

LET'S CHANGE ← PERSPECTIVE

A guide to help everyone have empowering conversations about diabetes – and kick out stigma



CHOOSE A TOPIC TO START CHANGING PERSPECTIVES

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This guide has been developed by Abbott in partnership with Deborah Christie, Professor of Paediatric & Adolescent Psychology and Consultant Clinical Psychologist with input and guidance from Diabetes UK. The contents have been informed by conversations with people living with diabetes and insights from a UK-wide survey of 1,500 people with and without diabetes living in the UK.

Deborah Christie, Professor of Paediatric & Adolescent Psychology and Consultant Clinical Psychologist

Diabetes doesn't necessarily discriminate, but people can

How do you feel when you walk into a room with other people? Do you feel that there is something about who you are or how you look that means people see you as different?

Stereotypes or negative views that result in prejudice or discrimination are experienced as stigma. These can be due to where people come from, how they look, their sexuality, their education or social status, a medical condition, to name but a few characteristics.

Stigma towards people living with diabetes is widespread

Stigma is driven by what society believes and values about people and is the main reason for discriminatory behaviour.

In the UK, 4.9 million people live with diabetes¹. Abbott's survey of 1,500 people showed that 73% of people with diabetes have seen stigmatising behaviour towards the condition², which negatively impacts their lives and can lead to worse health outcomes^{3,4}.

For many there is a lack of understanding of the realities of living with a demanding, unpredictable and relentless condition reflected in the way school, college or the workplace responds to someone with diabetes.

People living with diabetes can also develop negative attitudes towards their own condition. This self-stigma can make people feel guilty, inadequate, embarrassed and angry⁴. The negative impact on a person's emotional wellbeing can affect their ability to manage their diabetes⁴, which could increase the risk of developing diabetes-related health complications⁴.

We all need to work together to change perspectives

This guide has been developed to help everyone – not just people living with diabetes – address and challenge the unconscious bias that drives diabetes stigma.

By coming together to confront unconscious bias and reduce stigma of diabetes, we can begin to change conversations and, hopefully, perspectives to help improve the lives of people with diabetes.

Diabetes UK. Diabetes statistics https://www.diabetes.org.uk/professionals/position-statements-reports/statistics. Accessed Nov 2022.
Data on file, 2022. Abbott. Survey among 1,500 participants, 2022.
Valentine V. 2019. The most important thing we give to people is hope: Overcoming stigma in diabetes and obesity. ADA Outstanding educator in diabetes award lecture. 33 (1): 89–94.
Liu NF. 2017. Stigma in people with Type 1 or Type 2 diabetes. Clinical Diabetes. 35 (1): 27–34.

STEP ONE: UNDERSTAND DIABETES STIGMA

Challenging the stigma around diabetes requires understanding and education.

DAN'S STORY*

Many people believe that there are only two types of diabetes. After I've explained that I live with Type 1 diabetes, I've had people ask me: **"Is that the easy one?"** There are many different types of diabetes and all types of diabetes have their own challenges and none of them are easy.

Situations like this make me feel frustrated because it undermines the challenges that everyone living with diabetes faces.

I'd like people to understand that diabetes isn't selfinflicted, it is a chronic condition and isn't easy. And those harmless comments are not harmless at all. 83% of people with diabetes and 75% of the public say people don't know enough about the condition¹

Emotional distress

Depression Embarrassment Fear Guilt Self-blame Shame

DIABETES STIGMA HAS SERIOUS CONSEQUENCES²

Social isolation

Hiding diagnosis from friends, family or colleagues Avoiding social or work activities

Increased risk of long-term health problems

Delaying self-care, e.g. skipping insulin injections Avoiding healthcare appointments or tests

*Dan is a FreeStyle Libre ambassad

1. Data on file, 2022. Abbott. Survey among 1,500 participants, 2022. 2. Diagram adapted from Browne JL, Ventura A, Mosely K, et al 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. BMJ Open 2013;3:e003384. doi: 10.1136/bmjopen-2013-003384.



Educate yourself, and don't rely on others to teach you

Take 15 minutes to learn about diabetes: www.diabetes.org.uk/diabetes-the-basics

Key facts:¹

There are two main types of diabetes: Type 1 and Type 2. They're different conditions, but they're both serious and complex.

