

Diabetes related stigma

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Why focus on diabetes stigma

- Working from the premise that no one should be stigmatised because of a health condition
- Taking a collaborative and curious approach to tackling stigma
- Our research showed obesity related stigma as a theme in diabetes stigma



Understanding diabetes stigma

Exploring the prevalence, experiences and impact of stigmatising attitudes, language and behaviour on people living with diabetes

Establish the breadth of personal experiences as a result of stigmatising attitudes

Understand the impact of stigma both immediate, and long-term on those living with diabetes

Establish the range of views that people living with diabetes consider stigmatising

Identify the sources of stigmatising attitudes: direct and indirect

Who we spoke to

STAGE 1: 16 X 75 MIN ONLINE INTERVIEWS

- 6 x Type 1 diabetes
- 8 x Type 2 diabetes
- 2 x Gestational diabetes

Within the 16 interviews:

- 6 x South Asian participants
- 5 x participants diagnosed in the last 2 years
- 6 x participants have lived with diabetes for between 5-10 years
- 5 x participants living with for over 10 years

STAGE 2: OPTIONAL 2 WEEK DIARY

- 9 x Participants from stage 1 interviews
- 4 x Type 1 diabetes
- 3 x Type 2 diabetes
- 2 x Gestational diabetes

STAGE 3: SURVEY N=450

- People living with, or at risk of, diabetes
- Type 1 n=155, Type 2 n=281
- Broadly representative by age, gender and ethnicity of those living with diabetes.
- Boosted sample of those living with Type 1

ACROSS THE SAMPLE:

Diversity of ages, gender, social grade, disability, self identify as living with overweight or obesity

