

Parents' perspectives on the provision of glucagon injection kits for the treatment of hypoglycaemic events

Paula Maiden

When her daughter had a severe hypoglycaemic episode, the author, who is also a parent representative for the Families with Diabetes National Network, was thankful that they had a glucagon injection kit and knew how to use it. After reflecting on the incident, a survey was developed to establish whether other parents had access to the kit and felt that they had adequate training in its use. This article presents the results of the survey and questions why there should be any resistance to making the kits available. The author cites NICE guidelines and argues that parents and schools should always be prepared to treat a hypoglycaemic event and should always carry the kit. She calls on diabetes teams for support to make sure that every parent and carer feels able to act in an emergency.

The Families with Diabetes National Network (FWD NN) is the parent reference group linked to the National Children and Young People's Diabetes Network which aims to bridge communication between the network and parents of children and young people with diabetes. There are eleven regional networks across England and Wales that make up the national network. The Paediatric Diabetes Network Coordinator for each region recruits a minimum of two parent representatives who attend the regional network meetings to represent the views of families living with diabetes. The network's focus is very much on the whole family as the ripples of living with diabetes reach far, affecting all members.

Each network region has its own Facebook group, which not only enables representatives to make contact with as many families as possible, but also for the families to make contact with and find support from each other. The regional network pages are going from strength to strength and a growing number are now organising regular meet ups for the families, with speakers, activities and,

perhaps most importantly, the opportunity to come together and spend time in a safe environment with others who just understand.

The FWD NN aims to represent and empower families in the paediatric diabetes community, giving them a voice to help bring about change in the areas where they have the most concerns. With this in mind, we have created various surveys and questionnaires in order to gauge opinion from a wide audience. The glucagon injection kit survey, however, was a little different. It came about purely because of my own personal circumstances.

On the next page is a picture of my daughter, Jess. She was diagnosed with type 1 diabetes in September 2007 when she was aged just 15 months. We have been carbohydrate counting since the diagnosis and she has been on a pump since 5 months after diagnosis. We generally maintain good control with HbA_{1c} averaging 51–56 mmol/mol (6.8–7.3%). She had never been readmitted to hospital since her diagnosis, nor had she needed glucagon or experienced any severe hypoglycaemic episodes, despite experiencing some very low blood glucose levels.

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Article points

1. The Families with Diabetes National Network conducted a survey of the provision of glucagon injection kits for the treatment of a hypoglycaemic event.
2. The results of the survey suggested that parents and carers were not always provided with the kits or adequately trained in their use. Only 21% of families carried one at all times.
3. There was resistance from some parents, hospital teams and schools to the kits being kept and used in schools, despite NICE recommendations. This situation could be improved with more training and support.

Key words

- Care in schools
- Glucagon kits
- Hypoglycaemia
- NICE guidelines

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In August 2014, however, Jess experienced her first hypoglycaemic seizure with a blood glucose level of 2.9 mmol/L. Having woken to hear a high-pitched noise coming from her room, we found her to be hypoglycaemic. She began to fit before we were able to raise her blood glucose level. We administered glucagon and called an ambulance. We had managed almost 7 years without needing to administer glucagon, so we clung to the idea that with any luck it would be at least another 7 years before we had to again. Sadly this wasn't the case and, 6 weeks later, we found ourselves having to administer it a second time, this time with a blood glucose level of 4.1 mmol/L, a level at which we had previously felt "safe".

Following this episode, I discussed our experience with other parents on Facebook forums. It led to some worrying responses. There were parents and carers who had been told not to bother administering glucagon and just to phone an ambulance and wait. Others wanted the glucagon injection kit to be made available to them but were denied it, while some had never heard of it before.

In light of these responses, the survey was born with an aim to get a better idea of the availability and accessibility of glucagon for parents and carers. The survey was posted in a number of Facebook groups for families of children with type 1 diabetes and consisted of three questions that respondents could choose to answer if they applied to their situation. There was an overwhelming reaction with 879 responses being received in a period of just 10 days. This was clearly an issue parents and carers felt strongly about.



