Talking about Diabetes: Language Matters

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The *Diabetes Language Matters* movement supports better communication **with** and **about** those living with diabetes. It is not a new concept; it started in Australia in 2011, and since then, many countries have followed suit with their own versions of guides and position statements. See:
https://www.languagemattersdiabetes.com/

Diabetes is a complex condition affecting approx. 300,000 people in Ireland. No one causes their diabetes, yet people living with diabetes often encounter stigma, discrimination, and stereotypes. There is plenty of evidence to suggest we can improve our messaging, body language, and spoken word to be more supportive of the person living with diabetes. So, how we speak and write about diabetes matters!

There are different types of diabetes - to read more about them visit:
https://www2.hse.ie/conditions/diabetes/

In early 2023, the Diabetes Language Matters Ireland Working Group came together to develop an Irish version of a *Diabetes Language Matters* guide. This group consists of people with lived experience of diabetes, academics, and healthcare professionals.

This short Irish Language Matters guide aims to raise awareness of how improving communication with and about people with diabetes can make a difference in supporting people living with the condition. It was developed to support people working in the media as well as the general public in Ireland.

Why Diabetes Language Matters

The evidence suggests that the words used to describe diabetes and about people with diabetes have an impact on both the emotional and physical well-being of those living with the condition.

Words have the power to both heal and harm. They can create a space that is both positive, where a person can feel supported and understood, or negative, where they can feel stigmatised, undervalued, blamed, and misunderstood.

Many of us have not considered or realised the influence our words can have. We often do not reflect on whether we express a conscious or unconscious bias. Yet, how we communicate can have a profound effect on outcomes, self-management, and experience of healthcare for the person living with diabetes.

There is a lot of evidence demonstrating how words impact the person living with diabetes

- Language used in the media can be stigmatising

- Language used at diagnosis has a lasting impact on the person with diabetes

- Language around diabetes can be confusing, inaccurate, unrealistic and harmful

- Language affects self-management. For example, during a clinic experience a person can feel supported, understood and confident or belittled, criticised and patronised

- Language around diabetes can affect emotional wellbeing. People with diabetes report feelings of guilt, frustration, and anxiety around blood glucose levels and food choices which may be triggered by the language they hear around self-management

- Language contributes to social stigma which can include unhelpful comments and judgement leading to diabetes distress, depression and lowered self-esteem

- Language affects self-care, for example attending medical appointments and taking medication