What all types of diabetes have in common is that they cause people to have too much glucose (sugar) in their blood. But we all need some glucose. It's what gives us energy. We get glucose when our bodies break down the carbohydrates that we eat or drink. And that glucose is released into our blood.

We also need a hormone called insulin. It's made by our pancreas, and it's insulin that allows the glucose in our blood to enter our cells and fuel our bodies.

People with diabetes, depending on type, either cannot produce or have become resistant to insulin which ordinarily regulates glucose in the body. This causes glucose levels to become too high with the need for intervention to regulate, but with the right treatment and self-care, people with any type of diabetes can live a full and healthy life.

The management of any type of diabetes can be relentless for people living with it. Facing stigma on top of this can affect their emotional wellbeing and ability to manage the condition, which can lead to worse health outcomes.^{2,3}

Speak up if you hear stigmatising statements and don't let a person with diabetes deal with stigma alone.

DO SAY:

"That's not correct. I've been reading about diabetes, and this is what I've learnt..."

ADVICE FOR PEOPLE WITH DIABETES:



Talking to people about diabetes can help them understand the condition

If you feel comfortable, talking to people about diabetes can help them understand what the condition is really like. You don't have to go into loads of detail straight away; your diabetes is just another part of you that your friends, family and colleagues will get to know about.

DO SAY:

"That's a really common misunderstanding. Did you know that actually..."

DO ASK:

"It would mean a lot to me if you learnt more about diabetes. Can I share some information with you?"

STEP TWO: STOP HURTFUL JOKES AND COMMENTS

Through inadvertent jokes and comments based on common diabetes misconceptions, stigma is unfairly placed on people living with the condition. Diabetes is a serious and complex condition and not a punchline.

JOHNNY'S STORY*

Whilst buying sweets and chocolates, my friend exclaimed: "Look at all these sweets Johnny can't have!" They then bought lots of sugary snacks and enjoyed them in front of me. Whilst I could of course have had some sweets and just injected insulin to manage my glucose levels, the comment made me feel as though I had no other option but to pass on this occasion.

It made me uncomfortable because the comment was rude and inaccurate; however, I felt I could not say anything because of our close friendship.

If people had a better understanding of diabetes, it would reinforce how hurtful these backhanded comments are. 24% of those with diabetes say people's opinions have negatively impacted their ability to manage their condition¹





Words hurt. Think about the impact of your words and opinions

When someone tells you that something is disrespectful, you don't have to understand why they are hurt... just that they are

DON'T SAY: "It was just a joke"

DO ASK: "I'm sorry. How can I make this right?" Take some of the burden off people with diabetes and speak up if you hear inappropriate comments



DO SAY:

"Have you considered the impact of what you've just said? Diabetes is a serious and complex condition, and that comment wasn't appropriate."

ADVICE FOR PEOPLE WITH DIABETES:



Don't assume the person knows they're being offensive; it's possible that they don't understand what they're saying is hurtful

Throwaway comments are often caused by misunderstandings and misconceptions, but that doesn't mean they're acceptable



"I know you wouldn't say anything to intentionally hurt me, but what you said made me feel uncomfortable/upset/embarrassed because..."

If you are worried about how someone might react, it might be helpful to take the person aside or ask an ally to discuss on your behalf

STEP THREE: PUT AN END TO BLAME

The causes of diabetes are different and complex. No matter the type, or cause, diabetes requires careful and relentless management. Day in, day out, often for life.

VANESSA'S STORY*

People who I had only just met made judgements that the cause of my diabetes was linked to my lifestyle, saying: "**Oh, I see, was that because you ate too much sugar?**"

This made me feel upset, frustrated and a little emotional that people thought that I had brought the diagnosis on myself.

I think people need more education.

Almost **1 in 4** people living with diabetes feel personally responsible for their condition.¹ This can lead them to experience guilt, shame, blame, embarrassment and isolation, and have a negative impact on their ability to manage their condition²



Images are for illustrative purposes only. Not actual patient. *Vanessa is a FreeStyle Libre ambassador 1. Data on file, 2022. Abbott. Survey among 1,500 participants, 2022. **2.** Liu NF, et al. Stigma in people with Type 1 or Type 2 diabetes. Clin Diabetes. 2017 Jan;35(1):27-34. doi: 10.2337/cd16-0020.