The author's daughter, Jess.

Results

Question 1: Have your team prescribed a glucagon kit?

The survey showed that 58.5% ($n=514$) of respondents said yes, and they had been trained how to use it; 35% ($n=308$) said yes, but they had not been shown how to use it; and 6.5% ($n=57$) said no, we haven't been given one (Figure 1).

Every family should have access to a glucagon injection kit and be trained how to use it, as advised in the NICE guidelines (2004). These state that children and young people with severe hypoglycaemia should be treated as follows:

- Outside hospital, or where intravenous access is not practicable, intramuscular glucagon or concentrated oral glucose solution (e.g. Hypostop) may be used.
- Parents and, where appropriate, school nurses and other carers should have access to glucagon for subcutaneous or intramuscular use in an emergency, especially when there is a high risk of severe hypoglycaemia.
- Parents and, where appropriate, school nurses and other carers should be offered education on the administration of glucagon.

So, while at first glance it seems positive that more than 90% of families have a glucagon injection kit, a large proportion who have not been shown how to use it are being failed in terms of NICE recommendations. Some parents do not want to

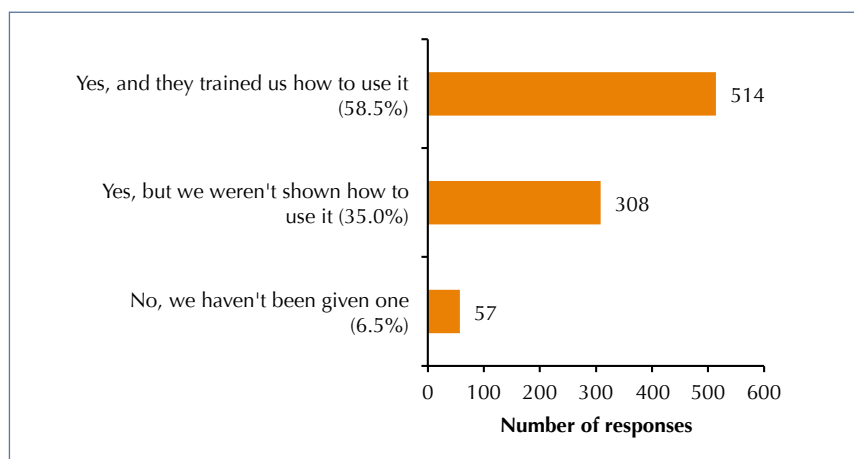


Figure 1. Responses to the question: Have your team prescribed a glucagon kit?

have a kit and are terrified by the thought of having to administer it. Of course, nobody should be made to feel they have to use it, but at least if families are trained they have the option available to them should the need arise. If the training was revisited and refreshed then perhaps that fear of having to use it would also be reduced.

Question 2: Do you carry the glucagon kit with you?

The responses showed that 21% ($n=183$) said yes, always; 54% ($n=465$) said yes, but only if we are travelling any distance from home such as on a day trip or holiday, and 25% ($n=215$) said no, never (although this included a number of responses from those who had responded to question 1 that they hadn't been given one; *Figure 2*).

Only around one fifth of families carried a glucagon injection kit with them at all times and a quarter never carried one. Comments and discussions which followed suggested there was a great deal of confusion over taking glucagon out and about as many families believed, and had indeed been advised by medical professionals, that glucagon must be kept refrigerated at all times. With this in mind, they believed it was not possible to have a kit anywhere but at home. We went about educating as many families as possible through Facebook groups and network pages that the glucagon kit can, in fact, be kept out of the fridge for up to 18 months or until the best-before date, dependent on which occurs first.