- Language affects clinicians' attitudes

- Language isolates people affected by diabetes leading to loneliness
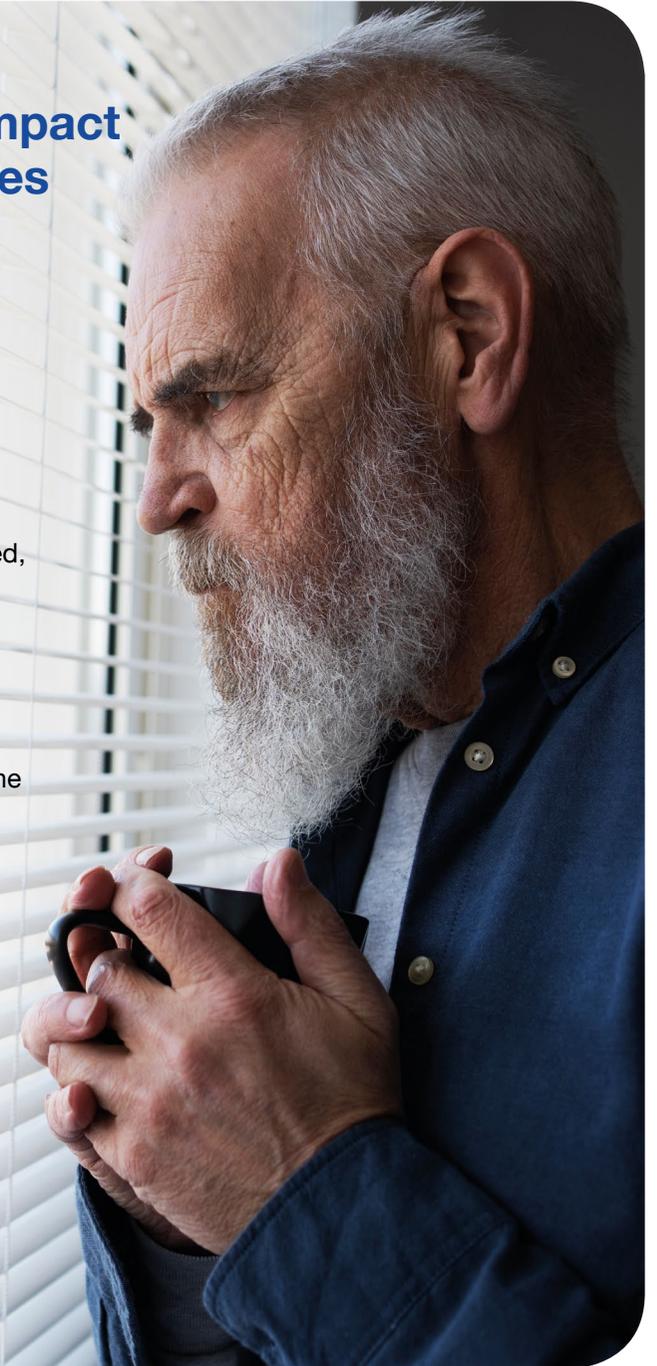
Recommended Language

It is recommended that language be:

- person-centred

- free of stigma

- neutral, non-judgmental, and based on evidence

- strengths-based, respectful, and inclusive

- collaborative with the person living with diabetes

When talking about diabetes in the media we ask that the messaging be trustworthy, reliable, honest, caring, and compassionate.

- Avoid using blameful language like "failed to control" or "non-compliant." Diabetes management is complex and influenced by various factors.

- Recognise the daily efforts of people with diabetes in managing their condition.

- Be understanding about the challenges people with diabetes face and the constant need for monitoring and decision-making.

- Using words like "be healthier" instead of "be healthy" takes away any assumption a person does not have any health promoting behaviours.

Quotes from People with Diabetes

"I get asked "Are you allowed to eat that?" or "Should you be eating that you can't eat sugar", all the time. Once a friend snatched the bar, I was using to treat a hypo out of my hand and threw it in the bin."

Rebecca, Person living with Type 1 diabetes, Cork

"When I see diabetes represented in such a simplistic way in newspapers, I get so annoyed. It's such a complicated condition to manage, it really isn't just about diet and exercise and usually, what is headlined as a life-changing therapy really isn't."

Martin, Person living with Type 2 diabetes, Co. Clare

"You really should be trying to lose some weight, aren't you going to put your baby at risk?"

Simone, Person living with Gestational Diabetes, Dublin

Who this document is for:

If you write or speak about diabetes or know someone living with diabetes, please think about your use of words and consider using some of the suggested alternatives below.

