

Parent Consultation: Preliminary report

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Introduction

Parents play a pivotal role in supporting their children to self-manage their type 1 diabetes. There is growing evidence that this role can have a significant impact on the health and wellbeing of parents.

Published Evidence

Caring for a child with type 1 diabetes has been described as an overwhelming experience. Parents live with constant worry about hypoglycaemia or hyperglycaemia, heightened feelings of responsibility for their child's health, and the desire to promote optimal growth and development¹. "A diabetes diagnosis in a child is associated with psychological distress among parents... parents of children with diabetes have greater parenting strain than parents of non-chronically ill children"². Parents have shown to "experience higher levels of anxiety and stress, and higher prevalence of clinically significant depressive symptoms"³.

Method

Diabetes Victoria consulted with parents and carers of children with type 1 diabetes to gain a better understanding of their needs. Parents and carers of children who attended a Diabetes Camps Victoria camp between October 2017 and April 2018 were invited to participate in one-on-one telephone interviews with Kim Henshaw, Consumer Advisor and Families Coordinator. Interviews were conducted with 34 parents and one grandmother. The children's ages ranged from 8 years to 17 years, and their lived experiences with type 1 diabetes ranged from 5 months to 12 ½ years.

Results

Parents spoke of the importance of connections with other families who have a child with type 1 diabetes. These connections provide support to help them cope with raising a child with type 1 diabetes and are especially important as their children transition through different life stages. Their concerns are validated in knowing other families are struggling with similar issues and understand what they are going through.

Parents expressed their gratitude for the camps program, which allows them to have a break from the everyday burden of diabetes. Many noted it was their first full night's sleep since their child's diagnosis. This is attributed to the feeling of security that their child is in the care of diabetes experts while having fun with their peers.

Conclusion

Parents and carers of children with type 1 diabetes need an opportunity to connect with other families while their children are being cared for at Diabetes Camp. From Monday 27 August Diabetes Victoria will support a 1-week crowdfunding campaign to fund events for parents and carers. These events will allow parents to connect with other families, learn about the latest developments in diabetes management and have a break from their child's day-to-day diabetes management.

¹ Whittemore R, Jaser S, Chao A, Jang M, Grey M. Psychological Experience of Parents of Children with Type 1 Diabetes. *Diabetes Educ.* 2012 Jul; 38(4): 562-579. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3401246/>

² Helgeson VS, Becker D, Escobar O, Siminerio L. Families with children with diabetes: implications of parent stress for parent and child health. *J Pediatr Psychol.* 2012 May;37(4):467-78. <https://www.ncbi.nlm.nih.gov/pubmed/22267104>

³ Rankin D, Harden J, Waugh N, Noyes K, Bardard KD, Lawton J. Parents' information and support needs when their child is diagnosed with type 1 diabetes: a qualitative study. *Health Expect.* 2016 Jun; 19(3): 580–591.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5055234/>