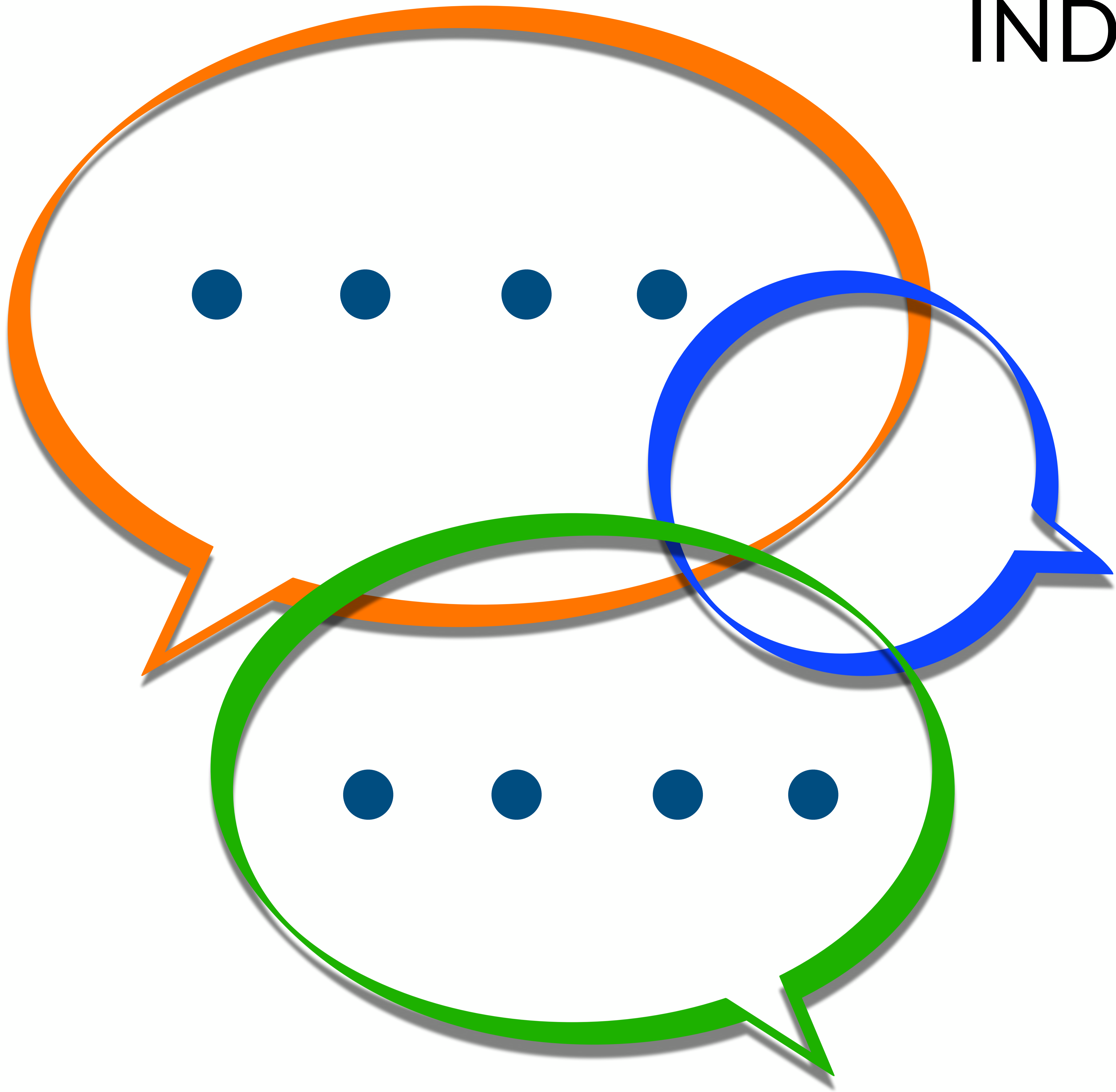


INDIA



LANGUAGE MATTERS

बातों ही बातों में

*A comprehensive guide of the importance of language in
Type 1 Diabetes care*

मीठी बातों के मायने In collaboration with NHS UK

The Lived Experience

“Raise your words, not voice. It is rain that grows flowers, not thunder”.- Rumi

The world of health is often fraught with language that brings more ‘fear’ than ‘comfort’ to a person who is already struggling with living a life filled with doubt and uncertainty. This is often done with good intent by health care professionals in an attempt to provide clarity and advice, but for a person like me, who is actually living with Type 1 Diabetes, it provides less motivation, and more hesitation.

When I was diagnosed with T1D at the age of 13, I felt there was an unsaid transition from being a person, to being a patient. The conversation around me was always about medication, blood sugar levels, doses and timings. Whenever the word ‘*suffers*’ was used, I would cringe – and still do. Sympathy was always an undertone. It hurt, being made to think that your life will only revolve within the four walls of a clinic. But even outside the hospital I still get told – ‘you got diabetes because you ate too much sugar’ – and it’s frustrating! The taboos and stigmas that revolve around T1D add further fear, confusion and doubt. There is a clear gap between what T1D is, and what it is made out to be.