It seemed that many of the families who carried glucagon at all times were those who had previously had need to administer it. A large proportion of families felt the need to carry the kit when they were any distance from home or away for any considerable period of time, such as day trips and holidays. It is unclear why families feel safer to travel without it locally, given that should a seizure occur, they are unlikely to be in a position to return home for it. The only option would be to call for an ambulance and wait for paramedics to arrive and administer the glucagon injection. It would seem wise to advise families to carry the kit at all times. It seems odd to be prepared to treat a severe hypo when you are away on holiday, but not if you have just popped to the supermarket. The very nature of type 1 diabetes is that it is unpredictable. There is no way of knowing if, when or where a child may be in need of glucagon.

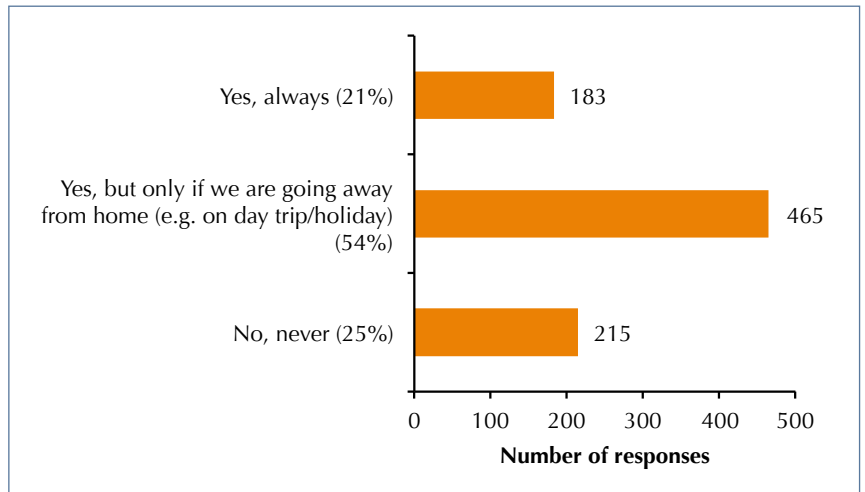


Figure 2. Responses to the question: Do you carry the glucagon kit with you?

As a parent caring for a child with a chronic condition, you regularly question yourself about the way the condition is being managed: Why did this happen? What could I have done differently? What did I do wrong? I only had to see my daughter's hypoglycaemic episode for a few minutes before the glucagon took effect. It would have been far more difficult to have been forced to wait until paramedics arrived before glucagon was administered.

Question 3: Does your child's school have access to the glucagon kit?

The responses showed that 26% ($n=200$) of schools did not and that these parents preferred the school not to have one or to be able to administer it; 22% ($n=173$) said no, as the hospital team won't train them; 10% ($n=78$) said no, the school refuse to have one on site; 19% ($n=151$) said yes, they keep one on site but only to be administered by parents/paramedics as advised by hospital; 8% ($n=63$) said yes, they keep one on site but only to be administered by parents/paramedics as the school refuse to administer it; and 15% ($n=117$) said yes, they keep one on site and have been trained how to administer it (*Figure 3*).

There was a greater variety of answers to this question because of a number of contributing factors. First, parents have to do what they believe to be in the best interests of their children. Sadly, not all relationships between home and school are good ones. It would be naive to suggest that all schools should be prepared to use glucagon, as it is difficult to persuade some to provide the most basic diabetes care.

