

HEADS UP ON DIABETES & STIGMA

NOBODY
CHOOSES
DIABETES



END DIABETES BLAME & SHAME

“I’ve definitely felt judged for injecting insulin before but the reality is I need insulin to live.”

Charlie, lives with type 1 diabetes



Acknowledgements

We thank all the people with diabetes who have shared their experiences of diabetes stigma with us.

This report is based on interviews with 52 adults with diabetes (type 1 and type 2) and national surveys of 1,078 adults with type 1 diabetes (aged 18-75 years) and 1,264 adults with type 2 diabetes (aged 22-75 years).

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We can end diabetes blame and shame and make life better for people with diabetes

In recent years, we've become increasingly aware of how our words and actions affect others. We are now more thoughtful and deliberate in the language we use around race, gender, age and health-related issues. We do this because we recognise that what we say and how we act can have a profound positive, or negative, impact on people.

But we are not always so thoughtful or deliberate in the language we use to talk about diabetes.

Diabetes has an image problem and a stigma problem. For some reason, it is still acceptable to make jokes about people with diabetes.

Many of these jokes are built on misinformation and misconceptions. The idea that people with diabetes are to blame for getting diabetes remains common.

The impact of this stigma is widely felt. Around 80 per cent of people with diabetes say they've been blamed or shamed for having the condition. Some common examples include people with type 1 and type 2 diabetes being blamed for causing their diabetes or its complications, being judged when eating certain foods, and being shamed for using insulin or checking their glucose levels in public.

More than two-thirds of people living with type 1 diabetes say they feel judged if they eat sugary foods or drinks, while more than 50 per cent of people with type 2 diabetes say people assume they are overweight. Research tells us that when people with diabetes feel judged or shamed, they may struggle to manage their diabetes. When people disengage from their diabetes healthcare, the risk of serious diabetes-related complications increases.

There are almost two million Australians living with diabetes which means that most of us know somebody who lives with the condition; someone who has been impacted by diabetes-related stigma. These are our parents, our children, our siblings, our friends, and our colleagues. They should not be stigmatised.

Ending stigma is up to us all. We need to understand that no one wants to get diabetes, no matter what type of diabetes they have. No one should be blamed or shamed about their diabetes. Living with diabetes is very demanding, and people are usually doing the best they can to manage their diabetes. If they need to check their glucose levels or take their medicines at work or in public – let's support them.

We can end the blame and shame surrounding diabetes – and make life better for people with diabetes – by being more careful with our words and actions, and by showing respect and support for all people with diabetes.

Greg Johnson
Chief Executive Officer



No one asks to get diabetes, and yet we often get blamed for it

Living with diabetes can feel like a lot. A lot to do. A lot to think about. A lot to remember. A lot of worry. And on top of that, there is a lot of diabetes-related stigma.

I was diagnosed with type 1 diabetes 23 years ago, and at the time knew very little about the condition. As I came to understand my new diagnosis, I learnt that what most people know about diabetes was tied up in misconceptions that were harmful to the way I felt about my own diabetes. There seemed to be so much judgement and blame about a condition I certainly didn't want! No one asks to get diabetes, and yet we often get blamed for it.

This feeling of judgment often made me wary of seeking help. I felt anxious that I'd be 'told off' by my healthcare team when my glucose levels were out of range, worried that they would say I wasn't doing enough to try to manage my diabetes. I was nervous in social situations in case someone asked the dreaded, 'Should you be eating that?'. Sometimes, I just didn't have the emotional strength to deal with the judgement.

Diabetes stigma comes in different forms. It's the disapproval from a healthcare professional when an HbA1c is higher than the previous one. It's the sideways glance from family when I reach for a piece of chocolate. It's the comments from colleagues when I post baking videos on Facebook. It's comedians thinking the health condition I live with every day is a punchline. It's the 6pm news story which dehumanises people with diabetes blurring out faces and hinting that laziness and overindulgence are the reason for our diagnoses. It's the cooking show host referring to a dessert as 'diabetes on a plate'. It's the stranger in a café making a comment when they see me attending to my diabetes as I mind

my own business. It's the accusation that we are not doing enough to look after ourselves, and if something happens – diabetes-related complications, low or high glucose levels – that we brought it on ourselves.