Diabetes is a complicated condition and is not caused by any one thing

CON'T

- Make assumptions. Much stigma around diabetes is based on misconceptions and misunderstandings around the causes of diabetes. Find out more at
 - www.diabetes.org.uk/diabetes-the-basics

> DO

- Look at the whole person and not their condition
- Be curious. Ask "Is it OK for me to ask you about your life with diabetes?"

ADVICE FOR PEOPLE WITH DIABETES:



Acknowledge and appreciate the hard work done by you to effectively manage diabetes

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• Be kind to yourself. When others inadvertently place the blame on people with diabetes, it can be easy to internalise these critical voices and make them your own. Compassion can help you break the cycle of self-blame, so give yourself the same care you would give to a friend

Connect with people who share your experiences:

- Join a local <u>support group</u>
- Speak to your diabetes team
- Talk to a trained advisor
- Get involved in the diabetes community on social media, e.g. #GBDoc
- If you feel comfortable, take opportunities to tell your story and help people to understand the decisions you face every day related to your diabetes

X) DON'T

• Don't blame yourself. Your story and your life with diabetes are unique to you



STEP FOUR: SHUT DOWN FOOD SHAMING TALK

Diabetes doesn't necessarily discriminate because diabetes affects people of all shapes, sizes, ages and backgrounds. But people can discriminate, by offering unwanted advice and opinions about someone's diet and lifestyle. People with diabetes can enjoy all that life has to offer through self-management. This takes a lot of time and experience and is different for every person.

ELISE'S STORY*

I was having a hypo (very low blood glucose) in the staff room at work and one of my colleagues came in. As I was eating a biscuit she said: "**Should you really be eating that**?"

I felt judged and embarrassed as other colleagues were there and no one said anything. These types of comments really make me feel isolated like no one understands what I'm going through.

We can eat pretty much like everyone else; we just have to inject insulin, too.

LAURA'S STORY*

When I was travelling in Malaysia on my gap year, my diabetes came up in conversation with a guy in the dorm room I was in. **He suggested I try a vegan diet** which he swore would do wonderful things for my health and even cure my diabetes.

I felt annoyed at the lack of understanding, and incredibly patronised!

7 in 10 people incorrectly think that people with diabetes should give up sugar¹



People with diabetes know how to manage their condition best

As you should in any situation, avoid comments that pass judgement on what someone is eating or their weight

DON'T SAY:

- "Are you really going to eat that?" "Should you be more careful with what you eat?"
- "You shouldn't eat sugar if you have diabetes"
- "If you try this diet/ lose weight, you'll cure your diabetes"

If you hear someone else passing judgement, help them understand why it's not appropriate



DO SAY:

• They are the expert in their own body. Telling someone how to manage their condition can be hurtful and unhelpful

ADVICE FOR PEOPLE WITH DIABETES:



It's no one's business what you eat. Do what you know is best for you and your body

Responding to these comments may help people in your life understand that they've acted inappropriately



DO SAY:

"I feel judged/annoyed/upset when you question what I eat. I know how to manage my diabetes and you don't need to worry about my diet."

If you don't feel like calling someone out, ask an ally to challenge this on your behalf



Images are for illustrative purposes only. Not actual patient.

STEP FIVE: CREATE INCLUSIVE SOCIAL SITUATIONS

Advice and comments based on common misconceptions can be hurtful to people with diabetes in the online world and in real life. It's important, as in all walks of life, to see the whole person, who is so much more than their diabetes.

KEN'S STORY

On social media my experience is that Type 2 diabetes is ridiculed and not taken seriously. People with Type 2 diabetes are not considered to really have diabetes as we can be 'cured' through the many 'diets' and interventions that people volunteer as truth.

These comments make me feel like a pariah and that those of us with diabetes other than Type 1 should not comment on diabetes.

ELISE'S STORY*

Sometimes I am not offered **'bad food'** at work or in social circumstances because people think you can't or shouldn't eat it.

It makes me feel excluded, isolated and embarrassed.

