

1. I agree on the whole that access to pumps for children is limited only to pushy parent advocates.
2. There seems to be no mandate to keep Paediatric Diabetic Consultants apprised of new treatments. Training must begin from the top down, not from the parents up as seems to be the case currently.
3. Hence, the UK has a disproportionately small population of pump users relative to other countries.
4. In the cost analysis, no reference is made to use of public funds and benefits (i.e. Children With Disabilities, school statements) to support parents of diabetics. These costs would be lower for parents of pumpers not needing to go to school to give injections, accompany school trips, or have statemented carers in their children's schools.
5. Failure to achieve good control for one year on MDI is not the best criteria for switching to CSII. A lot of time and effort is wasted.
6. No mention is made of reduced dental intervention in pumpers not requiring night time glucose.

I have attached my personal statement which includes some of the above thoughts.

Regards,

[REDACTED]

[REDACTED]

I was chatting with another pump user and his mum yesterday and we all
> commented that in the UK the pump was seen as the 'last option' (he was
> given the option of a pump at diagnosis, and 10 days training - overseas of
> course).

> In the UK one has to have 'failed' after things like DAFNE and MDI. That
> NICE also allows for pump withdrawal is disturbing and immoral IMO. If they
> tried to withdraw mine, I would consider every option including a legal
> challenge under the Human Rights Convention (knowingly causing a deterioration in
> health must contravene this, surely?), MP's, MSP's and the press. NICE needs
> updating. Insulin Pumps should be the FIRST line of defence, NOT the
> last, so when a person is diagnosed with type one, THEY get the option of MDI or
> pump and sufficient training on diabetes management. (I feel another letter
> to my MSP coming on)

>

> Anyway - we all know the benefits:

> Less injections

> Less pain

> Better hypo awareness

> Fewer hypos

> Much improved HbA1c (and reduced risk of complications, reduced misery,

> costly admissions etc)

> Better flexibility

> Not having to feed hypos for sport, alcohol (so better weight management

> is possible - although I gained half a stone as am no longer peeing out

> sugar, but that's another story, & it's back to the exercise bike)

> Better management of illness/ exercise and other changes with temp basals

> and patterns

Regards,

[REDACTED]

In general terms the study appears to be thorough, taking into account a wide range of factors and views. It pays attention to concerns of parents and although

understandably driven by fiscal factors the findings acknowledge the impact of pump use and MDIs in relation to quality of life and specifically empowerment of the individual.

The report acknowledges the key role played by CWD. This bears out our personal experience; most of what we knew about pumps before we entered dialogue with our NHS support team we learned from [REDACTED] and the CWD community. CWD offers important community support with real-life, real-time case studies and shared personal experience. This is vital in a situation where concerned parents and worried users are struggling with new technologies and face a new set of questions and challenges. The shared personal experience of long term (more than two years) users cannot be easily replicated for healthcare professionals through training. The set up is not for everyone; it is e-mail/ web access based. But for those for whom this is accessible it is an important part of the learning process for pump use/ management.

The criteria by which success - or otherwise - of pump use is measured is primarily the **lowering of HbA1C levels**. Our experience of switching, at first to MDIs and latterly to use of a pump, shows a quantitative reduction in HbA1C levels well in excess of the minimum levels required (1.0 mmols). This appears to be the case in most - but not all - cases so far trialed. The use overall of **less insulin** in treatment/ management of T1DM to be an important factor. **Reducing episodes of hypoglycemia and hyperglycemia** is another measurable target when considering pumps and MDIs. Since Phoebe started using the pump we have noted a marked reduction in both extremes, something that has allowed Phoebe more flexibility in her lifestyle choices and improved her quality of life.

Wider conclusions in the report bear out factors recognised for some time in the T1DM community in the UK.

Namely that **support generally for the use of pumps in the UK is shockingly poor** - all the more deplorable when one considers a majority of pump research was conducted in this country. In our view children should be placed on a MDI or pump regime on diagnosis - or at least at the cessation of the co-called 'honeymoon' period - as a matter of course. It is no longer in question that these forms of treatment essentially - and again in *most* cases - reduce HbA1C levels. Whilst pumps do not suit everyone they are, where the opportunity to use them arises, overwhelmingly beneficial not only to sufferers of T1DM but also to their primary and key carers - parents, teachers and fellow students.

Our personal experience bears this out. Phoebe has used the Medtronic Paradigm pump for eighteen months. After an initial 'settling in' period - surprisingly short - she became, at aged eleven, both comfortable and proficient with its use and routine. The freedom of lifestyle choices - being able to attend functions with previously unmanageable/ unsuitable eating arrangements such as parties or school outings - has been as important to Phoebe as reducing her HbA1C. Quality of life is of high importance to sufferers and primary carers, and we are pleased that the report takes this into account. We all understand the need to drive down HbA1C levels and the long-term benefits that delivers. When NICE is looking to cost the effects of reduced HbA1Cs it must consider the life-long reduction in costs to the NHS via reduced complications across the board. But the quality of life factor adds to that benefit; freedom to exercise and participate in an active lifestyle are key factors in maintaining general health in T1DM patients. The fine control delivered by skilled pump use enables users to enjoy flexibility in eating and exercise schedules, increasing the opportunities to keep fit. Phoebe dances competitively, training on average three nights and one day a week, with regional and national competitions every three or four weeks. Using a pump has helped create a level field for competition, reducing the likelihood of hypo's and again

allowing her more flexibility to train and compete, sometimes over a day-long program. These benefits are less easy to measure than blood sugar levels; but they are just as important in the short and long term.

One area of concern raised in the report is the requirement for additional training for healthcare professionals. Obviously if pumps were made more readily available - and again, it is clear to those of us fortunate enough to be able to use pumps that everyone should have access to this form of treatment - then more NHS staff will need to be trained in the operation and management of pumps and set change operations. Speaking from our own experience, and acknowledging that a certain fundamental understanding of the operating and support platform is required by healthcare staff, it is the primary carer - or, in the case of teenagers/ young adults, the user - who requires the most intensive training. Again it is important to acknowledge the vital role played by community support groups. In our case we receive excellent support from our diabetes team at the Alex (Children's hospital) and particularly from the community nurses, but the most valuable day-to-day help comes from fellow carers and users via the CWD network. When Phoebe first expressed an interest in using a pump, and we started the process of trials and application through our PCT, the doctor at the Alex was as much in the dark about the value - and operation - of pumps as we were. We've learned together, along with the nurses, about working with the pump. Even with this gradient of learning curve we have found the process relatively straight forward and the results have exceeded our initial hopes and expectations. It is important to us that the NICE report has considered and acknowledged that the T1DM community has an experienced support community in place to aid the widespread integration of better controls via pump technology.

In summary the NICE report appears to give a detailed, realistic and balanced view of where we are and the criteria for proceeding on an expanded program of pump use. It should be highlighted that we are lagging far behind other countries in our use of pump technology available today. Furthermore, with valuable research ongoing into closed loop systems and as technology advances towards a true artificial pancreas we must ensure that T1DM sufferers in this country are at least up to speed with current available apparatus, and that means biting the budget bullet and making the technology - and support - available on a wider and more equitable scale.

The technological learning curve can only increase - for users, carers and healthcare professionals - and generations will be unable to take advantage of the advances yet to come.

We hope this commentary proves useful and you are able to pass on some of our remarks.

Please feel free to contact either of us for clarification or further comment at any time.

Kind regards

A black rectangular redaction box covering the signature area.