Sometimes, I say something if someone is being stigmatising about diabetes. Often my concerns are dismissed with replies of 'It's just a joke', or 'Stop being politically correct'. But it's not a joke to me, or to many others with diabetes.

Here's the thing.

When stigma-laden fingers are pointed, they are pointed at real people. Real people living with a demanding and at times overwhelming health condition, and trying to do the very best we can in the moment.

We shouldn't have to worry about being blamed and shamed on top of that.

Everyone has a role to play in addressing diabetes stigma – it can't just be up to people with diabetes calling it out. That's why this report is so important. It provides evidence to support what people with diabetes have been saying – that blaming and shaming affects our mental health, and how we feel about our diabetes. Following the recommendations in the report is actually quite simple, but the impact it will have on people with diabetes is significant. That sounds like a win to me!

Renza Scibilia
Lives with type 1 diabetes

DIABETES: STIGMA, BLAME & SHAME

Diabetes is Australia's fastest growing chronic condition.

“As a Councillor of Wyndham City Council, a resident indicated to me that because of my diabetes and related health problems, I was not up to serving as the Mayor. Fortunately, I did not let diabetes deter me and I was elected Mayor four years later”

Bob, lives with type 2 diabetes



There are almost two million Australians living with diabetes. And more than 80 per cent will have experienced diabetes stigma at some point in their lives.

Behind these numbers are real people. The stigma surrounding diabetes is also real – and it has a very real impact on self-care, physical health, emotional well-being and quality of life.

Type 1 is ‘you poor thing’, type 2 is ‘you stupid thing’

Man, age 57, type 2 diabetes

Research into diabetes stigma is in its infancy. It shows that many people without diabetes do not think of diabetes as a stigmatised condition. However, that is not the reality of people living with diabetes.

The purpose of this report is to raise awareness of this problem, and the simple steps that we can all take to reduce diabetes stigma. This report explains what diabetes stigma is and how it affects people with diabetes. We acknowledge that the experience of diabetes stigma can be different for each person with diabetes. It can also be affected by other types of bias, e.g. racism, sexism, weight bias.

This report also considers the role we all play in promoting diabetes stigma. The report concludes with practical suggestions for what we can all do to reduce diabetes stigma.

By reading this report and acting on its recommendations, we can all play an important part in reducing diabetes stigma.



2 million

**More than 2 million
Australians live with
diagnosed diabetes.**



80%

**And more than 80 per cent
will have experienced
diabetes stigma at some
point in their lives.**

WHAT IS STIGMA?

The word ‘stigma’ means a mark or sign of disgrace, one that sets a person or group apart from others.

To ‘stigmatise’ means to treat a person or group unfairly, to judge, blame and shame them. It can lead to a lack of support or empathy for the person or group. It can also lead to stereotyping, exclusion, rejection, and/or discrimination.

There are many forms of stigma. Sometimes it is based on negative attitudes or prejudice. Sometimes it is based on a lack of understanding.

Signs of stigma

Stigma occurs in many ways:

- inaccurate or misleading information, e.g. about the cause of a condition
- offensive information and harmful stereotypes, e.g. about the abilities of a person with the condition
- being unsympathetic
- mocking or making jokes.

There are many effects of stigma. Stigma can lead to people feeling:

- misunderstood, embarrassed and isolated
- ashamed, guilty, and distressed.

What is the difference between stigma and discrimination?

While stigma refers to the perception of being treated differently to others, discrimination is when people are actually treated differently.

Stigma can lead to people experiencing discrimination. That is one of the many reasons why it is important to take action to reduce stigma.

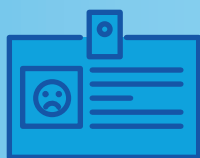
In Australia, there are laws against discrimination. This includes discrimination on the basis of disability. For the purpose of these laws, diabetes is considered to be a disability.

“There is still somehow a feeling of stigma attached to getting type 2 diabetes because you feel it’s your fault and you did it to yourself, so initially I was very upset”

Woman, age 59, type 2 diabetes

“The one comment that has stuck out to me was ‘Oh you’re type 2 so not a real diabetic, it was self-induced, lose weight and you won’t be diabetic anymore!’”