A new initiative, *Language Matters*, aims to bridge that gap. To make people like me feel like a *name*, and not just a *number*. To make us feel like *people* and not just *patients*. To turn the conversation from *sympathy* into *empathy*. And to inform and address families with facts, in a way that will offer them *comfort* and not *confusion*.

A lot of the reasons mentioned above, push people living with diabetes to hide, stay quiet and be scared of their condition. The hope is, that with *Language Matters*, health care professionals will become constant guides, who are approachable and empathetic – people we choose to go to constantly, not are forced to go to. Hopefully, *Language Matters*, can help bring T1D out of the darkness, into the warm shining light.

Because at the end of the day, change can be made baaton, hi baaton main..

Jazz Sethi, living with Type 1 Diabetes
Founder, Diabesties



Joining Hands

“Coming events cast their shadows before” - Thomas Campbell

My first diabetes clinic as a junior doctor was in the UK in 1977. No blood glucose monitoring, no glycated haemoglobin and only urine testing, red and black line diets and glass syringes. Not only was the spoken language inappropriate – but so was the body language. The senior physician sitting behind a desk wearing a suit and a white coat was like a school headmaster – with the misbehaving pupil sitting in a small chair across the desk from the consultant. Lessons on how to boil (sterilise) syringes were given and often the newly diagnosed person with type 1 diabetes was advised to practice injecting into a piece of fruit like an orange! They left the consulting room in fear and not understanding their condition.

The Scottish poet Campbell wrote the words at the top of this preface. If the coming event is a happy life, long-living and free of the complications of diabetes, then the “shadows” as outlined above will not result in that event occurring. Young people were frightened and understandably in fear after that consultation – and often the coming event was characterized by poor understanding of diabetes, poor glycaemic control and the development of late complications.

This need not be so: huge advances have occurred in the management of diabetes. In Manchester we moved the diabetes “clinic” outside the hospital into a special centre: no white coats were permitted and the writing desk placed against the wall so that we sit with our patients. Moreover, huge advances have been made in the treatments – pumps, continuous glucose monitoring and so on. These will only work if the healthcare provider is empathetic, speaks the same language and listens. But not only must they listen – they must hear! Then the appropriate shadows are cast and a fulfilling, healthy long life free of complications will hopefully follow.

The language we speak to those with diabetes is pivotal – especially when diabetes is first diagnosed, but our body language is equally important. Let’s help our patients fit diabetes into their lives – and not be terrified or “taken over” by the diagnosis.

This is therefore a most important guide on “Language Matters” and I hope all those in one of my favourite countries, India, who read this find it helpful in their approach to not only newly diagnosed but long-standing patients with type 1 diabetes.

