

Out-of-hours services: Results of a survey by the Families with Diabetes National Network

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Citation: Burton A, Fazakerley K (2015) Out-of-hours services: Results of a survey by the Families with Diabetes National Network. *Diabetes Care for Children & Young People* 4: 56–8

Article points

1. Out-of-hours diabetes provision for children and young people varies around the country, with some parents having access to the specialist diabetes team, while others only have access to a non-specialist.
2. A Families with Diabetes National Network survey of 581 parents of children with diabetes found that 16% had 24-hour access to their diabetes team, while others rely on the local children's ward or have other arrangements.
3. While the majority of the respondents (67%) who had used out-of-hours care felt well-supported, others had felt the need to seek further advice from online resources.

Key words

- Hypoglycaemia
- Out-of-hours provision
- Social media

Authors

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The level of out-of-hours provision for paediatric diabetes care around the country varies greatly, with some people able to contact a member of their specialist diabetes team at any time in an emergency and others only having access to their local paediatric ward where the clinicians may not have in-depth knowledge of diabetes management. The Families with Diabetes National Network conducted a survey to find out about parents' experiences of out-of-hours provision and found that in the absence of 24-hour support from the diabetes team, parents who had felt unsupported by the alternative out-of-hours provision would often use social media to seek advice about emergency situations. The authors suggest that a national 24-hour helpline could be set up or 24-hour online support provided to cope with out-of-hours emergencies.

Type 1 diabetes is undoubtedly a 24-hour condition and does not always pick the most convenient time to behave unexpectedly, especially for newly diagnosed children whose families are just beginning to learn how to deal with high and low blood glucose levels, illness, hormonal changes and all the other challenges that a diagnosis of diabetes brings. While some families are fortunate enough to be able to phone their diabetes specialist nurse or consultant at any time of the day or night if they need help, others are less well provided for and may only be able to contact a non-specialist who is unfamiliar with type 1 diabetes.

The provision for out-of-hours services (from 6 p.m. to 9 a.m.) for children with diabetes varies widely across the country and, although some diabetes teams are able to offer access to the team using a rota to ensure there is one member of staff available at all times, others will rely on the paediatric ward or the on-call paediatric registrar.

In order to better understand the way that out-

of-hours services are currently used, the Families with Diabetes National Network conducted a survey through its Facebook groups. The survey was advertised in clinics using posters and some clinics also promoted the survey by email. A range of questions, most of which had multiple-choice answers, were presented, although respondents were able to select "Other" for each question and enter free text. It was not compulsory for all of the questions to be answered. This article presents some of the highlights from the responses.

The survey was completed by 581 parents of offspring with diabetes who ranged from babies to young adults. Of these, 37% ($n=214$) were following a multiple daily injection regimen and 62% ($n=360$) were using insulin pumps either with or without continuous glucose monitoring. The majority (nearly 80%) received their care at their local hospital, with the remaining 20% travelling out of their area for care.

We established that 57% ($n=339$) of

respondents had used an out-of-hours service in their area, while 36% ($n=211$) had never used one and 7% ($n=42$) had used one outside of their area. Of those that had never used one, 57% ($n=121$) had not needed to, 26% ($n=55$) were unaware that it was available and 18% ($n=38$) were sure it was not available.

Naturally, there is concern among healthcare professionals about the timing of out-of-hours calls, so we asked those that had used such a service at what times they had used it. The responses showed that 42% ($n=204$) had called during the evening between 6 p.m. and 10 p.m., 32% ($n=155$) between 10 p.m. and midnight, 20% ($n=98$) between midnight and 7 a.m. and 10% ($n=47$) in the morning between 7 a.m. and 9 a.m.

In order to understand what provision is currently available outside normal working hours, we asked parents what arrangements were in place in their areas. Of respondents to this question, 51% ($n=275$) had been told to call the paediatric ward at their local hospital. Nearly 20% ($n=106$) had to use the on-call paediatric registrar, 16% ($n=87$) had a mobile number that gave 24-hour access to their diabetes team, while the remainder did not know or had other arrangements not covered by the options already described.

Given the picture we had built up, we were interested to learn how parents would seek advice after hours. More than half (55%; $n=300$) told us that they sought advice from social media, mostly Facebook with one mentioning Twitter. While those that had access to 24-hour support were clearly able to contact their diabetes team, the remainder mentioned their local accident and emergency department or children's ward, sometimes with reservations. A few cited a variety of sources of information including friends, NHS Direct, the internet and calling 999. It is worth mentioning that the numbers who said they would use social media is very likely to be higher than in the wider population of families with children with diabetes because of the way the survey was distributed. There was a marked difference between day and night, with 90% ($n=486$) of responses citing their diabetes team as the main source of advice during the day.

The survey also asked about parents' experience of using out-of-hours services. Of those that had

Box 1. A Facebook conversation that helped one parent deal with their daughter's "out-of-hours" hypo (time of conversation about 9 p.m.).

Parent 1: Sorry - me again. We can't seem to get the hypo to go away. She tested at 20:20 and it was 3.2 then she had a Fanta and a biscuit. Tested again a little later and it was 5.6 so she went to sleep but she has just come down now again saying she feels low. Tested and 3.5... ??? What do we do?

Parent 2: Treat again, wait until she has come up then give her a milky drink and a biscuit. Sounds like everything is too high

Parent 2: You need to allow the quick-acting carbs to get into her system before giving her slow-acting ones as they will slow the quick, ones down (if that makes sense).

