

# Telling it like it is: the lived experience of young people with type 1 diabetes

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Imagine you are a young person aged 16-24 years.

Try and remember what you were doing at that age and that time in your life. Life may have been fantastic, exciting and fun. You may have been having the time of your life. Or life may have been scary, filled with uncertainty or just plain confusing!

Now imagine you have just been diagnosed with a condition that you will have for the rest of your life...or until a cure comes along, if a cure comes along. You have been diagnosed with type 1 diabetes. You are told you must manage everything you eat and drink, regularly and routinely prick your fingers to test your blood sugar levels and in order to survive, you must inject yourself multiple times every day...in multiple areas of your body...for the rest of your life...without fail.

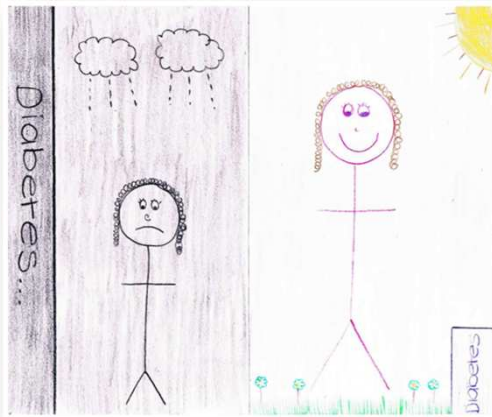
How does that make you feel? What questions do you have? What does this mean for your social life? How would you tell your friends, would you tell them? Does this mean you won't be able to go on school activities or travel away from home? Can you still play sport? What will people think if they see you injecting yourself?

If I asked you to tell me what it's like for you to live with type 1 diabetes, what would you tell me?

What is life like for young rural people living with type 1 diabetes?



Annalese, aged 24 years, diagnosed aged 12 years:  
"I took this photo about two years ago, and I like it because...I don't really know why. I guess it's because no matter how much you dress your self up, you ALWAYS have diabetes there...What a pain!"



Mel, aged 24 years, diagnosed aged 16 years:  
"The drawing I drew represents me...and the diabetes is overruling me...obviously makes you feel down when it controls your life. And then that's the opposite one where I'm controlling the diabetes and it makes you feel a lot better...if you're on top of it, you just forget that you have diabetes".



Michelle, aged 18 years, diagnosed aged 5 years:  
"As I am looking out over the water, I cannot see where it ends, which represents the unknown future ahead for me and my diabetes. Being a diabetic means a possible future of complications, and that scares me. However, having a strong support network (which is represented by my dog next to me), makes it easier to look ahead into the unknown".

## THE ART OF YOUNG PEOPLE

Participants are creating a piece of art (of their choosing) that is a visual representation of their experience living with type 1 diabetes. Participants are asked to discuss the artwork, thus adding further depth to their lived experience. Examples may include a photograph, drawing, poem, painting or verse.

## THE SIGNIFICANCE OF THE STUDY

Findings will provide an understanding or awareness of what life is like for a young person with type 1 diabetes living in a rural environment, the challenges they face and the impact (or influence) chronic illness may have on these aspects. Healthcare professionals will be better placed to provide relevant, contextual and adolescent specific care to young people experiencing chronic illness; care that takes into consideration the impact type 1 diabetes has on a young person at various points in their life by tailoring care that 'fits' into the young person's life. Support networks and programs can be designed specifically to meet the needs of young rural people with type 1 diabetes.

## RESEARCH QUESTIONS

What are the experiences relating to being a young person with type 1 diabetes living in a rural setting?

How does type 1 diabetes impact on the participants' everyday existence?

Are the experiences of the participants in their 'adolescent years' any different to their peers who do not have type 1 diabetes?

## AIMS AND OBJECTIVES

- To provide the participants with a voice to tell their story of what life is like living in a rural setting with type 1 diabetes
- To inform healthcare professionals about the participants' experiences
- To improve the care of young people with type 1 diabetes living in a rural setting
- To utilise the findings in the development of recommendations enabling healthcare professionals to tailor care provided to young people
- To inform other young people with type 1 diabetes about the participants' experiences so that these experiences may resonate with other young people

## METHODOLOGY & METHODS

A qualitative approach will be implemented and underpinned by Max van Manen's method of phenomenological inquiry. Phenomenological inquiry provides opportunity to explore and describe lived experience of a particular phenomenon, to 'paint a picture' of what living with type 1 diabetes is actually like. The challenges faced and the impact (or influence) chronic illness may have will be highlighted.

Participants will be male or female, 16-24 years of age, living in rural Victoria and have type 1 diabetes. Interviews will be digitally recorded and transcribed and transcriptions analysed for themes, utilising van Manen's approach to phenomenological inquiry. Themes will be utilised to describe what life is like for young rural people with type 1 diabetes, essentially, their lived experience.

## BACKGROUND

Adolescence is a challenging period in a young person's life, even without alterations to their health. Adolescents diagnosed with a chronic illness, such as type 1 diabetes experience lifelong changes that some may find difficult to accept and cope with. Being adolescent, living with a chronic illness and residing in a rural environment triples the challenges.

When an adolescent, or young person is diagnosed with a chronic illness, a number of psychosocial issues are triggered. These psychosocial issues may include problems adjusting or coping with alterations to their health, increased school absences, increased risk of social isolation, anxiety, depression and poor self-concept and self-esteem (Darvill, Thomas & Henry, 2009).

According to the IDF (2011), coping emotionally with type 1 diabetes may be difficult for many children and adolescents. The IDF suggest being diagnosed with diabetes can result in discrimination, place limitations on social relationships and may impact on a child's academic performance..

## References

Darvill, J., Thomas, K., & Henry, P. (2009). Children with chronic health problems and their families in M. Barnes & J. Rowe (Eds) (2009). Child, youth and family health: strengthening communities (206- 229). Churchill Livingstone: Sydney

International Diabetes Federation (2011). IDF Diabetes Atlas, (5th ed). Brussels, Belgium: International Diabetes Federation <http://www.idf.org/diabetesatlas>