Professor Andrew JM Boulton, MD, FICP, FACP, FRCP

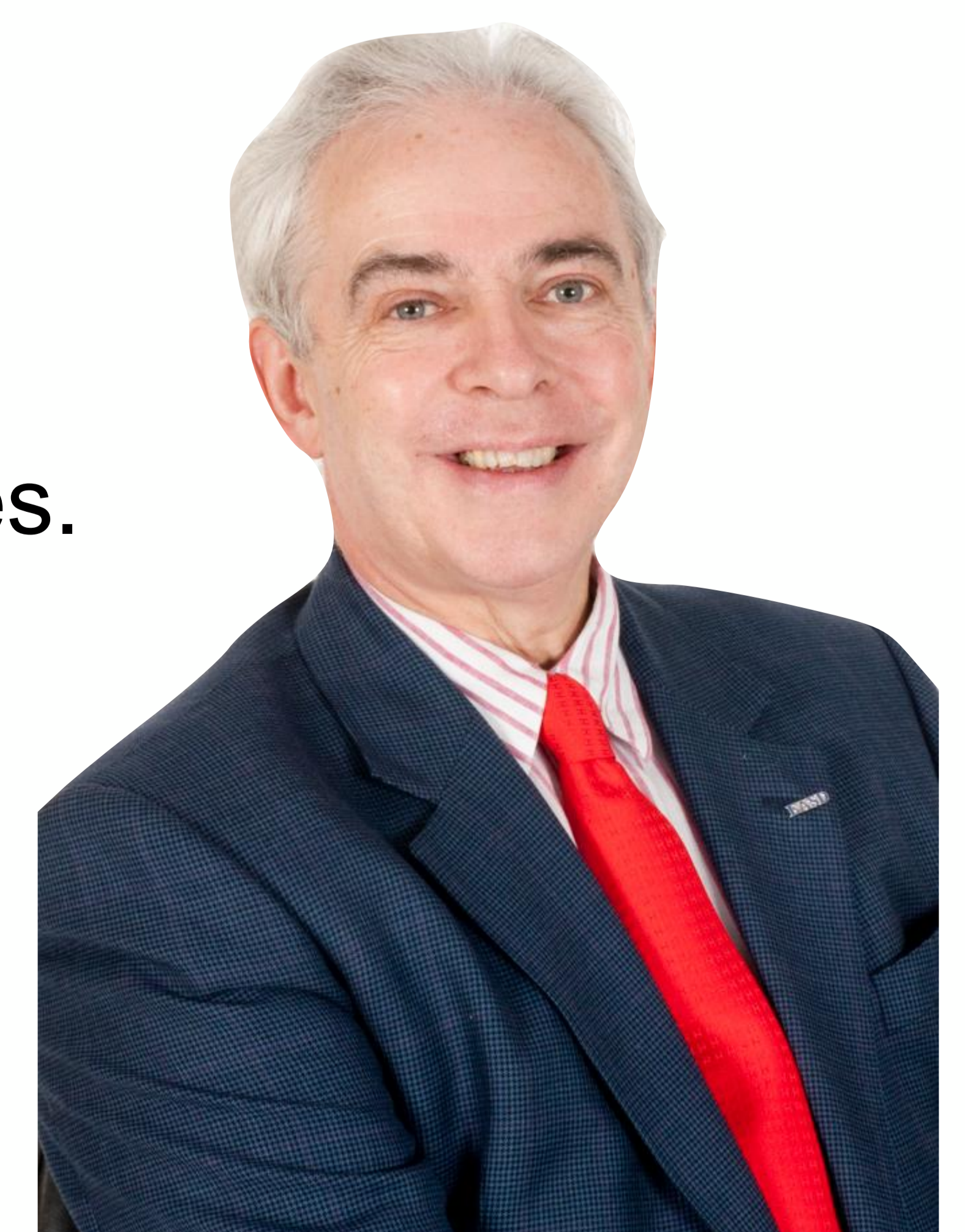
President, International Diabetes Federation.

Past-President, European Association for the Study of Diabetes.

Professor of Medicine, University of Manchester.

Consultant Physician, Manchester Royal Infirmary.

Visiting Professor, University of Miami.



Views from the top

Diabetes Diversity, in terms of the chronic metabolic state, population temperament, outcomes, care and values is too evident. As a Diabetologist passionate about Paediatric Diabetes care and standardisation, my heart goes out to the gap of understanding between the physician and the population fighting this constant fight against the evil of diabetes.

A pen is mightier than the sword – is an old proverb implying the importance of the use of the words used to convey the message about the gravity of the disease which requires the HCPs to be the coach in the lifelong match against Diabetes. The kids, who we all love shall grow into stubborn adults who are like wet clay requiring moulding. Any wrong words and the scars might make a permanent impression!!!

The need of the hour is to bridge this gap through kindness and proper warmth of heart using appropriate language to pass on the implications that Diabetes might bring along with it without offending these angels who require timely coaching and empowerment.

My honest opinion is that we need to be the guide to these travellers, traversing the harsh path of diabetes, through use of kind yet meaningful training to extract the best from them.

Communication is the key skill to portray our abilities to make a difference in the lives of the people with Diabetes and “Language matters” is portraying the use of effective mannerisms to convey just the best ways to bring a change.

Lots of warmth to the empowered leaders and more power to the younger ones!!!

My best Wishes for Language Matters

Dr. Banshi Saboo
President, RSSDI



From the other side

Health care professionals often feel frustrated at their inability to motivate persons living with diabetes to manage themselves properly. The reason, more often than not, is their inability to explain their prescription in a friendly manner.

Modern medicine is based upon the study of pathogenesis, and physicians tend to think, speak and act in terms of pathology. This approach, however, may not be pleasant for persons living with diabetes, who prefer a more 'salutogenic', or health-oriented style. Most diabetes care physicians, unfortunately, are not trained or qualified in communication skills. *Language matters* steps in to correct this lacuna.

Language matters shares the nuances of person-friendly, optimistic and motivational conversation, in a simple and effective manner. The practice-based text, which includes real-life examples, encourages the reader to analyse his/her earlier conversations, and improve future interactions.

Language matters is the VAT of diabetes therapy. It imposes no tax upon the practitioner; rather, it is a Value-Added Therapy which will help improve diabetes care in our country.

Dr. Sanjay Kalra

President, Endocrine Society of India;
Bharti Hospital, Karnal, India



Bridging the gap

Life is never easy- the daily ups and downs, the responsibilities, the roles, the battles with curveballs thrown at you by society, family, luck- and they all add up to making life anything but simple.

Add in the issue of Type 1 diabetes, the multiple times one has to keep an eye on their levels, the need to take insulin simply to keep one self alive, trying to be aware of the fluctuations brought on by stress, a mistimed dose or indeed a Coca Cola which the waiter forgot to mention wasn't of the Diet variety- and life is even more complicated.

