

Diabetes care events: Over 20 years of volunteering

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Article points

1. Care events for children and young people with diabetes are provided by Diabetes UK. They organise two types of events: one for the young person and their family and one for young people alone (starting from age 7).
2. The care events provide children and young people with a safe and fun environment to meet some other young people with diabetes, and to learn more about their condition from the healthcare professionals involved.
3. Healthcare professionals involved in the care events report that it is an excellent opportunity to understand the young people's difficulties in managing their diabetes.

Key words

- Care events
- Children and young people
- Diabetes UK

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Some evidence exists that suggests that residential camps and events for children and young people with diabetes are an excellent way of bringing together young people and healthcare professionals in an informal and fun environment. Although there is a lack of evidence for the impact of these events on outcomes, such as glycaemic control and adherence to medications, anecdotal evidence from healthcare professionals and the young people who attend the events suggests that the young people benefit greatly from being around other young people with diabetes. They grow in confidence and are able to talk to healthcare professionals in informal surroundings. Healthcare professionals also report that involvement in these events changes their clinical practice for the better as they are able to interact with young people in some real-life situations, rather than in a clinic setting. This article describes the care events run by Diabetes UK and discusses the benefits for all involved.

Residential camps for children and young people (CYP) with diabetes are held both locally and nationally in the UK and internationally. The main goals are to facilitate a safe place to practice self-care, encourage thought around diabetes management, gain knowledge and skills, and to socialise with other CYP with diabetes. Records indicate that the first of these residential camps took place in 1925 in Michigan in the US (American Diabetes Association [ADA], 2012).

Diabetes care events for CYP and their families have been provided for over 65 years in the UK by Diabetes UK. They are funded and organised by Diabetes UK (formerly the British Diabetic Association), which is the leading charity for people with diabetes.

Events for CYP are available in two main formats: family events and CYP events. Both events rely heavily on volunteers to help organise the format of the event, and to

help with the support and care the families and CYP receive. Volunteers apply via the Diabetes UK website and if successful they will have training on safeguarding and the management of diabetes. Safeguarding is paramount and potential volunteers supply references and have enhanced checks through the disclosure and barring service. All travel, accommodation and subsistence costs for the volunteers are met by Diabetes UK.

Costs for families for both types of events are subsidised by Diabetes UK but many families may receive additional financial support from local parent groups, charities or a Diabetes UK bursary. If a young person is receiving social support then social services may be able to provide funds to support attendance.

Family events

Family events are held over a weekend and usually at a hotel. Diabetes UK consider



Figure 1. John Pemberton, paediatric diabetes dietitian (right) enjoying an ice cream with the young people at the Blairvadach Outdoor Education Centre, Dunbartonshire, Scotland.

“The doctor at the event is asked to present a session to the whole group explaining clinical research and new developments.”

geographical location with the aim of reaching as many families as possible. There are currently three English, one Scottish and one Northern Irish events each year. They tend to start on a Friday afternoon and finish with Sunday lunch. Before each event, the hotels are briefed by the volunteer organiser, dietitian and senior nurse on the group’s medical and dietary requirements, and on those related to programme delivery.

Families that have a young person with diabetes up to age 17 years old apply to attend an event through the website. Places are limited due to hotel capacity but usually each event has around 25 family places. The children and adults follow different programmes on the events but children return to their parents overnight and are with them at breakfast. Volunteers are allocated to either the CYP programme or adult programme, depending on the skill mix and role required.

The CYP’s programme has a team of volunteers comprising a mix of healthcare professionals and adults with type 1 diabetes or who have a connection to someone with type 1.

Following the initial meet and greet and gathering of updated medical details for each child, the children meet their volunteer “helper” and play getting-to-know-you games before returning to their parents. The children usually bond very quickly with other children and develop friendships lasting beyond the event.