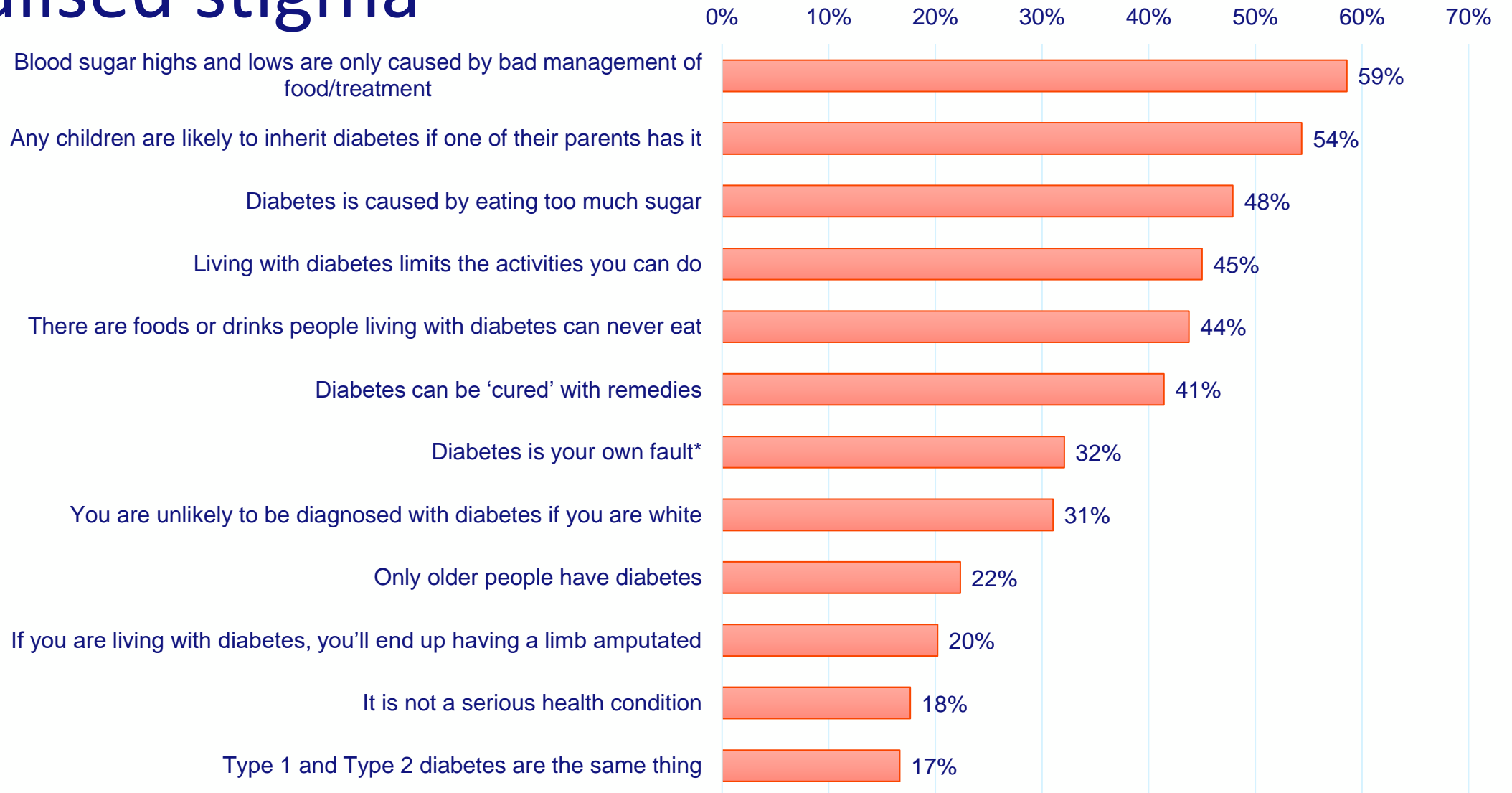


People living with diabetes believe many of the myths and misconceptions themselves



Internalised stigma

SELF BELIEF IN MISCONCEPTIONS



Q. To what extent, if at all, do you believe any of these misconceptions yourself? n=58-190

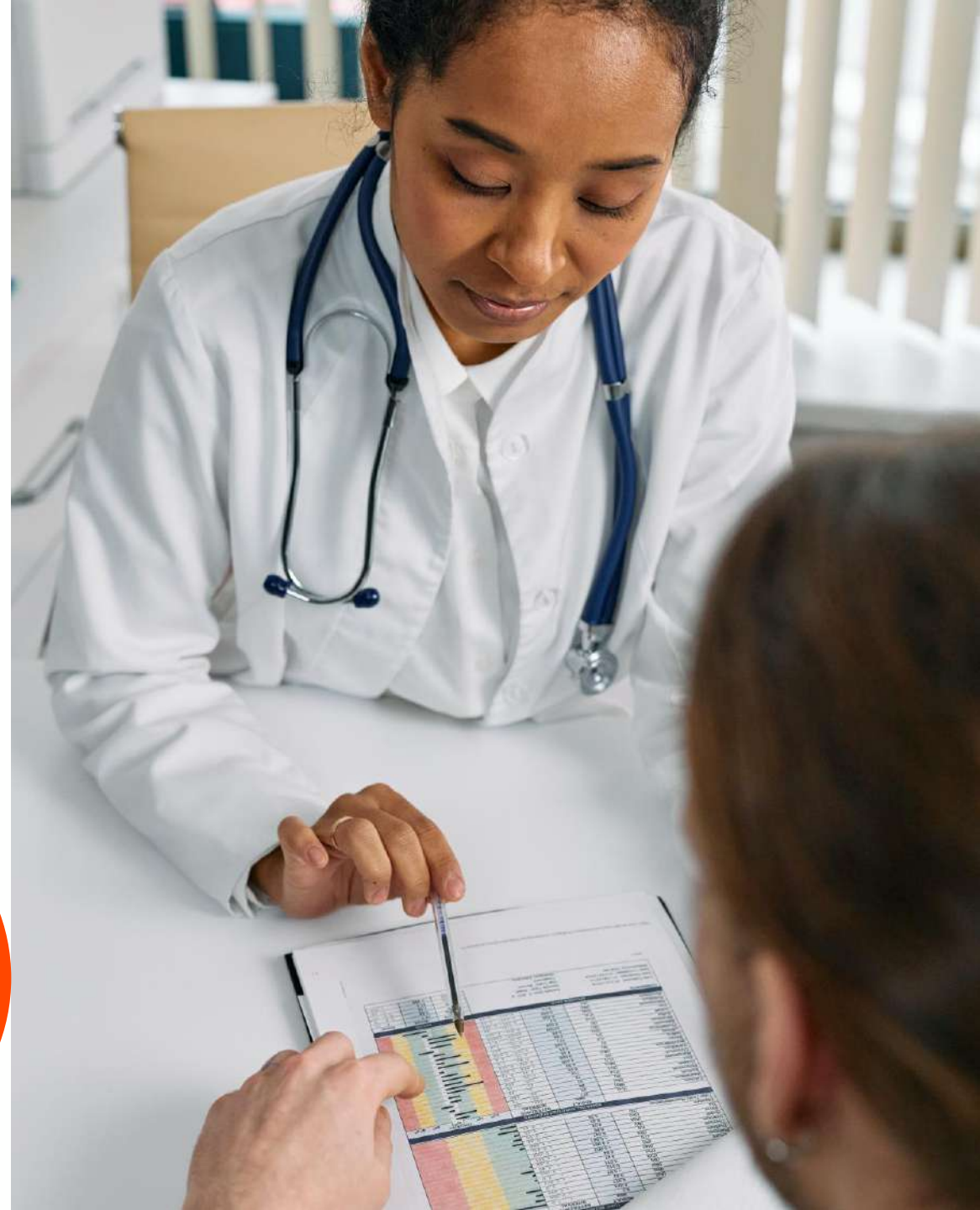
Stigma means that over half of people living with diabetes miss healthcare appointments