As health care professionals who don't have to live with Type 1 diabetes and its challenges, the focus of this piece of work is to raise this simple issue- a simple fact that we don't live the lives of others- and to keep that at the back of our mind when we see those with Type 1 diabetes. In the fleeting moments of our patients lives when we can be a guide, that's all we can be- and not try to dictate what could or should work based on the books we have studied. Lived experience is something different- yet in the heat of a busy clinical life, we sometimes forget the primary role of a physician- to be one of a teacher, a guide, a healer- and not to be one who forgets the impacts our words leave behind.

It has been a personal privilege to be part of the "Language Matters" work in diabetes in the United Kingdom- and a humbling experience to be asked to contribute to an Indian version inspired by those living with Type 1 diabetes.

I hope you find this useful- and simply a guide to help us all build better relationships with our patients who we can only be transient guides to- in their journey of life.

In the words of Iron Man? *"Heroes are made by the path they choose, not the powers they are graced with"*

Professor Partha Kar

National Specialty Advisor, Diabetes, NHS England
Consultant Diabetes, Portsmouth, UK



LANGUAGE MATTERS - India

Language and Diabetes

This guide provides practical examples of language that will encourage positive interactions with people living with diabetes and subsequently positive outcomes.

The language used by healthcare professionals (HCP's) can have a profound impact on how people living with diabetes, and those who care for them, experience their condition and feel about living with it day-to-day. At its best, good use of language; verbal, written and non-verbal (body language) which is more inclusive and values based, can lower anxiety, build confidence, educate and help to improve self-care. Conversely, poor communication can be stigmatising, hurtful and undermining of self-care and have a detrimental effect on clinical outcomes. The language used in the care of those with diabetes has the power to reinforce negative stereotypes, but it also has the power to promote positive stereotypes.

People with diabetes internalise messages from the media, from those around them, but most of all from their healthcare providers. When these messages are perceived negatively, whether it is intended or not, this can lead to feelings of shame, guilt and resentment. People who are ashamed of a condition will find it much harder to engage and manage that condition proactively.



Type 1 Speaks

“Healthcare today, is a word that you may be able to sell.. But will you ever be able to sell healing?”

In this document, you will find practical examples of common phrases that can be substituted with others and tips for a more healthy and positive communication with your patients.

EMPATHY:

The dictionary defines empathy as “the ability to understand and share the feelings of another.” - as HCP’s you are often taught to distant yourself from the person you are caring for - however, in a condition which requires constant care, constant management and constant support, weaving empathy into your practice will lead to more positive outcomes.

Type 1 Speaks

“I want my healthcare professional to be a friend, more than a doctor. I understand that he/she will give me prescriptions and medical advice, but more than that, I want them to understand what I’m going through and not judge me for being a ‘non perfect’ type 1..”



The following section sets out the principles for good practice for interactions between healthcare professionals and people living with diabetes, drawn up with reference to the experience of people who have diabetes, healthcare professionals and published research;

- Recognise that some words, phrases and descriptions are potentially problematic, whatever the intention of the user.
- Use language (including tone and non-verbal gestures) that is: - free from judgment or negative connotations, particularly trying to avoid the threat of long-term consequences or scolding (‘telling off’); is inclusive and values based language. - person-centred, (also known as ‘personfirst’) to avoid labelling a person as their condition. - collaborative and engaging, rather than authoritarian or controlling.
- Review the use of common expressions and what underlying attitude they may convey, regardless of intention.
- Avoid language which attributes responsibility (or blame) to a person for the development of their diabetes or its consequences.
- Avoid language that infers generalisations, stereotypes or prejudice, or links one individual with previous experience of others of a similar background or in a similar situation.
- Use or develop an empathic language style which seeks to ascertain a person’s point of view of their condition, rather than assume.
- Listen out for a person’s own words or phrases about their diabetes and explore or acknowledge the meanings behind them.
- Become alert to the use of language, and non-verbal communication i.e. body language and recognise if it may be creating a negative effect.
- Consider how to limit any negative effects from language used, both for yourself and with others around you

BASICS

What the Research Says and how it is relevant to us


A 2018 study conducted in the UK highlighted how communicative, empathetic language has a direct impact on behaviour and communication. Terms like 'non adherent' and 'non-compliant' (similar to '**woh sunti nahi hai**') clearly lead to a disconnect between the person and the HCP and the use of 'third person' language can be seen as 'labelling'. The study highlights how language can be perceived as apportioning blame, stereotyping and being judgmental and can increase already prevalent stigma.

The research also outlines cultural appropriation, something which is very relevant in our community. Care can be compromised by different beliefs, language barriers and educational backgrounds - and HCPs must be gentle and sensitive to the needs of the different people they encounter and interact with. Conflict of religion, socio-economic status or belief should not subconsciously be woven into the narrative of language used for care.