Ros, lives with type 2 diabetes



20%

have been discriminated against in the workplace because they have type 1 diabetes



55%

said “some people assume it is my fault I have type 1 diabetes (e.g. I ate too much sugar, I could have prevented it)”

WHAT IS DIABETES STIGMA?

Diabetes-related stigma refers to the negative attitudes to diabetes or people living with or affected by diabetes, based only on an aspect of their condition or its management.

People with diabetes report that stigma is a significant concern to them. They experience it across many areas of life, including their personal relationships, the workplace, and in social situations. It can have negative effects across many aspects of their life, including the way they manage their diabetes.

Why is there stigma surrounding diabetes?

Stigma often occurs due to a lack of understanding. For example, incorrect ideas about the causes of diabetes and how diabetes is managed. These misunderstandings lead to fear, blame and shame.

There is also a culture of personal responsibility, which can promote unrealistic ideas about how diabetes is managed.

Why does diabetes stigma matter?

Throughout history, people with physical and mental health conditions have been blamed, feared or misunderstood.

There are many examples of stigma interfering with how health conditions are managed. For example, cholera, syphilis, HIV/AIDS, epilepsy, obesity and mental health disorders. In each case, moral judgments about the reasons for the condition, and fear of people with the condition, affected compassion and the help made available.

Stigma can affect a person's physical, mental and social well-being. It affects their willingness to seek help from others, including from health professionals. It can undermine their efforts to manage their diabetes.

Stigma also undermines public health efforts. For example, if there is a societal view that people with diabetes have brought their condition on themselves, then there is less interest in supporting those people, e.g. with donations to charities that support them, or with government funding for treatments and research.

Understanding diabetes stigma

SOURCES

Media
Individuals
Groups
Communities
Health professionals
People with diabetes

EXPERIENCES

Being judged
Self-blame and shame
Treated differently
Threat to identity

CONSEQUENCES

Emotional, e.g. fear, worry, distress, depression, anger, grief.

Social, e.g. identity, relationships, isolation

Self-care, e.g. hiding diabetes, skipping injections or glucose monitoring, unhealthy food choices

Health, e.g. blood glucose, blood pressure, lipids, weight, diabetes-related complications

Opportunities, e.g. work

MITIGATING STRATEGIES

Education, respect and compassion, social support, health promotion and social marketing campaigns



26%

said I have been told that I brought my type 2 diabetes on myself



67%

said some people make unfair assumptions about what I can and cannot do because of my type 1 diabetes

THE EXPERIENCES OF DIABETES STIGMA



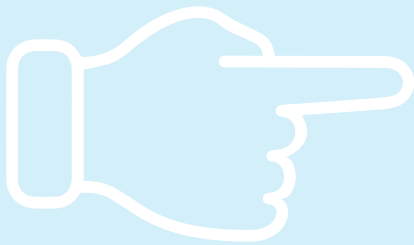
“I was once told that I would not make it far as an athlete because of the possibility of future diabetes complications that may prevent me from running.”

Meriem, lives with type 1 diabetes



“I felt guilty in the early days for the first, probably 10 to 15 years, I felt guilty because it was my fault”

Woman, age 59, type 1 diabetes



Some examples of the ways that people with diabetes experience stigma include:

- being blamed for causing their diabetes or its complications
- being judged, e.g. when eating certain foods
- being treated differently, e.g. stares or comments when they inject insulin, have a hypo, eat certain foods
- self-blame and shame for having diabetes

Because of stigma (or fear of stigma), people with diabetes sometimes hide their condition from others. This is because they:

- fear being judged or blamed for causing their condition
- do not want to deal with people's misconceptions about the condition and how to manage it (e.g. around food choices and treatments)
- do not want to answer lots of questions about diabetes

- do not want to worry or shock people, or attract sympathy
- fear of being discriminated against
- wish to distance themselves from society's negative portrayals of people with diabetes.

People with diabetes also report feelings of self-blame or guilt for developing diabetes or its complications, for their changing medication needs over time, or for having glucose levels that are 'off track'.

The causes of, and treatment for diabetes are different for people with type 1, type 2 and other types of diabetes.

**One thing remains the same:
Nobody asks for any type
of diabetes.**



TYPE 1 DIABETES

The figures below show the percentage of adults with diabetes who 'agree' or 'strongly agree' with the statement.

