



Participant Information Sheet

Title	Understanding caregiver experiences of caring for a young child with type 1 diabetes: a qualitative study.
Short Title	Parenting a child with type 1 diabetes: A qualitative study
Protocol Number	RGS0000005659 V1 15.08.2022
Coordinating Principal Investigator	Dr Keely Bebbington
Location	Telethon Kids Institute

Why are we doing the study?

Children and adolescents with type 1 diabetes (T1D) are more likely to experience an anxiety disorder than young people without T1D, and this can have long-term impacts on their psychological wellbeing and physical health. Anxiety is also common among parents of children living with T1D. Little is currently known about how anxiety presents in caregivers of young children with type 1 diabetes.

What will the study tell us?

By understanding the experiences of parenting a child with T1D we hope to identify avenues to better support parents to manage their own anxiety about their child's type 1 diabetes and raise healthy, confident children.

Is there likely to be a benefit to you?

We cannot guarantee you will receive any direct benefits from this research; however, you may benefit from having the opportunity to talk about your experiences with managing this condition. By participating in this research, you will also be helping build evidence related to the burden of living with T1D and how best to support families.

Is there likely to be a benefit to other people in the future?

The findings from this qualitative study will help inform a larger study where we will develop a program to support caregivers of children with T1D to raise healthy, confident children.

Who is carrying out the study?

This research project is being conducted by the Children's Diabetes Centre at Telethon Kids Institute.

Who can be involved?

Parents/caregivers of children aged 10 years or younger with T1D. Participants will need to have access to the internet.



Do you have to take part?

Participation in any research project is voluntary. We will respect your decision whichever choice you make. If you decide to take part and then later have a change of mind, then that is ok, and you can withdraw from the study at any stage. If you decide that you will take part in this project, we invite you to sign the consent form attached. Your decision whether you take part or not take part, or to take part and then withdraw, will not affect your child's routine treatment, relationship with those treating them, or relationship with the Telethon Kids Institute or Perth Children's Hospital.

What will you need to do to take part in this study?

If you decide to take part in this study, you will firstly be asked to complete a short online survey designed to gather some background information. You will then be asked to participate in semi-structured interview conducted by an experienced member of the research team. This can take place in person, over the phone or online, via Zoom, as you prefer.

During the interview you will be asked questions, for example, 'What was it like adjusting to living with type 1 diabetes?' and 'What are some of the things you worry about in relation to your child's diabetes?'. We will discuss possible and convenient times for the interview on recruitment. We expect the interview to take no longer than an hour.

The interviews will be recorded, and these recordings will only be accessible by the research team. We may use a third-party transcription service to transcribe the audio recordings for later analysis. You will receive a reimbursement for your time on completion of the interview.

What are the possible risks and/or side effects?

This is a low risk study, meaning we do not anticipate any risks from being involved in this project. In the unlikely event that you become upset or distressed because of participation in the research, we will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff and will be provided free of charge.

What if you want to withdraw from this study?

Participation in this study is voluntary; therefore, you can withdraw from the study at any point during the project. Withdrawal will not affect your relationship with the researchers or the Children's Diabetes Research Centre.

Where will the collected information be kept?

All information collected for this research project will be treated as confidential and securely stored. All data including electronic and voice recordings will be stored on password protected computers accessible only by the diabetes research team. All written data will be kept in a locked cabinet in a restricted access area within the Telethon Kids Institute. At the completion of the study, de-identified files will be archived and retained for 5 years.

What about your privacy?

In most situations, we will treat what you say as being private and confidential. The only circumstance we will reveal any information is if the law requires us to do so. As soon as the information collected is collated it will be de-identified, that is, names will be removed, and the information coded so that no one can associate what has been said with anyone. Any data



that is published and/or presented will be provided in such a way that individuals cannot be identified.

What happens when the study ends?

You will receive a summary of the results of the project by email approximately 3 months after the project is completed.

Who has approved the study?

The ethical aspects of this research project have been approved by the Child and Adolescent Health Service Human Research Ethics Committee. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

Who do you contact for more information about this study?

If you would like any more information about this study, please do not hesitate to contact Dr Keely Bebbington on 6319 1766. She will be happy to answer your questions. You are entitled to retain a copy of the project's Participant Information and Consent Form.

Who do you contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints about the way we ran this study, you can contact the Executive Director of Medical Services at Perth Children's Hospital (Telephone No. (08) 6456 2222). Your concerns will be drawn to the attention of the Ethics Committee who monitors the study.

What do you do next if you would like your child to take part in this research If you would like to take part in this research study, please contact Keely on 6319 1766 or email Keely.Bebbington@telethonkids.org.au

Thank you for your time.