Read more about the research here:

(<https://onlinelibrary.wiley.com/doi/full/10.1111/dme.13801>)

Type 1 Speaks



"One of the most incredible things I am grateful for, is that I could call my doctor at any hour and know that he would answer. He never scolded me for a high sugar and never judged me for a high A1C.. His 'it will be better' got me through a lot and that motivated me to manage my sugars better"

Practice

In the following section of this document, we set out some common examples of language use and suggest alternative responses or ways to deal with them. These are by no means comprehensive but are intended to highlight major themes and demonstrate the negative impact of language in everyday diabetes practice and how this could be addressed and reduced.

FROM PEOPLE WITH T1D

Below are a list of phrases that could be said in different tone / language / approach:

“Suffers from Type 1”

“suffers” is a strong word, which also has connotations of ‘is bound by’. As persons with T1D, we know that we have to live with this condition for the rest of our life. However, a simple change in the phrase, could make us feel like we are *supported* in this constant continuous condition. Suffer is also a word which has a negative undertone to it.

TRY: “is living with” instead

This phrase is supportive, and in some cases motivating as well.

“Patient with Type 1”

“Patient” has a universal indication of being ‘unwell and sick’. People with T1D can live normal lives with monitoring and correct administration of insulin. The word ‘patient’ in India directly leads to images of being in a hospital bed.

TRY: “Person with Type 1” instead.

This phrase actually gives an identity to the person living with diabetes outside the walls of a hospital..

“For sure you are (Not eating right, not taking insulin)”

“For Sure” implies assumptions. Often, a person with diabetes could be doing everything right and still be having fluctuating sugars.. It feels as if, we are not trying enough, and we are failing. Failure is a discouraging sentiment to feel.

“conversation, instead of confrontation”

TRY: “Maybe, you are.....” instead.

This is definitely a conversation starter, which the person with diabetes will be open to, and is more likely to open up to.

“You have to do better”

We understand that we may be off chart, and off sugars, and off range. We know if we are not on the right path, and everyone tells us that. We need someone to help us do better, not just tell us we need to do better. It also leads to feeling very alone.

TRY: “Let us work together to do better.” instead.

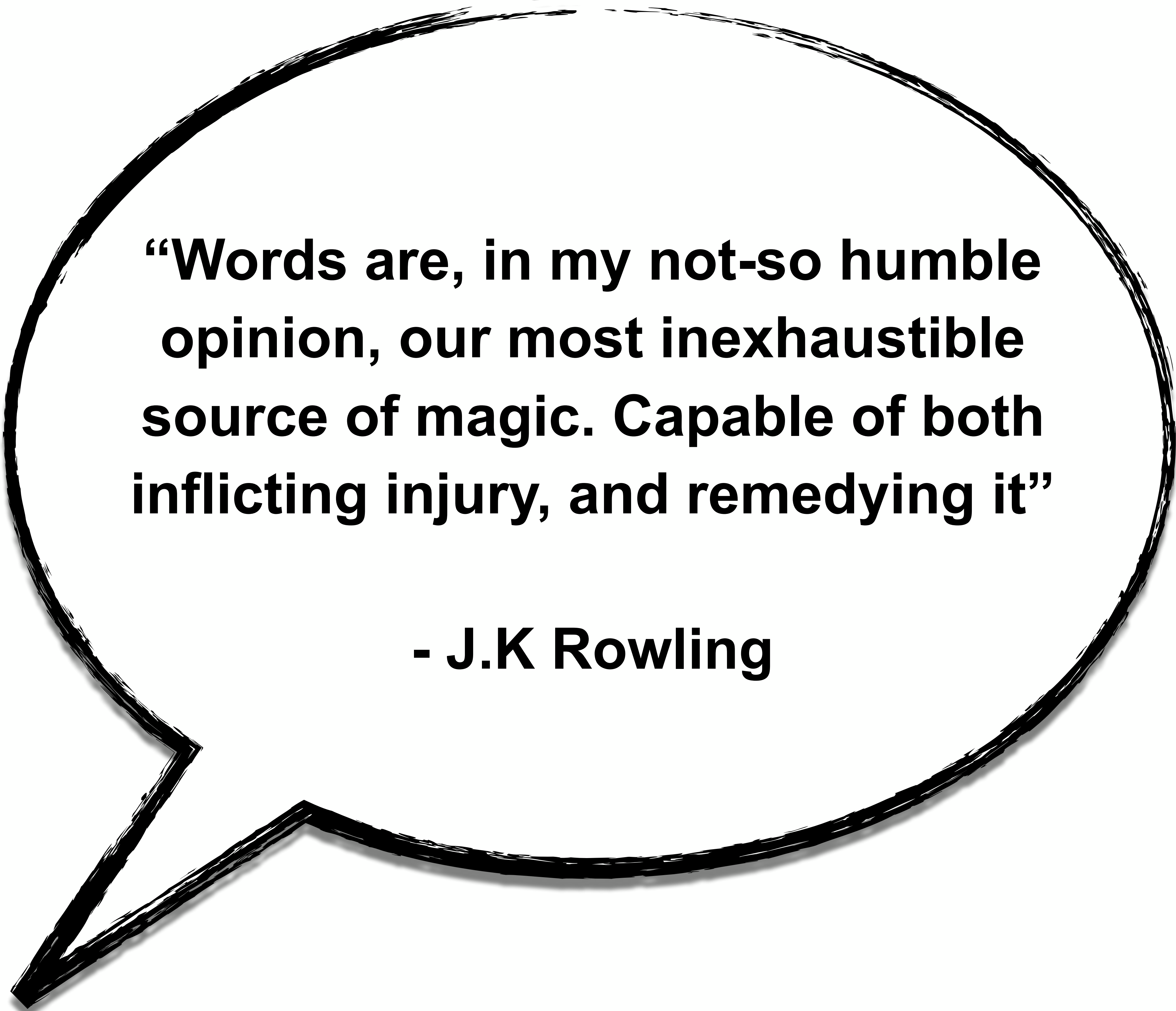
This is a partnership - and it makes us feel like we are not alone. It makes us feel like our HCP is on our side.