67%

“Because I have type 1 diabetes, some people **judge me** if I eat sugary foods or drink”



67%

“Some people make **unfair assumptions** about what I can and cannot do because of my type 1 diabetes”



55%

“Some people assume it is **my fault** I have type 1 diabetes (e.g. I ate too much sugar, I could have prevented it”



49%

“**I feel embarrassed** about what people might think if I need help with a hypo”



45%

“Some people think **I'm irresponsible** when my diabetes management isn't perfect”

Samples: N=1,078 adults with type 1 diabetes (aged 18-75 years) and N=1,264 adults with type 2 diabetes (aged 22-75 years)

TYPE 2 DIABETES

52%

“Because I have type 2 diabetes, some people **assume I must be overweight**, or have been in the past”

“

46%

“There is a negative stigma about type 2 diabetes being a **‘lifestyle disease’**”

“

37%

“Because I have type 2 diabetes, some people **judge me** for my food choices”

“

33%

“There is **blame and shame** surrounding type 2 diabetes”

“

26%

“I have been told that **I brought my type 2 diabetes on myself**”

THE IMPACT OF DIABETES STIGMA

“Diabetes doesn’t define Jack, it’s just a speed bump on his journey in life”

Brooke, mother of Jack who lives with type 1 diabetes

“Joking about my health isn’t funny! Diabetes is no laughing matter”

Jack, lives with type 1 diabetes



Feeling or experiencing stigma can impact:

- emotional health, including feelings of failure, guilt, shame or self-blame
- social relationships, including being treated differently, loss of relationships and increase feelings of isolation
- school, work or other opportunities
- diabetes self-care, including feeling embarrassed or self-conscious when managing diabetes in public, e.g. declining or choosing certain foods, or when injecting insulin or checking glucose levels

IMPACT ON

Emotional health

Diabetes stigma can lead to feelings of guilt and self-blame, psychological distress, depression and anxiety. People with diabetes who experience or perceive stigma are more likely to report anxiety and depressive symptoms.

“You don’t forget the day, the person who said it and you think ‘Really? What an idiot, uninformed person you are...’ – but it does upset you”

Woman, age 53, type 1 diabetes

“I felt guilty in the early days for the first, probably 10 to 15 years, I felt guilty because it was my fault.”

Woman, age 59, type 1 diabetes

IMPACT ON

Social relationships and feelings of isolation

“In my 20s, I used to hide it from any boyfriends that I started to see...I just thought that maybe not everyone wants a sick girlfriend”

Woman, age 33, type 1 diabetes

“When I first got it, I didn’t even tell my husband. I told nobody. I actually felt so ashamed to have diabetes. I felt completely ashamed of myself.”

Woman, age 54, type 2 diabetes

IMPACT ON

Self-care and health

Because of stigma (or fear of stigma), people with diabetes sometimes hide their condition from others. In doing this, sometimes they:

- delay injecting insulin or checking glucose in public (or not do them at all)
- inject insulin, take tablets or check glucose only when in private (i.e. in a toilet or at home)
- make unhealthy food choices because they don’t want to feel awkward or seem different to others

In the short-term, this can lead to high and low glucose levels. In the long term, high glucose levels can increase a person’s risk of diabetes-related complications.

“I remember feeling that I needed to be somewhere a bit more private to do it, and it was just the blood sugar test, it wasn’t even the injection, and so I didn’t do it”

Man, age 29, type 1 diabetes

IMPACT ON

School, work and other opportunities

Stigma can also mean a loss of opportunity for people with diabetes. This can be because other people make unfair assumptions about what they can or can’t do, or what they should or shouldn’t do.

“I felt hugely segregated in primary school and I really hated it so I really didn’t want to go on [school] camps”

Man, age 29, type 1 diabetes



TYPE 1 DIABETES

The figures below show the percentage of adults with diabetes who 'agree' or 'strongly agree' with the statement.