People with diabetes know what they can and can't do; we can make that judgement call ourselves and don't need that decision made by someone else. People with diabetes report feeling self-conscious¹, judged and constantly monitored, which fuels self-blame²

*Elise is a FreeStyle Libre ambassador

1. Data on file, 2022. Abbott. Survey among 1,500 participants, 2022. 2. Schabert, J., Browne, J.L., Mosely, K. et al. Social Stigma in Diabetes. Patient 6, 1–10 (2013). https://doi.org/10.1007/s40271-012-0001-0.



Don't make assumptions. The first step to inclusivity is putting aside any preconceived ideas about other people

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- Try to understand that diabetes requires careful and relentless management, including monitoring glucose levels and administering insulin or other medications
 - You don't need to feel sorry for the person with diabetes, it's just part of their daily life – but you can ask if they need you to support them in any way
- Be an ally if someone else is making the management of their diabetes difficult or uncomfortable
- Treat people with diabetes as equal
- Allow people with diabetes to make their own decisions about their condition and what they choose to do

ADVICE FOR PEOPLE WITH DIABETES:



Diabetes doesn't need to get in the way of your social life

DO:

- If you feel comfortable, explain that diabetes doesn't prevent you from doing anything that you want to
- Let friends and colleagues know about your condition and what this entails: from how often you need to check your glucose levels and when you need to inject or take medication, to what to look out for/do if you have a hypo. The more you are able to normalise this for others, the more they can do the same as an ally. Having support in social situations can make all the difference
 - Don't ever feel like you need to hide your diabetes or management from anyone to make others more comfortable

- Suggest social activities at times that work better for you and your diabetes
- Plan ahead to make sure you have everything you need to manage your diabetes to help you be better prepared and enjoy your time



STEP SIX: REMOVE WORKPLACE LIMITATIONS

Having diabetes should not stop you from having equal opportunities in every aspect of work life.

MARK'S STORY

Shortly after being diagnosed with Type 2 diabetes, I was away on site with work (ironically at a confectionery factory!) I was running classroom training on a software package.

I was, at the time, sticking religiously to my insulin injection schedule. In order to inject I asked the students if they minded and no-one said anything, so I turned my chair away from my students and injected.

That evening **I got a phone call from my boss saying I had made the trainees feel uncomfortable** by doing so. He asked if in future I could go to the loo to inject.

I felt annoyed, embarrassed and frustrated. I felt that it was a fairly callous disregard of the effect diabetes was having on my life. Just over 70% of the general public wouldn't inform work colleagues if they lived with diabetes¹



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Lead by example to create a welcoming environment

If you witness stigma in the workplace, it's important to address it straight away

DO SAY: "Your comment or behaviour wasn't okay"

Every person with diabetes is an individual, which means the best way to make someone feel comfortable is to ask what they need



DO ASK:

"If you were giving me advice on how to really show up as a colleague to make the workplace fair and welcoming, what would you say?"

Introduce or request diversity sensitivity training to improve the working environment for colleagues with long-term conditions

For more information, read the Diabetes UK guide to supporting people with diabetes in the workplace

ADVICE FOR PEOPLE WITH DIABETES:



The better your colleagues understand your diabetes, the easier it will be to get the support you need

- It's a good idea to tell your line manager about your diabetes. If they know about your condition, they will be better equipped to give you the support you need
- If you feel comfortable, encourage your colleagues to ask you questions and give them the information they need to better understand and support you
- For more information, read the Diabetes UK Guide to Work and Diabetes



FURTHER SUPPORT

Talk to your diabetes team – they will be able to offer advice and support

Diabetes UK is the major organisation for support, information and research relating to all types of diabetes mellitus.

Phone: 0345 123 2399

Email: helpline@diabetes.org.uk

URL: www.diabetes.org.uk

Find your local Diabetes UK group: www.diabetes.org.uk/how_we_help/local_support_groups

JOIN THE CAMPAIGN

Abbott's *Let's Change Perspective* campaign is set to explore and highlight elements of stigma faced by people with diabetes and help create better conversations around this complex condition. **We need to act now**. By coming together to confront unconscious bias and reduce stigma of diabetes, we can begin to change perspectives and improve the lives of people with diabetes.

For more information, visit letschangeperspective.abbott

Share your own experience with diabetes stigma and advice on social media about how you think we can start to change the conversation and, hopefully, perspectives.

#LetsChangePerspective

LET'S CHANGE PERSPECTIVE



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