72%

Would find training for HCPs in how diabetes affects people differently useful

1 IN 5

Experience stigma from HCPs at least a few times a year

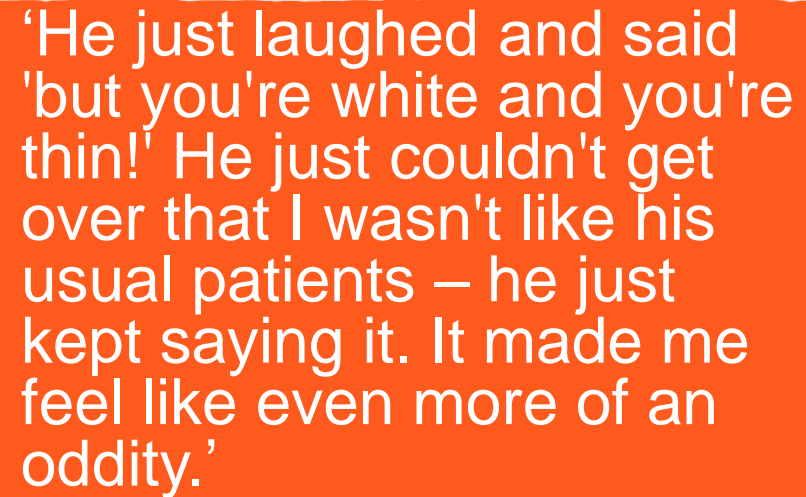


**Making comments
that can confuse
patients or make
them feel more
'othered'**

**Feeling 'told off' if
your sugar levels
are fluctuating or
your 'lifestyle' has
not improved**

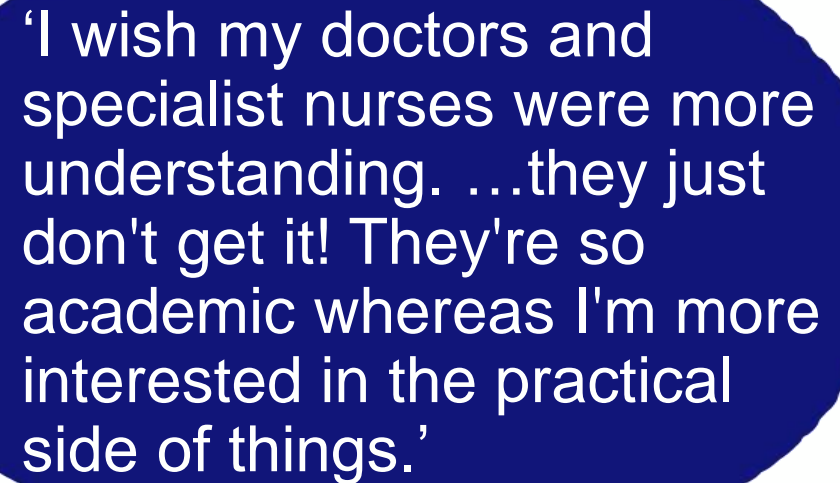
**Being treated like 'a
diabetic' rather than
a person.**

**Not understanding
that everyone's
symptoms and
experiences will be
different**

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'He just laughed and said 'but you're white and you're thin!' He just couldn't get over that I wasn't like his usual patients – he just kept saying it. It made me feel like even more of an oddity.'

