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**CHANGING**

THE WAY WE TALK ABOUT

**DIABETES  
COMPLICATIONS**

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~~BLAME~~

~~STIGMA~~

~~JUDGEMENT~~

Diabetes is a highly stigmatised health condition, and diabetes-related complications attract their own particular brand of stigma. For many people living with diabetes, talking about complications is considered taboo and off-limits, often because they believe that a complication diagnosis means they have somehow failed in their diabetes management.

The first mention of diabetes-related complications is often at the time of diagnosis when healthcare professionals, in an endeavour to encourage people with diabetes to follow management guidelines, use complications as a threat of what will happen if treatment plans are not followed. Not only can this approach be frightening to the person with diabetes, but it can also be the main thing they remember from their diagnosis, detracting from important management information.

For many people, the underlying message from diagnosis is that developing complications is fairly and squarely the fault of the person living with diabetes. This is both unfair and simply not correct. The ‘blame-and-shame’ nature of developing (especially type 2) diabetes in the first place is amplified if there is a diagnosis of complications, and the person with diabetes is seen to have failed in their treatment.

This thinking doesn’t take into account that some people are diagnosed with diabetes as a result of a complication diagnosis. How can someone be accused of not managing a condition they didn’t even know they had?

Stigma makes people feel judged, and being judged often leads to people with diabetes not seeing the treatment required to best treat the complication as early as possible. It can also mean people with diabetes feel isolated – as though they are the only one dealing with a difficult time – when in fact, many others have similar experiences.

But what if the conversation around complications changed? Instead of the fundamental message being about blame and shame, we shifted to open, safe, and non-toxic discourse. Instead of complications being spoken about with shame and in hushed tones, people felt comfortable sharing their experiences and seeking help. That has been the motivation behind a recent online initiative which hopes to get people to comfortably



## HOW TO TALK ABOUT DIABETES COMPLICATIONS

The shroud of secrecy and shame that permeates discussions of diabetes complications needs to change. Many people with diabetes complications don’t like to even mention ‘the C word’ because they don’t want to be blamed and judged for what has happened to them, or they may feel that it’s their own fault and they have failed themselves.

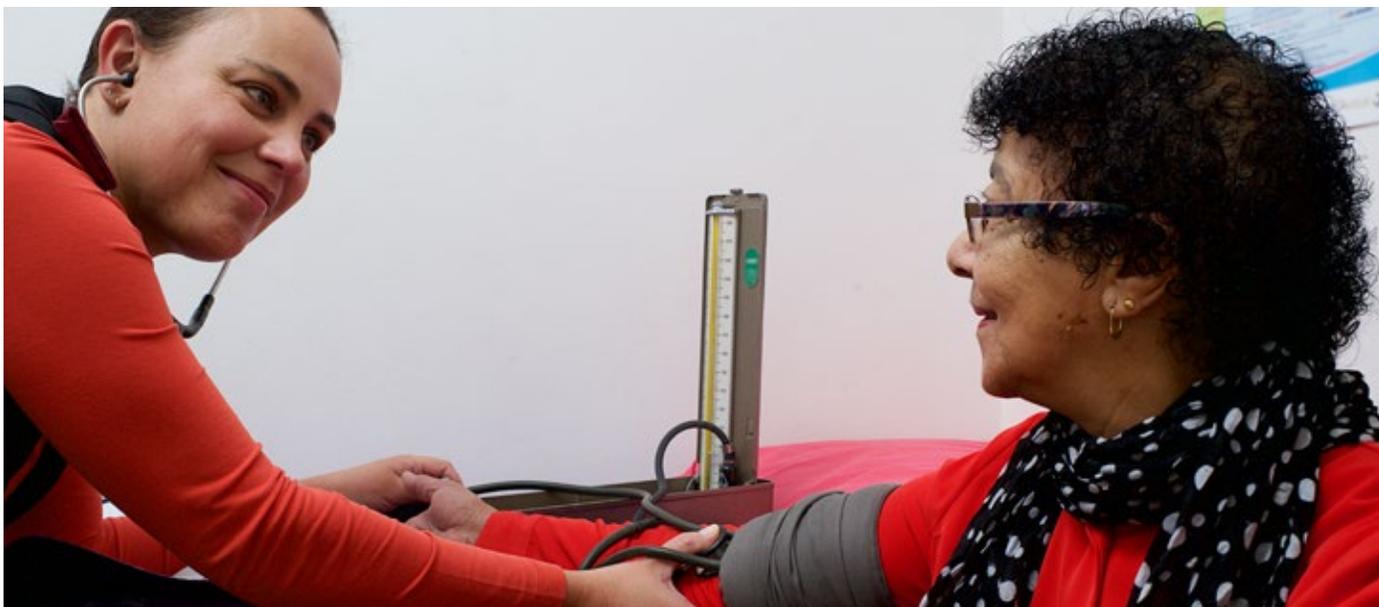
Instead of the muted, reluctant mutterings, we need to bring talk of complications out into the open and not be afraid to address what admittedly can be a scary topic.