Words/ phrases to avoid	Preferred Language	Why?
'Diabetic'	Ask individuals if they prefer diabetic or person with diabetes. If this is not possible, using Person/People with Diabetes is preferred.	A Person with Diabetes is not defined by their condition. Put the person first to avoid using their condition to describe them.
Sufferer 'Suffering' from or with diabetes.	Person living with diabetes (PLwD): While some people may find diabetes management and its complications challenging and distressing, not everyone 'suffers' with diabetes.	Referring to people with diabetes as "diabetic sufferers' positions them as helpless victims, unable to lead a normal life with diabetes.
Patient (If not an inpatient and/ or outside of the clinic context).	Person living with diabetes or as above or with lived experience/ service user.	The term 'Patient' implies they are passively receiving care rather than being actively involved in their own care. Patients are people, and people are individuals, with their own preferences, priorities and lives beyond diabetes.
Non-diabetic / Normal / Healthy (to describe those without diabetes).	Person without diabetes.	The opposite of normal is abnormal, and people with diabetes are most definitely not 'abnormal'.
Compliant or non-compliance 'He is non-compliant with taking his insulin'.	Engaged/ involved. 'He takes his medication when he is reminded using his app'. His/Her diabetes management plan is not working for them at the moment.	Diabetes relies on self-management; it involves collaboration between the healthcare team and the Person with Diabetes. The aim is to focus on what someone does well and how this can be built on.
Sugar level (as in blood sugar level).	Blood glucose level.	This can lead to confusion that only sugary foods raise glucose levels when, in fact, all carbohydrates can contribute to glucose levels. This can also stigmatise eating certain foods, causing fear of eating some nutrient-dense foods, e.g. fruit.
'Control' (As in 'poor/well controlled diabetes'). 'Her blood glucose levels are poorly controlled'/or 'Well controlled diabetes'.	Managed. 'Checking her glucose levels when suits her schedule'. Use phrases like glucose levels are within / above / below target ranges. Use words that don't imply judgement or shame.	The word 'control 'implies blood glucose is easily kept in range - which is nearly impossible to achieve. People with diabetes will be supported by their diabetes team on the target results that are individual to them.
Normal weight, Obese	Ask permission to discuss weight rather than just to assume. Raise issue in a sensitive way. "Ideal weight" could be used instead of normal weight. If a person has a high BMI they may prefer to use larger weight/plus size.	Body weight is influenced by numerous factors that are outside a person's control. Use language that is not shaming or stigmatizing. People with diabetes will be supported by their diabetes team on the targets that are individual to them. There is a separate Language Matters Obesity document which may be helpful to refer to **https://tinyurl.com/bdtxk9db**
Diabetes can be 'reversed' or put into remission (Avoid making general statements about diabetes without stating which type you are referring to)	Always make sure to state which type of diabetes you are referring to when making broad statements otherwise this could be misleading and inaccurate.	Type 2 diabetes remission is possible in some cases, but may not be feasible for all. Type 1 diabetes cannot be put into remission.
In relation to the topic of **"Diabetes complications"**, avoid using scaremongering words such as **"killer/deadly disease"**. At risk of going blind from this 'deadly' disease	Raised glucose levels over time can pose a risk for a number of complications.	Avoid scaremongering or using terms that have overtly negative tones. The term complications is complex, unclear and may be fear-inducing. The key is to raise awareness and focus on prevention, health checks, detection and treatment plans.

In summary

Language will continue to evolve as our understanding of all types of diabetes grows.

Harmful, stigmatising words are mostly unintentional. It can take time to change our language and while we highlight the need for change it should always be done in a non-accusatory manner particularly on social media.

Stay informed and open. Keep up to date by referring to guidelines by reputable organisations and keep listening to the diabetes community.

Links for further resources and reading

- dStigmatize

- NHS England - Language Matters:
  Language and Diabetes

- Obesity UK - Language Matters: Obesity

- Diabetes Australia - Our Language Matters

- Language Matters Diabetes

- HSE Diabetes

- End Diabetes Stigma

Examples of Language in the Media

✘ Typical Headlines:

Suffer with diabetes? Then this diet could ERADICATE your deadly type 2 diabetes

Soup and shake diet can reverse diabetes

Urgent HSE warning over major pregnancy risk that could cause blindness

Health Today

DIABETES REMISSION: HAVING A HEALTHY AND BALANCED DIET IS KEY FOR EVERYONE
- but it can be even more important if you live with diabetes.

NEW TREATMENT OPTIONS FOR TYPE 2 DIABETES OFFER REMISSION FOR SOME

Health Today

Health Today | June 2023

New HSE screening service aims to limit sight loss risk in pregnant women with diabetes

✔ Better Headlines:

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