43%

“Some people think **I brought type 1 diabetes on myself**”



39%

“**I feel embarrassed** when I have to manage my type 1 diabetes in public”



31%

“To avoid negative reactions, **I don't tell people** I have type 1 diabetes”



20%

“I have been **discriminated against** in the workplace because I have type 1 diabetes”



10%

“**I have been rejected** by others (e.g. friends, colleagues, romantic partners) because of my type 1 diabetes”

Samples: N=1,078 adults with type 1 diabetes (aged 18-75 years) and N=1,264 adults with type 2 diabetes (aged 22-75 years)

* This information was volunteered spontaneously, with no prompt from the interviewer

TYPE 2 DIABETES

31%

“I **blame myself** for having type 2 diabetes”

“

23%

“I **feel guilty** for having type 2 diabetes”

“

16%

“Some people treat me like I’m **‘sick’** or ‘ill’ because I have type 2 diabetes”

“

12%

“I am **ashamed** of having type 2 diabetes”

“

6%

“I have been **discriminated against** in the workplace because of my type 2 diabetes”

THE ROLE OF THE COMMUNITY IN REDUCING DIABETES STIGMA

“I’m a 47-year-old woman.
I’m quite capable of
picking what I eat”

Sarah, lives with type 2 diabetes



The media

The media, healthcare professionals, family and friends, and school teachers have all been identified as sources of stigma and stigmatising practices.

Diabetes is frequently reported in the media. New research or campaigns are often news headlines and unfortunately, in a lot of cases, reporting is not accurate and can be seen as stigmatising. Many people with diabetes identify the media as a source of stigma and stigmatising practices.

Issues contributing to stigma surrounding type 2 diabetes:

- General focus on diabetes being preventable
- Focus on type 2 diabetes being a 'lifestyle disease', promoting the myth that it is completely preventable and within the individual's control
- Sensationalist reporting around the type 2 diabetes epidemic

- Inappropriate imagery, e.g. person who is overweight, doughnut, used to illustrate media stories about diabetes
- Scare tactics used in public health campaigns
- Lack of public knowledge and misconceptions

Issues contributing to stigma surrounding type 1 diabetes:

- General focus on diabetes being preventable
- Portraying the myth that type 1 diabetes is only diagnosed in childhood
- Type 1 diabetes rarely receives specific media coverage, with the focus tending to be primarily on type 2 diabetes
- When type 1 diabetes does receive media coverage, it is often inaccurate
- There is a lack of distinction made between type 1 diabetes and type 2 diabetes, with much of the coverage referring to 'diabetes' generally.

“All you see is ... these big bums and tummies and all that and you think ‘do people think I was like that?’”

Woman, age 60, type 2 diabetes

“The media ... with the best of intentions, creates the impression that type 1 diabetics are ill, facing a bleak future”

Man, age 68, type 1 diabetes

“[Their campaigns are]... patronising ... hurtful ... because they're telling the community that I gave myself the disease”

Man, age 56, type 2 diabetes

“I have complications and I have had medical professionals say to me: ‘Well, it’s your own fault because you’re diabetic’”

Woman, age 52, type 1 diabetes

Healthcare professionals

Healthcare professionals support people with diabetes by providing self-management recommendations, education, and detailed clinical insights.

Most people with diabetes describe positive and helpful interactions with their healthcare professionals. But many can also recall negative and discouraging interactions.

When healthcare professionals focus on what the person with diabetes has ‘done wrong’ in the past, rather than encouraging and supporting positive changes in the future, people with diabetes report feeling judged, discouraged and blamed. This impacts negatively on their self-care.

Some health professionals think that using scare tactics will motivate people with diabetes to manage their condition better. However, it is not that simple. Fear is only effective when the person feels able to manage the threat. If they do not have the resources to manage it, then they tend to manage their fears and anxieties, rather than managing the threat itself.

There is a lot that a person with diabetes can do to maintain glucose levels in the recommended target range. However, there is not enough acknowledgement of how much glucose levels can be affected by factors beyond the control of the person with diabetes. For example, weather, hormones, stress, illness, other medications and many more issues can impact on glucose levels.

Responding to these negative experiences, people with diabetes report changing healthcare professionals, or avoiding healthcare completely. Alternatively, they seek advice and support from family, friends or via the internet to avoid having to experience stigma from health professionals.

Friends, families and colleagues

Friends, families and colleagues often have close insight into the daily management routine of a person living with diabetes.