Male living with type 2, 67yrs

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'I wish my doctors and specialist nurses were more understanding. ...they just don't get it! They're so academic whereas I'm more interested in the practical side of things.'

Male living with type 1, 40yrs

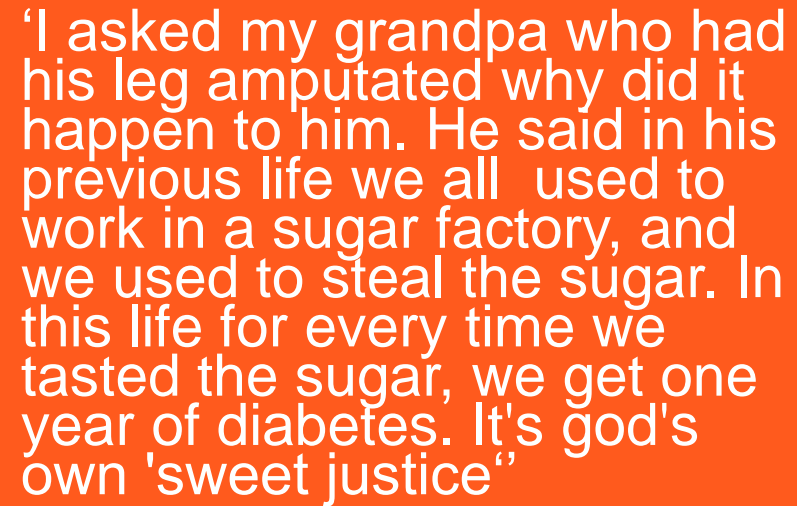
**People with South Asian
heritage often experience
stigma intensely**



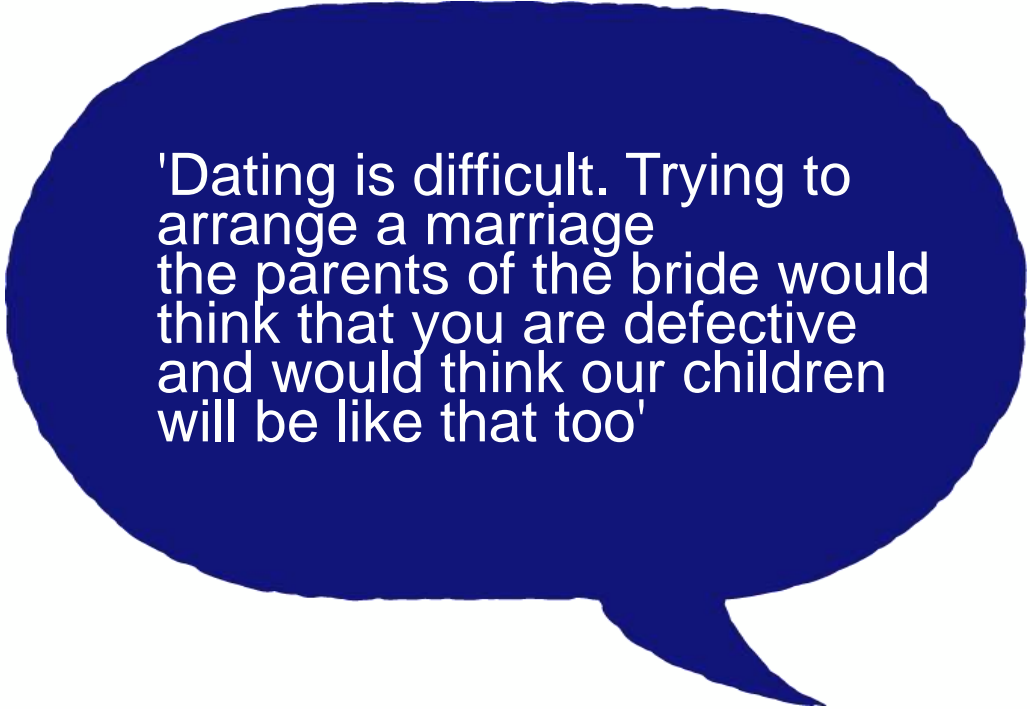
Seeking to understand why you have this condition when the rest of the family doesn't