The words we use are also important. We need to use language that is clear, honest, and open. Any notion that a person with diabetes ‘brought this on themselves’ needs to be banished! This isn’t about what has happened to get to the point of being diagnosed with a complication. It’s about moving forward: prompt treatment, and reducing the risk of future complications. Sometimes it can be as simple as changing one word. Is your foot issue a complication of your diabetes, or complicated by your diabetes?

Also worth considering is that it is rarely only about the physical manifestation of the diabetes complication. The emotional and psychological impact of being diagnosed with a diabetes complication is just as significant and needs addressing as much as any clinical treatment.

And perhaps we also need to accept and speak about how complications are simply part of living with diabetes. We can do all we can to minimize the risks of developing complications, but there are no guarantees that we will live a life free of adverse health diagnoses, even with the most pragmatic care. By reframing complications in this way, blame is removed and people may start to accept and understand that it may happen and seek treatment as required. Risk is a key word when talking about complications. The longer someone lives with diabetes, the more they are at risk of developing complications.

*#TalkAboutComplications.*



### ✓ WHO BENEFITS WHEN SPEAKING OPENLY ABOUT COMPLICATIONS?

Undoubtedly, if the focus of diabetes complications moves to being open and judgement-free, everyone will benefit. People with diabetes will feel comfortable speaking of their experiences, and will speak about their concerns, symptoms, and treatment options sooner rather than later.

Healthcare professionals will feel more comfortable having conversations that, in the past, have been difficult and awkward.

Friends and families of people with diabetes will better understand what complications are all about, and how they can offer help and support; and the general community will gain a better understanding of complications as well.

And with better understanding, legislators will advocate and implement more accessible and better-funded screening programs, meaning people with diabetes will be able to easily and conveniently access regular screening to identify complications and receive appropriate treatment sooner.

### WHY WORDS MATTER

In recent years, there has been a growing movement to really consider the words used when speaking to and about people with diabetes. Diabetes Australia launched a language position statement, *A New Language for Diabetes*, in 2011 (revised in 2016), and last year, the American Diabetes Association, together with the American Association of Diabetes Educators, released language guidelines. A team in the United Kingdom also released a language and diabetes guide in June 2018 called *Language Matters*. The aim of such documents is to encourage the use of language that engages, supports, and motivates people with diabetes, rather than use stigmatizing language that leads people to feel guilty, ashamed, afraid, and distressed about diabetes.

There is an inextricable link between language and diabetes complications. When we speak about ‘preventing’ complications, we ignore that despite best efforts, complications can’t always be avoided. Whilst it is essential to acknowledge that evidence does indeed show that there are ways to reduce the risk of developing complications, it is equally important to present this information in context, and ensure people understand there are no guarantees.

Currently, the language used when speaking about complications suggests that people with diabetes have failed if they receive a complications diagnosis. This leads to people feeling guilty and blamed, and the flow on effect can include people not seeking the medical care they require for fear of being judged.

## WHAT WOULD HAPPEN IF WE CHANGED THE WAY WE SPEAK ABOUT DIABETES COMPLICATIONS?

Opening up the way we speak about complications with a focus on inclusion, no judgement, no blame, and clear facts would result in many benefits. When we stop seeing complications as a failure of self-care, and instead accept that for many they are simply part of diabetes that needs managing, diabetes-related stigma will be reduced.

If people felt comfortable sharing stories about complications, it would reduce feelings of isolation. Because few people write or speak about living with diabetes complications, many believe they are the only ones going through the experience and don't know where to turn.

Encouraging people to speak about their experiences facilitates peer support opportunities, and opens up peer-to-peer learning. We know that people feel less isolated when they have the support, understanding, and empathy of peers.

Feeling comfortable about discussing complications will mean people with diabetes seek support and advice from their healthcare team sooner. If they know that their healthcare providers will not be judgemental, people with diabetes are more likely to maintain regular complications screening schedules and pursue help sooner rather than later.

## HOW TO RESPOND WHEN SOMEONE SAYS SOMETHING STIGMATIZING

It is often hard to know what to say if someone says something negative about diabetes complications. Here are some ideas that you may want to commit to memory:

- In the same way that no one asks to get diabetes, no one asks to get diabetes complications.
- Complications happen due to a number of complex reasons and we do not always know how to stop it from happening. We know how to reduce risk, but there are no guarantees.
- I am doing what I can to manage my diabetes to reduce the risk of complications. A good analogy is this: The more times you cross the road, the more you are at risk of getting hit by a car. So you cross as carefully as you can. Some days you may be in a hurry; some days you are distracted. This adds to the risk, but the goal remains the same: To get to the other side as healthy as possible, even if we must accept and deal with a few complications along the way. ■

