diabetes education in childhood. *J Adv Nurs* 2001; **33:** 296–306.
10. Christie D, Romano G, Thompson R, *et al.* Attitudes to psychological groups in a paediatric and adolescent diabetes service: Implications for service delivery. *Pediatr Diabetes* 2008; **9:** 388–392.
11. Boland EA, Grey M, Oesterle A, *et al.* Continuous subcutaneous insulin infusion: a new way to lower risk of severe hypoglycaemia, improve metabolic control and enhance coping skills in adolescents with type 1 diabetes. *Diabetes Care* 1999; **22:** 1779–1784.
12. Weissberg-Benchell J, Antisdel-Lomaglio J, Seshadri R. Insulin pump therapy. *Diabetes Care* 2003; **26:** 1079–1085.
13. Bode BW, Tamborlane WV, Davidson PC. Insulin pump therapy in the 21st Century: Strategies for successful use in adults, adolescents and children with diabetes. *Postgrad Med* 2002; **111:** 69–77.
14. Pickup J, Keen H. Continuous subcutaneous insulin infusion at 25 years. Evidence base for the expanding use of insulin pump therapy in Type 1 Diabetes. *Diabetes Care* 2002; **25:** 593–598.