Asking you to hide your condition from other family members or potential spouses

Seeking to rationalise your diagnosis via religion or 'karma'

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'I asked my grandpa who had his leg amputated why did it happen to him. He said in his previous life we all used to work in a sugar factory, and we used to steal the sugar. In this life for every time we tasted the sugar, we get one year of diabetes. It's god's own 'sweet justice'

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'Dating is difficult. Trying to arrange a marriage the parents of the bride would think that you are defective and would think our children will be like that too'

How we'll tackle diabetes stigma

- Published our research findings to raise awareness
- Funding research projects into stigma
- Proactively talking about stigma

Short term:

- Enabling people to share their experiences
- Supporting people who experience stigma
- Engaging with existing audiences including HCPs

Long term:

- Changing the public's knowledge, attitudes and behaviours towards diabetes

Throughout all our work:

Learning from people with lived experience and aligning with our tackling inequality commitments

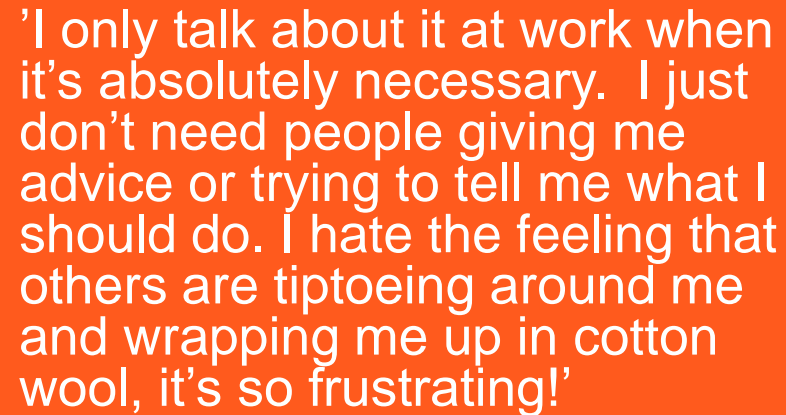
Thank you

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DIABETES UK
KNOW DIABETES. FIGHT DIABETES.


Friends, family and colleagues are the most prominent sources of impactful stigma



An orange speech bubble with a white outline and a tail pointing towards the bottom left. The text inside is white and reads: 'I only talk about it at work when it's absolutely necessary. I just don't need people giving me advice or trying to tell me what I should do. I hate the feeling that others are tiptoeing around me and wrapping me up in cotton wool, it's so frustrating!'

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Male living with type 2, 62yrs

A dark blue speech bubble with a white outline and a tail pointing towards the bottom right. The text inside is white and reads: 'My family make plans around my diabetes, without even asking me. They say things like, 'we were gonna have pasta, but then we remembered you so we're doing grilled chicken instead.'

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Female living with type 1, 30yrs

'My aunt said stop crying, you're only doing it to get attention, she thinks that's what I'm doing with the diabetes too – crying for attention.'

Female living with type 2, 37yrs

1 IN 5

Experience workplace stigma at least every few weeks

1 IN 4

Experience stigma in the home at least weekly

The impact of stigma

Stigma at work and home has the highest impact on self

Stigma in the media is annoying and frequent but has less impact on self

At work with colleagues or customers
In the home with friends and family
In restaurants or when eating outside of the home
In supermarkets or when food shopping
From doctors, nurses or other healthcare professionals
In the media: TV, radio, film or online

STRENGTH OF RESPONSE	FREQUENCY IT HAPPENS	IMPACT ON SELF
HIGH	MEDIUM	HIGH
MEDIUM	HIGH	HIGH
HIGH	LOW	MEDIUM
MEDIUM	MEDIUM	MEDIUM
HIGH	LOW	LOW
HIGH	HIGH	LOW

Q. Of the different locations/people you've experienced negative attitudes which has the biggest negative impact on you? n=143-280