The parents are split into groups and they discuss what questions they wish to have answered during the weekend. Later these questions are divided into medical, nursing and dietetic categories, and experienced parent volunteers answer these during group sessions the following day. They usually consist of understanding diabetes physiology, schools management, pumps and continuous glucose monitoring, and management of hypoglycaemia and sick days. Frequently, questions arise about new research development and technologies. Towards the end of the weekend the senior doctor at the event is asked to present a session to the whole group explaining clinical research and new developments.

The CYP have a day out at a local zoo or attraction on the Saturday in which they

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1. The events are organised according to age, with individual events for 7–10 year olds, 11–15 year olds and 16–17 years.
2. The children and young people have outdoor activities and games throughout the week, which not only challenge the abilities and courage of the young people to manage their diabetes, but also the abilities and courage of the staff to manage diabetes in real-life situations, rather than in clinic settings.
3. Although recognised as an important part of care in some countries, it is difficult to find any quality evidence to determine whether events or camps improve sustained quality of life, long-term improvements, adherence to medications or HbA_{1c}.

observe their peers and volunteers with type 1 managing their glucose testing, injections, pump and possibly hypoglycaemia. This stimulates conversations, drawing comparisons and detailed discussions. The CYP learn in a relaxed, comfortable environment with peers and therefore are able to absorb information and gain understanding differently than in the clinic. During that day, many children will try something new with their diabetes. It may be changing an injection site, administering their own injection or treating hypoglycaemia differently. This is always an emotional time for the family, child and the volunteer involved.

CYP events

The events for CYP are also residential and are either weekend or week-long experiences. The CYP attend without parents or guardians, and the volunteers have responsibility for the young people for the duration of the event. The events are organised according to age, with individual events for 7–10 year olds, 11–15 year olds and 16–17 years. These events are also planned and coordinated by volunteers, in conjunction with

a team at Diabetes UK.

The CYP have outdoor activities and games throughout the week, which not only challenge the abilities and courage of the young people to manage their diabetes, but also the abilities and courage of the healthcare professional volunteers to manage diabetes in real-life situations, rather than advising in clinic settings. All events contain educational components and these are delivered in an age-appropriate way. The impact of physical activity and exercise does not always follow the text books or theories and healthcare volunteers need to be flexible, proactive and able to plan the management with the young person. This includes overnight testing of blood glucose levels, carbohydrate counting, healthy eating, insulin management and emotional support.

Supporting evidence for the benefits of these events

Studies on the benefit of diabetes events are scarce. Although recognised as an important part of care in some countries, it is difficult to find any quality evidence to determine whether events or camps improve sustained quality of



Figure 1. Carol Metcalfe (centre) with a DSN colleague, Jo McBride, and some young people at a care event at Center Parcs.

life, long-term improvements, adherence to medications or HbA_{1c}. Studies on insulin dose management and blood glucose management during camps show that diabetes management is individual to the young person and generic advice regarding alterations of insulin doses may not apply (Gunasekera and Ambler, 2006; Miller et al, 2011).

It is recommended that strict guidelines should be in place for safety and the ADA has published a position statement for management of diabetes at a camp (ADA, 2012). Diabetes UK also has guidelines regarding roles, responsibilities and safeguarding on their events and volunteer staff are expected to attend a training event to cover these issues.

Kime (2014) reported that young people often feel isolated because of their diabetes; however, in her study, young people who had attended a local or national event found it helpful to be with others with diabetes and it was perceived that having diabetes was normal. Feedback from the events I have been involved in has suggested that the CYP really benefit from being around others with the condition.

Cuttell et al (2005) found that a local residential weekend with a transition to adult service theme improved knowledge and some life skills.

What do healthcare professionals gain?

I have been personally involved in diabetes care events for over 20 years. Alongside a core group of other nurses, doctors and dietitians, plus an army of people with diabetes and parents of children with diabetes, I have planned and executed too many events to count.

We have encountered a variety of both challenging and fun learning experiences, which have shaped our understanding of living with diabetes. The events will almost certainly change healthcare professionals' practice, due to a greater understanding of the daily trials and complex decisions CYP and their carers have to face. It also will explain why advice given in clinic is not always heeded when one is also faced with the dilemma of how to incorporate that advice into practice. Michele, a diabetes

dietitian who regularly volunteers at the events, explains her thoughts on volunteering:

"It gives a good insight and I always think after, how I can change my practice at work to help support young people? Rather than just repeating guidelines and recommendations, I try to give practical tips and support to help them make small changes and talk about what maybe works well for others that they could try."