“Look at her - she is doing so well”

Everyone is different. Some people excel at their management and some people struggle. Comparison, makes us feel small, inferior and like a failure. We want to do better, but comparison is a feeling of dejection that will not help.

TRY: “Let’s see what we can learn from her” instead.

This is motivating, and aspirational.



“Words are, in my not-so humble opinion, our most inexhaustible source of magic. Capable of both inflicting injury, and remedying it”

- J.K Rowling

The Inner Circle

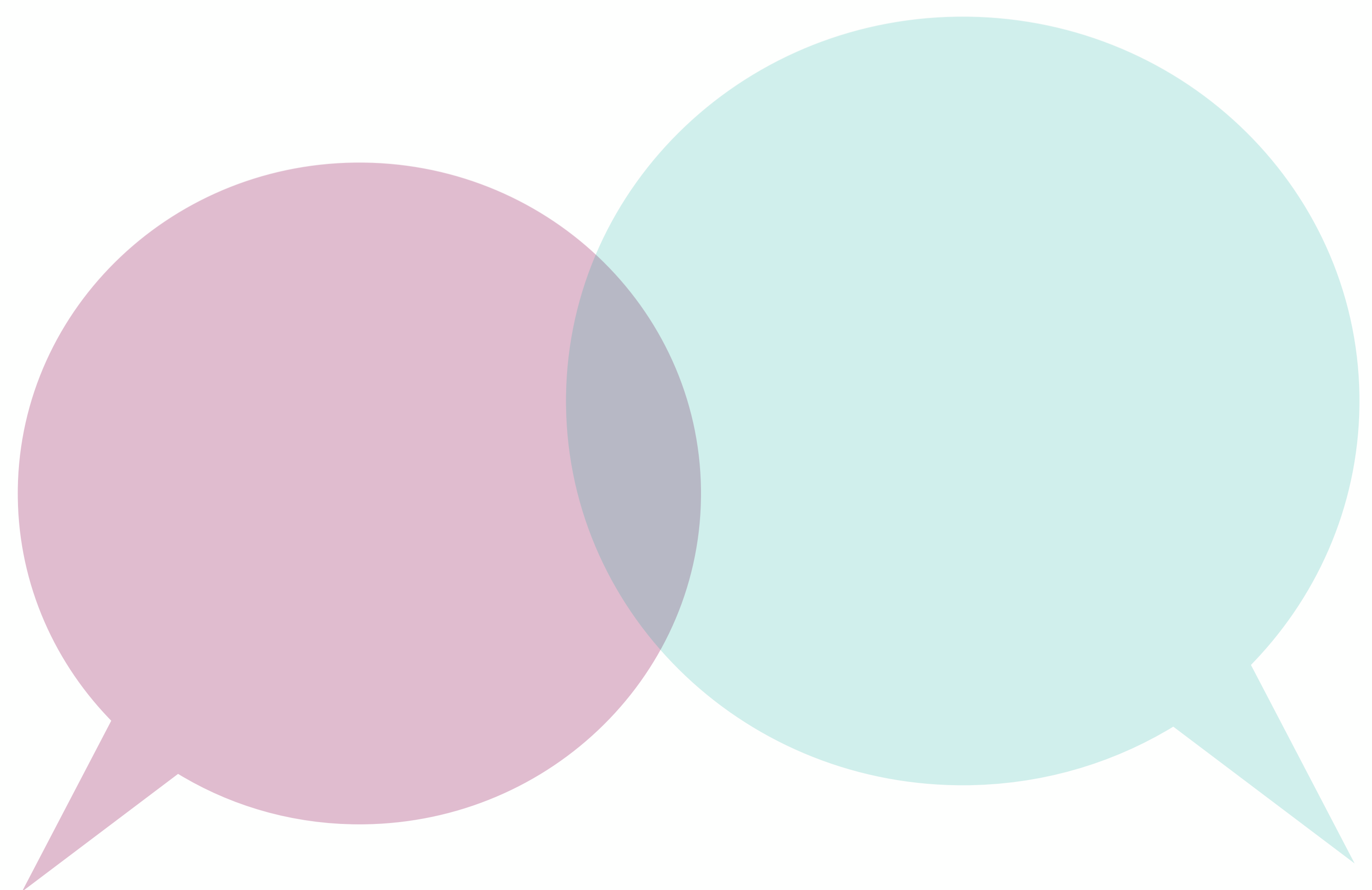
In India, it's usually the entire family (parents, extended family and friends) that is involved with a person's diabetes care. The person with diabetes will be having frequent conversations with their family members and often the tonality and words can make a negative impact. Below are a list of phrases that stem out of paranoia that could be avoided. As a HCP, try to have a healthy conversation with the family and help them get their facts right.