In witnessing day-to-day self-care activities, they may form unfair opinions of how the person with diabetes could 'do better'. While the behaviours of loved ones are usually well-intentioned, people with diabetes can experience these as unfair, judgmental and blaming.

People with diabetes report feeling blamed by others when it was perceived they were not managing their diabetes optimally.

Judgement may occur if the person without diabetes felt the person with diabetes was not eating particularly healthy foods, or if they witnessed the person with diabetes having a severe hypo. There was judgement associated with weight gain and the diagnosis of diabetes-related complications.

Some people with diabetes have reported being worried about disclosing their diabetes to their partners for fear it could negatively impact the relationship. Some people with diabetes have had a relationship ended by their partner (or their partner's family) as a result of their diabetes.

“She asked me if I exercise and I said ‘I do the gym twice a week’... ‘that’s not enough, you need to go five times a week!’”

Woman, age 35, type 2 diabetes

“A little too much readiness ... to believe that a type 2 diabetic is not going to do the things they should do to help themselves”

Man, age 56, type 2 diabetes

REDUCING DIABETES STIGMA IN OUR COMMUNITY

We can all do more to reduce diabetes stigma and support people with diabetes.

The International Diabetes Federation (IDF) has identified diabetes stigma as a problem that needs urgent attention. One of the IDF's key priorities is to "champion a world free from discrimination and stigma for people with diabetes".

Most cases of stigma arise because of thoughtlessness or misunderstanding. We cannot

expect everyone without diabetes to know everything about what it is like to live with and manage diabetes. What we can expect is kindness, respect and understanding.

Diabetes Australia is committed to raising awareness of diabetes stigma and to reducing it in our community.

"I once had people assume I was on drugs. But mostly they might wonder why I have food on-hand and why I'm taking a break"

David, lives with type 1 diabetes



As an individual, what can I do to reduce diabetes-related stigma?

- 1** Be kind, show respect, and support people with diabetes; do not contribute to the stigma they may experience
- 2** Understand that people with diabetes did not ask to get diabetes, no matter what type of diabetes they have
- 3** Understand that diabetes can be a demanding condition to live with; people are usually doing their best with the resources they have
- 4** Do not make people with diabetes feel uncomfortable when they manage their condition in public; they are doing this to stay healthy
- 5** Do not treat people differently just because they have diabetes; if they need help or special consideration, they will ask for it
- 6** Do not share or promote stigmatising images of diabetes on social media; do not make diabetes the punchline of a joke
- 7** If you are reporting on diabetes, check your facts, use respectful language and use appropriate imagery
- 8** Challenge stigmatising portrayals or reports of diabetes or people with diabetes: #SupportNotStigma
- 9** Acknowledge and encourage accurate, non-stigmatising portrayals of diabetes and people with diabetes
- 10** Do not discriminate against people with diabetes; it is against the Commonwealth Disability Discrimination Act 1992.

WHOLE OF COMMUNITY STRATEGIES TO ADDRESS DIABETES-RELATED STIGMA

- Develop and co-design education campaigns/approaches which focus on providing facts and evidence about diabetes, accompanied with lived experience to highlight how misconceptions about diabetes lead to stigma. Implement campaigns in different settings, including:
 - ◆ Schools
 - ◆ Places of employment
 - ◆ Community settings
 - ◆ Families
 - ◆ Healthcare settings
- Focus on listening to the lived experience of people with diabetes and their personal stories of stigma. Use media platforms to centre these stories to help understand the negative impact of diabetes stigma.
- Encourage and support more research into better understanding of diabetes-related stigma, its impact on people with diabetes and effective strategies to reduce stigma in the community.
- Work with diverse communities to develop culturally appropriate communication and education programs to address stigma in different communities
- Work with journalists, reporters and others writing and speaking about diabetes in the media to provide accurate portrayals of people living with diabetes, underscored with facts about the condition.
- Utilise different media platforms to dispel myths, challenge stereotypes and provide accurate representation of real life with diabetes.
- Broad adoption of Diabetes Australia's Language Position Statement as the document that is referenced when writing or communicating about diabetes.
- Call out the good! Highlight campaigns, media examples, which accurately portray diabetes and living with the condition.

SOURCE MATERIALS AND FURTHER READING

The data presented in this report have been published previously in the following articles and reports:

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