

ABCD/DTN Conference presentations

The 4 articles which follow are written accounts of presentations at the ABCD Conference and the DTN meeting held in Bristol in September 2024, and have been prepared by the presenters.

Exploring the value of peer support for people living with type 1 diabetes

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Workshop overview

The aims of our workshop were to reflect upon the challenges of living with type 1 diabetes (T1DM) and to use examples of successful peer support to explore how it can help to meet those challenges head-on.

Challenges

Geraldine Gallen began the workshop by looking at the challenges faced on a daily basis by those living with T1DM. Research shows that 180 health-related decisions are taken on average every day by those trying to “keep all the plates spinning” (Figure 1). This figure illustrates just some of those considerations that live permanently in the minds of those with the condition.

In addition to the targets that have to be met in all other aspects of life, targets for HbA_{1c} and Time in Range become part of the daily life of those with T1DM. And it is difficult to meet those targets, as illustrated by the National Diabetes Audit statistics that only 10% achieve an HbA_{1c} target of lower than 48mmol/mol and only 32% achieve lower than 58mmol/mol. Freestyle Libre Time in Range data shows that only 15.9% achieve both >70% time in range and <4% time below range.

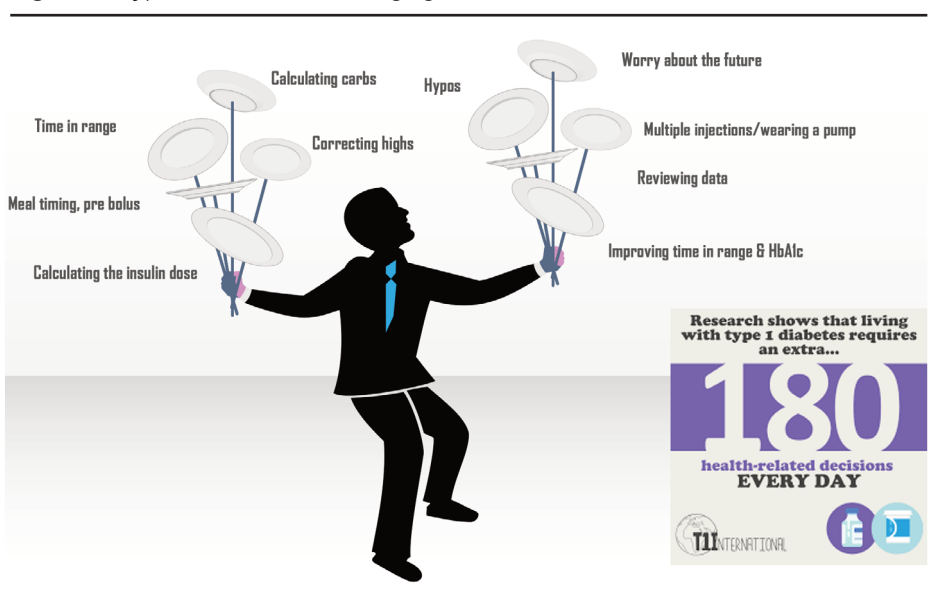
Benefits of peer support

We then looked at the benefits, commencing with a slide illustrating the camaraderie and natural community feel when those living with T1DM get together.

We looked at topics of conversation. Some key topics that were often discussed were the adoption of technology, and commonplace issues that arise daily for those living with the condition.

We reflected on how these discussions can help to reduce some of the burden on healthcare professionals,

Figure 1. Type 1 diabetes is challenging



improving the knowledge of patients so that the benefits of time in clinic can be maximized. Peer support can help share the role of improving life and wellbeing for those with T1DM (Figure 2).

The NHS in England have now recognized that peer support plays a fundamental role in diabetes care, as demonstrated in their document “The six principles of good peer support for people living with type 1 diabetes”, produced jointly with six people living with

Figure 2. Benefits of peer support

- **Embracing Diabetes Technology**
 - Choosing systems
 - Personal preferences
 - Seeing technology in real life
- **Everyday questions**
- **Peer support for the wider network**

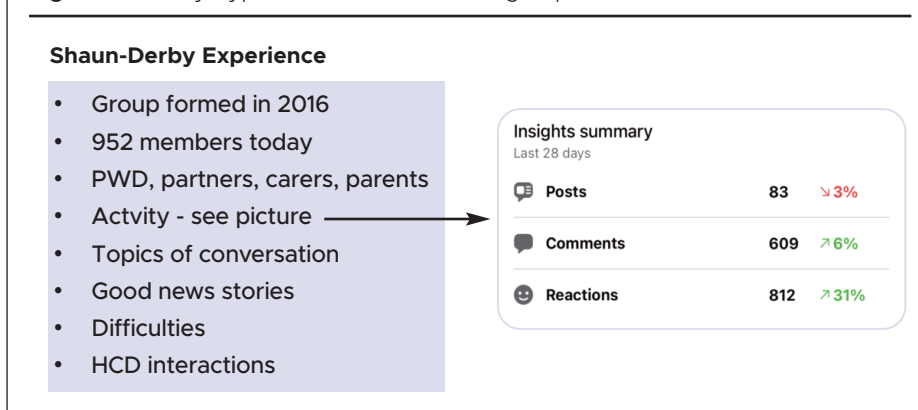
the condition, breakthroughT1D (formerly JDRF) and Diabetes UK.