मुझे इंसुलिन के अलावा कुछ और दो
(give me anything but insulin)

Desperate times call for desperate measures. Parents are ready to try anything else apart from insulin. This is the time to be **firm** yet **supportive**, clearly stating how important insulin is, yet understanding that it is going to be tough to get used to. We often find that analogies are useful here to break the ice: *"Insulin is like air and water, we need it to survive"* - the fear of the unknown can get simplified with these references.

इंसुलिन की आदत हो जाएगी
(will get addicted to insulin)

This is a great opportunity to use this phrase as a positive. Try: "उसे इंसुलिन लेने की आदत डाल लेनी चाहिए" (*should get used to insulin*) - reiterating how one must take it everyday and not forget a dose. Compare it to regular activities like having breakfast each morning, going to school etc. We find that de-mystifying insulin can speed up the acceptance process.



उसकी जिंदगी बर्बाद हो गई है
(my Childs life is ruined)

Often parents use this line in front of their child who is living with T1D. This is where the HCP must intervene and show support. Giving references (not comparing) of people who have achieved things with diabetes helps. This is also a time for the parents to accept the child's condition - offer them guidance and support.

किसी को बताना मत
(don't tell anyone)

The HCP here must try and convey the importance of telling the right people. For example, 'स्कूल में सूचित करना महत्वपूर्ण है, अगर एक हाइपो हो (*important to inform the school authorities, incase of a hypo*). Giving practical rationales of why one must be vocal about the condition will help them understand it better. This is also a great opportunity to introduce the child and parents to support groups.



TYPE THE 'TYPE!'

What often causes patient confusion and anxiety, is the constant overload of information from social media, news and other factors that talk about 'curing' and 'reversing' diabetes. However, none of these sources ever mention the '**type**' of diabetes. This incorrectly informs the ones affected by it. Stay cautious about the messages you spread, and please, always, mention the TYPE of diabetes when making statements.

LANGUAGE WITHOUT WORDS

Smile! A smile can say things no amount of words can. It instantly breaks the ice, it comforts the person with diabetes and his/her family. Body language can either be a great barrier or a great connector, and the easiest way to make a tense situation warmer, is simply, by smiling.

It's not just what you say that makes a difference, it's the 'way' you say it.

NO FEAR - I AM HERE

Fear tactics have never proven to be effective in the long run. Using fear to motivate a person with diabetes, leads to anxiety, insecurity and denial. Fear will cause distance and may make that person hide important information from the HCP. Manipulating results, doses and treatment plans to please the HCP might become common practice. Try using positive reinforcement instead of fear based consequence. With T1D establishing a healthy, supportive, empathetic relationship is of paramount importance and using fear tactics will only act as a road block.



Type 1 Speaks

"My doctor always scolds me. He frightens me and tells me worst case scenarios.. I am scared to go to him"

SEX, MARRIAGE AND MORE

Already taboo in our Indian society is the conversation around sexual health and marriage. Add T1D to the mix and it is a boiling pot of stigma. It is natural for the person with T1D and their families to have questions about these topics. As an HCP, try to be sensitive yet informative about sexual health, complications with diabetes and how marriage is not something to be worried about. What helps here, is to use statistics about incidence of T1D after pregnancy. Often the best way is to normalise the situation, and that normally comforts the person with T1D and their families.

NOT CONTAGIOUS

One of the biggest misconceptions Indians face is that T1D is contagious. This often translates into a taboo especially when it comes to talking about marriage. Take some time to talk about non communicable diseases and explain that they are not to worry about 'spreading' their condition.