During the event the CYP have unlimited access to healthcare professionals and adults with diabetes, and the neutral environment allows for open and honest conversations. These conversations can be uncomfortable at times as the CYP will tell you what they feel about clinics, hospital admissions, schools or occasionally they may disclose a safeguarding issue.

Joanne, an adult insulin pump DSN explains:

"It is nice for the young people to see healthcare professionals away from the hospital environment. I hope that we can empower them to try new things and have the courage to self-manage. I do think the adult service is very different service and hope that I can show them we are not all scary."

I initially volunteered when the first paediatric DSN (PDSN) manager I worked with suggested it would be a good way to start my education while I was waiting for my diabetes course. Due to the shortage of PDSNs at that time, my involvement was appreciated and I was asked to attend more events. The requests also included my husband, who is also a nurse, and eventually our daughter.

I gain a great deal from these events, which is part of the reason I continue to volunteer. I am able to network with other healthcare professionals, share good practice, and keep my knowledge and practice fresh and current.

One of the best sources of learning is from the volunteers who have diabetes. The stories and experiences they recall of their management and care is fascinating, frightening at times,

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1. As healthcare professionals involved in these care events, we have encountered a variety of both challenging and fun learning experiences, which have shaped our understanding of living with diabetes.
2. During the event the children and young people have unlimited access to healthcare professionals and adults with diabetes.

“All of the volunteers would agree that apart from the knowledge and skills gained, and the friendships that are forged, the events offer you the chance to challenge yourself at a new activity or skill.”

humorous and heart-breaking. It is a real privilege to work with them and it has enabled me reflect on the impact I have upon CYP and their families.

Many of these volunteers with diabetes have attended events as a child. The positive memories of the events often encourages them to support other CYP. James, a volunteer with type 1 diabetes, explains why these events have a really positive impact on CYP with diabetes:

“With diabetes being a 24/7 condition, there are moments when you encounter problems, muddle through and forget all about them. One of the great things about spending time with healthcare professionals is that you can get advice on problems that you wouldn’t remember having later. Another great thing the young people get from it is the ability to have an informal chat, have conversations and float ideas about without fear of judgement. It gives young people who have difficult relationships with parents and/or diabetes teams an opportunity to ask big questions. Also it allows for a shift in attitude. Towards a sort of ‘yes you can attitude.’”

Feedback

Feedback from Diabetes UK surveys following an event has not been published but it includes the following. Text message received from PDSN, Alison:

“Just seen my lady who went to the Centre Parcs event and want to say a very big, big thank you. She looked so well and positive, just wish I could have bottled it to show others the value of these events.”

Feedback from parents:

“It was great seeing my daughter laughing and happy with other children in the same situation and watching her confidence grow throughout the weekend”

“Hearing the experiences of Alma and Nigel (volunteers with diabetes) and the panel discussion on the second day was enlightening

and inspiring.”

“The chance to speak to the diabetes nurses casually over the course of the weekend was invaluable: Their insight, empathy and practical advice was hugely appreciated. As for the kids, the safari trip, followed by swimming followed by the disco made for an amazing and memorable day.”

All of the volunteers would agree that apart from the knowledge and skills gained, the opportunities to challenge yourself at an adrenalin-filled activity, the lasting friendships that are forged, events offer you and the CYP the chance to have a great deal of fun.

Of course, we now have revalidation on the horizon and volunteering will certainly be part of my portfolio. Diabetes UK will now provide a certificate stating hours volunteered for revalidation purposes.

The new calendar of care events is usually published around the Christmas/New Year period on the Diabetes UK website (www.diabetes.org.uk). I cannot recommend highly enough the value of these events for both CYP and their families, and all healthcare professionals involved in diabetes care. ■

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