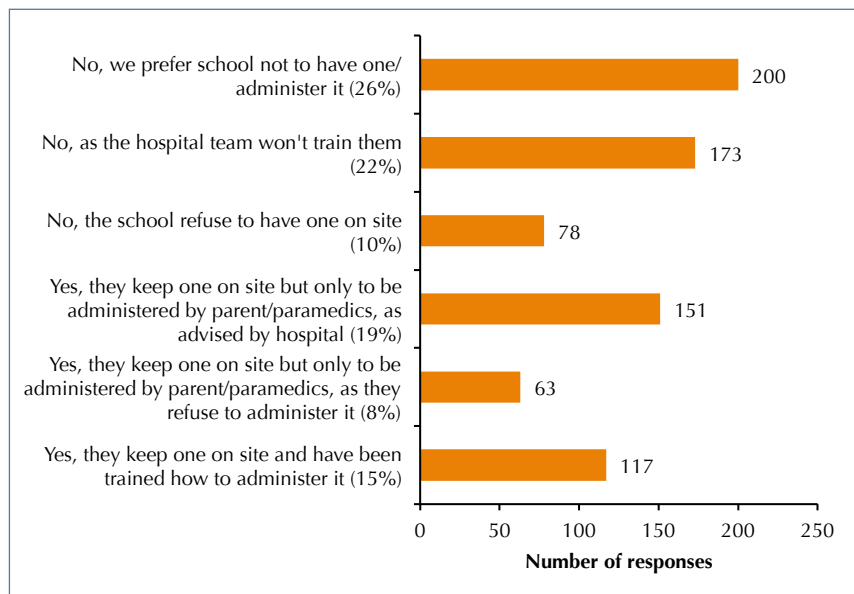


Figure 3. Responses to the question: Does your child's school have access to the glucagon kit?

As demonstrated by the responses, quite a significant number of parents actually prefer that their child's school does not have glucagon available, as they may not have total confidence in the school and would prefer it to concentrate on the basic elements of diabetes care. However, what was surprising was that in twice as many cases, the lack of access to a glucagon injection kit in schools was due to a refusal by the hospital teams rather than the schools themselves. When these teams were questioned further on this, a number of reasons were given. Yet, most of the arguments against training in schools have credible counter arguments:

“We can't keep them [the school staff] up to date on the training”

Why not let the parents train them instead? The glucagon instructions clearly state that friends, family members, work colleagues, etc., should be made aware of the injection kit and when to use it. None of these people, other than possibly the parents, will have had “official” diabetes specialist nurse training. And even when the parents have had initial training, it is rarely refreshed.

“It's safer to just phone for an ambulance and they'll administer it”

Why wait for an ambulance if you have someone on hand willing to give the injection? Surely it is safer to give an injection than to leave a child in a seizure

unnecessarily? And no-one can guarantee how long an ambulance will take to arrive, particularly in busy cities or during rush hour.

“It's dangerous to have in school”

It is far less dangerous, to both the user and the recipient, than an adrenaline pen, which is often accepted in schools.

“It's different from an adrenaline pen because you have to mix the glucagon”

To “mix it”, you simply have to inject the saline then draw back the mixed solution. It can't be mixed incorrectly and you can't overdose or cause harm with it.

“It's too much to expect of teachers”

These are the same people we are trusting to administer insulin to our children, which, done incorrectly, can be far more dangerous and even fatal. It should follow that they can be trusted to administer glucagon.

“There is no reason for them to have it”

The NICE guidelines say different.

Conclusion

The glucagon injection kit was created specifically for non-medical professionals to treat a severe hypoglycaemic episode. The FWD NN believes that it should be readily available for all parents and carers of children with type 1 diabetes, as should training in how to administer it. Over time, parents become the experts in their own child's diabetes. They care for their child between clinic appointments, liaise with schools and make decisions regarding their child's diabetes every day. Where a parent makes a reasoned decision that they would like glucagon to be available to their child during their school day and the school staff are willing, it would be beneficial if the diabetes teams could help to make that happen.

It is, thankfully, rare that such severe hypoglycaemic episodes occur but, from experience, when it happens to your child, numbers and statistics are irrelevant. What matters in that moment is having the ability to do something for your child, and the availability of glucagon provides parents and carers the power to do that. ■

NICE (2004) *Type 1 Diabetes: Diagnosis and Management of Type 1 Diabetes in Children, Young People and Adults* (CG15). NICE, London. Available at: <https://www.nice.org.uk/guidance/cg15> (accessed 10.08.15)