NOT YOUR FAULT

Since there is such a lack of awareness about T1D in India, people instantly associate 'eating too much sugar' as the prime cause for the diagnosis. There is instant blame that families, and sometimes the PWD put upon themselves after hearing the diagnosis. It is paramount for the HCP to spend a few moments re-iterating that nothing that they would have done differently, would have altered the result. Take some time to speak about what an 'auto-immune' condition is and offer comfort with once again outlining that 'its not your fault'.

CONCLUSION

As people with diabetes, we request all the Health Care Professionals to seek to be more

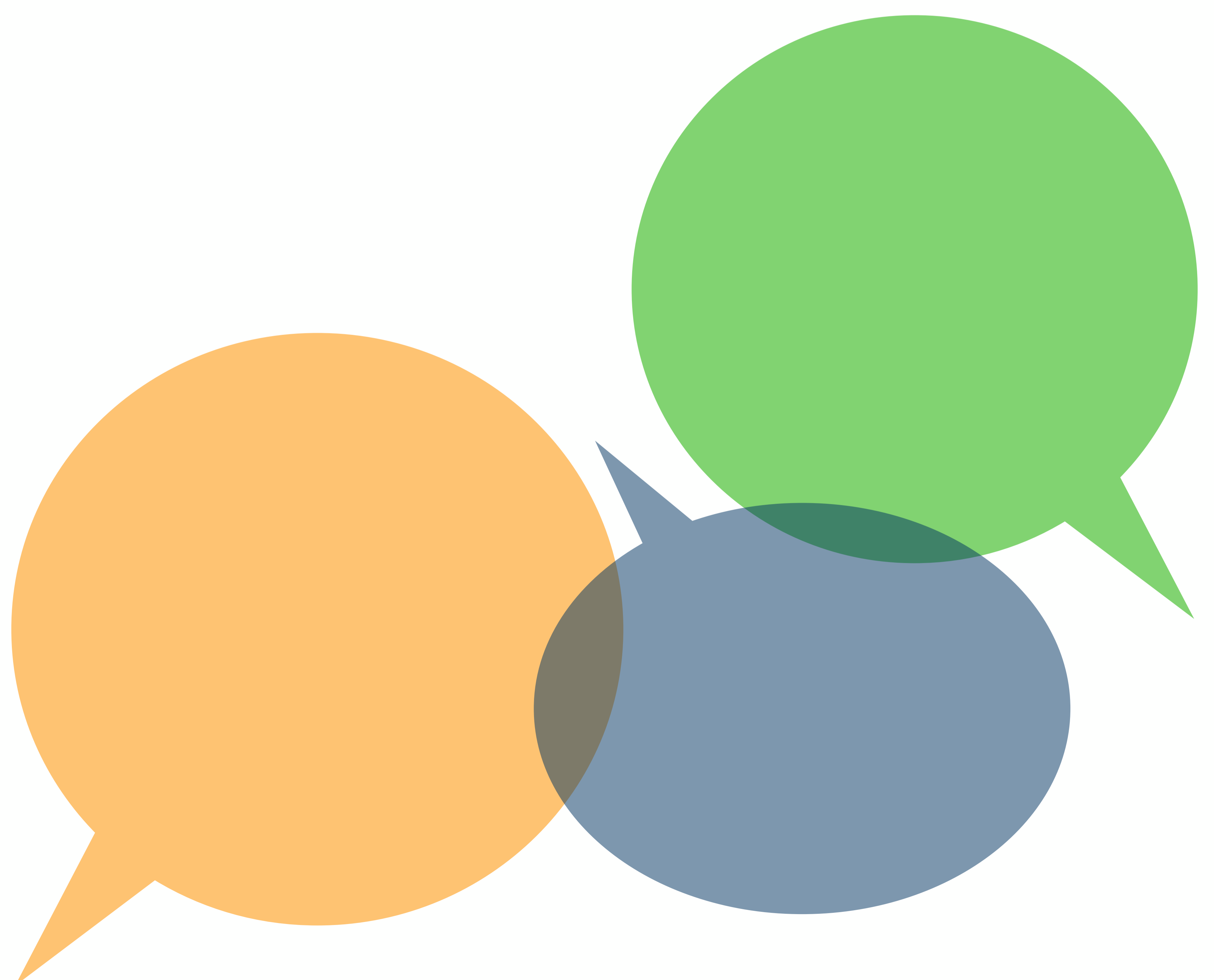
Empathetic (for example 'it sounds as though your diabetes is really hard to manage right now), and less Stigmatising (for example, 'you're in denial')

Empowering and Inclusive (for example 'what changes do you feel are needed right now') and less Shaming and Blaming (for example 'its being so overweight that is causing you to have these problems')

and, more Encouraging and Understanding (for example 'I can see the effort you're putting in, keep up the good work') and less Disapproving and Threatening (for example 'you aren't meant to take your insulin like that')

We are **better together**.

Lets build a new tomorrow, बातों ही बातों में



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