Parent 1: Ok. Thanks.

Parent 3: Have you been told about the 15 rule for hypos? This is an excellent leaflet by UCLH ([University College London Hospitals] one of the top paed diabetes hospitals in the UK) about hypos <https://www.uclh.nhs.uk/PandV/PIL/Patient%20information%20leaflets/Hypoglycaemia.pdf>

You need to not give the biscuit whilst the Fanta is doing its stuff. Sometimes hypos breed hypos and hopefully this is the last one. Are you giving enough Fanta? (check the leaflet). Don't be tempted to give too much though. Xx

Parent 4: I'd call your DSN in the morning to discuss adjusting your doses. My DS's [son's] insulin needs dramatically reduced not long after dx [diagnosis], and then after a few months steadily started rising again. Is it possible she could be getting a tummy bug? We had that to contend with not long after dx and I couldn't for the life of me figure out why it was impossible to get his levels up!

Parent 1: She had the biscuit after the Fanta The diabetic team had told me to give her a small mini tin of Fanta if she had a hypo

Parent 5: When my son was first dx we were basically having to give him something every couple of hours to keep his levels up. Through constant monitoring of blood sugars and amount of carbs eaten, we could look at certain areas. Her regime may need changing, could be a lot of factors. Treat her hypos for now, monitor and record and refer back to her team tomorrow. Best of luck

Parent 1: I've just given her a small chocolate now

Parent 3: You need to look at how many carbs in the small mini can of Fanta. If it is less than 15 she may need more. The mini cokes are 15 or you can measure out 100 mL of Lucozade, but check the bottle. Did you give the chocolate once she was back up to an ok number? that's not too bad as the chocolate will have a fat content and that should keep levels up a bit xx

Parent 5: You are doing fab

Parent 2: Has she come up ok? Chocolate is slow acting and isn't the best for hypos, she needs Lucozade or glucotabs, jelly babies

Parent 4: Is she already above 4? Chocolate is a good slow-release carb (believe it or not... the fat content slows down the sugar absorption) so if the Fanta has got her above 4, that's fab.) Mini cans of Fanta or coke are just the right size. We use glucose tablets (x3) too.

Parent 1: She has come up to 6.2 now. Should I give her anything else before I attempt to send her to bed for the 3rd time?

Parent 3: She's had the chocolate now. I would test in an hour xx

Parent 2: That sounds fine, maybe test her before you go to bed.

Parent 5: Yes agree re check in an hour, let us know how she is doing

Parent 1: Ok thank you! Will do.

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used the service ($n=388$), 60% ($n=234$) felt they were well supported. However, the remaining parents felt less supported, commenting that it depended on who they spoke to and the level of knowledge that the person had. When asked if they were confident in the advice they received, 32% were not confident. Their explanations included the following:

“They did not know what to do when his levels were high.”

“Non-specialist nurse. However, she phoned someone who knew more than she did and got back to me.”

“This particular nurse had no knowledge of it whatsoever and openly admitted it.”

“The children’s ward were not very knowledgeable about type 1, they waited to speak to the PDSN [paediatric diabetes specialist nurse].”

“He had very basic knowledge as he was a general kids’ doctor not a diabetes specialist.”

“He told me he had limited knowledge on type 1.”

“I could even hear them turning the pages in the sick-day rules booklet as they read it out word for word!”

Most (73%; $n=99$) of those who had said they had not felt supported by the out-of-hours service had sought further advice using Facebook or the Children with Diabetes mailing list, which also has a group on Facebook. The use of Facebook for out-of-hours advice naturally concerns healthcare professionals, but it can be a source of reassurance and advice if used properly. Not all advice will be accurate, but there is a self-regulating tendency in well-moderated groups with many parents responding to an initial post to build up a plan of action and offer support. A recent conversation which is typical of the use of Facebook for out-of-hours advice is shown in *Box 1*.

Our last question was: “If there is one person you would like to be available out-of-office hours,

who would it be? Please put these in order of preference.” The order of preference of the five options provided (shown below) clearly illustrates that parents need expert advice, yet more than 50% of our respondents had been given the paediatric ward number for out-of-hours calls:

1. PDSN.
2. Paediatric diabetes consultant.
3. Medical professional trained in type 1 diabetes.
4. General paediatric consultant.
5. Children’s ward.

Conclusions

After reading all of the comments submitted and looking at the data, we concluded that there is clearly a need for more robust out-of-hours advice for families with children with type 1 diabetes. Target HbA_{1c} levels are getting lower, yet fear of hypoglycaemia remains uppermost in the minds of parents, especially at night time. It is not surprising that, given these fears and the perceived lack of professional support, many families choose to run blood glucose levels higher overnight, which makes optimal control difficult. Extremes of blood glucose, both high and low, can result in expensive hospital admissions that could be avoided with better out-of-hours support. Anecdotal evidence suggests that inexperienced ward staff and paediatric registrars might even encourage admissions if they are unable to offer expert advice.

There are many potential innovative solutions to the problem of providing out-of-hours services. Local on-call rotas can be excellent and have worked very well in certain areas. However, a national helpline may appeal to parents especially where no expert advice is available locally out of hours. The growing use of social media by families for out-of-hours support could also suggest another alternative solution for healthcare teams to use the internet to provide real-time online support. Some clinics are already using Skype for consultations and many now have websites where key information can be accessed at any time. There are many new technologies available to the population at large. There could be huge gains to both patient and healthcare professional alike in harnessing them. ■