We looked at the principles agreed to be used as the basis for any new peer support groups set up alongside the NHS service. They should be:

- Driven by the shared experiences of people living with T1DM
- Reciprocal, with opportunities for people to ‘give and get’ as well as to learn from one another
- Safe and encouraging, allowing people to share their experiences free from any judgement
- Accessible and inclusive, available to everybody with T1DM
- Person-centred, taking account of each person’s strengths, values, needs and feelings
- Complementary, working hand-in-hand with health and social care providers.

The Derby Type 1 Facebook group

We then moved on to look at our own

Figure 3. Derby Type 1 Diabetes Facebook group

experiences of peer support groups, starting with the Derby Facebook group (Figure 3). This group was started back in 2016, when social media interactions between those with T1DM were increasing greatly, Diabetes UK had held a couple of conferences for those living with the condition and in general, probably for the first time for many, peers were starting to learn from each other. As well as sharing tips for living with the condition, people started to feel the huge mental health benefits of sharing their difficulties and realising that they were not alone.

The group had 952 members in September 2024, all in the Derby and Derbyshire area, and including people with T1DM and their partners, carers, parents and friends. To give some idea of the activity in the group, we reproduced the Facebook activity monitor, showing that in the last 28 days there had been 83 posts, 609 comments in relation to those posts, and 812 reactions to those posts.

To illustrate the areas of interest and conversations in the group we provided examples of some of the topics discussed over the last few days. Typically, the topics discussed frequently include: questions about the use of technology, including access, opinions on different insulin pumps and hybrid closed-loop systems; comments and shared frustrations over the relentlessness of T1DM and its emotional impact; everyday life issues such as insurance and procedures at airports. There are also some fun posts too to lighten the mood. There is plenty of education and learning in the group, all of which will hopefully make clinic time with healthcare

professionals more effective and efficient.

There have been some good news stories over the years within the group: we've had someone heading to Wembley who realised halfway there he had forgotten his insulin, only to find that another member of the group was there with spare insulin. And more recently, a young family with a child with T1DM was in Derby for a football tournament and had a mishap with a Libre sensor – they joined the Derby group, and we were able to provide a replacement in time for them to take part in the tournament. Good deeds are what the group is all about.

There were questions about healthcare professional interactions, and discussion followed about their frequency and nature. There are very few in the Derby group, perhaps two or three a year, but these work both ways. If there are concerns about members, these are flagged to the local team, and equally if the local team want to communicate with the community, they put in requests that we share information. Healthcare professionals and people with T1DM work together in partnership.

We touched on the difficult situations and disagreements that sometimes arise in the group: often these revolve around perceived inequalities in access to technology and occasionally the administrators have to step in. In the eight years since its inception, only two or three members of the group have been removed, for contravention of the group rules. These rules are very much in line with the six principles, and mainly cover how people are to interact with each other.

Engaging young people in peer support networks

We considered some of the specific benefits and challenges of peer support for young people with diabetes. National Diabetes Audit data shows that young adulthood is associated with an increased median HbA_{1c} and increased rates of diabetic ketoacidosis (DKA). Therefore, we need to continue to consider how to improve outcomes for young adults in particular. Peer support could be one method to help young adults feel more involved and engaged in their care.

We spoke about the value of having spaces for young adults with diabetes to meet and share their experiences. This can lead to both in-person and virtual networks being formed and creates a forum for young adults to discuss the issues most important to them. Discussions do not have to be exclusively focused on diabetes, but importantly there is a mutual understanding of the challenges posed by living with diabetes day-to-day.

Finally, we considered how young people can access peer support. It is important to signpost what groups there are, as this allows individuals to access peer support when they want and need it. A list with some examples of peer support resources was provided. This included a variety of in-person events, virtual communities, and other resources such as podcasts.

The King's College Hospital peer support experience

Geraldine Gallen completed the practical side of the workshop by talking about the King's College recent experience of setting up their own peer support group. A group of people with T1DM had come together and put themselves forward to get the project off the ground. A group of dedicated individuals is vitally important to give the group momentum and to deal with the administration. With the help of other support groups, they were able to put the group structure in place and use the Facebook rules in a similar way to the Derby group – peer support amongst groups as well as within them!

King's set up a launch event, promoted by the healthcare professionals

in the team. Healthcare professional support is vitally important to give the group the gravitas it needs and to give potential members confidence. There were more than 100 people at the launch event, and the professionals were struck by the amount of conversation occurring naturally in the room.

The professionals at King's can already see the benefits, and the group is going from strength to strength. It is a safe and inclusive support group and will hopefully become a key partner in the T1DM service.

Conclusion

Peer support in T1DM has really taken off in recent years. So many of those who live

with this relentless condition are feeling the benefits, through interaction online and in person, with others sharing their experiences. The six principles guidance is out there, so all healthcare teams should look at their options for supporting access to peer support groups in their community.

With the addition of a peer support network to the services already in place for those with T1DM, the benefits for the community are huge. Reach out to other groups, who will help, and make peer support an integrated part of T1DM care.

The DTN conference workshop was held on 4th September, 2024.



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Conflict of interest Nothing to declare.

Funding None.

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Br J Diabetes 2024;**24**(2):171-173
<https://doi.org/10.15277/bjd.2024.469>
