

INDIA

LANGUAGE MATTERS

*The importance of language while communicating with
people living with Type 2 Diabetes in India*



"It is a battle for us living with diabetes, we don't want to be alone in this battle. We want somebody to say 'I am here with you, don't be scared' ".

JD, person living with Type 2 Diabetes Mellitus , Mumbai



Words are events, they do things, change things. They transform both speaker and hearer, they feed energy back and forth and amplify it.

-Ursula Le Guin



PREFACE

A person living with diabetes spends approximately 60 - 120 minutes with their Health Care Professional (HCP) over the period of a year. However, the person lives day in and day out – 3,50,400 minutes a year with their condition. The communication that takes place in these precious minutes can have a profound impact on the behaviour of a person, possibly for the rest of their lives!

While in our individual capacities, we tried to improve our communication with people living with diabetes, the idea for working on how “Language Matters” to people living with Type 2 Diabetes germinated during our interaction with Dr Partha S Kar, Diabetes Lead of the NHS, UK. Dr Reshma Nayak, dedicated to improving the experience of healthcare for persons with chronic conditions was an invaluable asset in our journey.

In order to understand the experience of persons living with Type 2 Diabetes in the Indian socio-cultural context, we conducted a series of focus group discussions across the country to capture patient perspectives and detailed qualitative content analysis was performed to distill what we learned.

We also went on to conduct a survey of over 900 doctors who treat diabetes to reflect on their communication during consultations. What emerged was that there was a disconnect between what the doctor intended to communicate and what the person sitting across perceived.

This document is an effort to shed some light on the need gaps we discovered, with some practical suggestions to improve our interactions. We do acknowledge that all that the doctors do and say during a consultation is intended for the welfare of the patient and the gap is partly due to lack of adequate training in communication in the Indian medical school curriculum.

This document is not meant to blame or judge HCPs, it is only meant for introspection and reflection on how we can communicate our intentions in a better way to make the experience of the condition more positive!

Every Word Matters!



Dr Tejal Lathia,
Consultant Endocrinologist,
Apollo & Fortis Hospitals,
Navi Mumbai



Dr Chitra Selvan,
Associate Professor, Endocrinology,
M.S. Ramaiah Medical College,
Bengaluru

FOREWORD

Healthcare in the modern world continues to evolve – and diabetes care is no different. New medications, dietary changes, smoother insulins all make their position felt as we deal with diabetes – whatever the background or type. Perhaps along the way, we sometimes forget the most basic of all things – the essence of the healthcare professional (HCP) – patient relationship – the simple art of communication, the simple art of asking “How are you?” rather than a quick, brusque “How is your diabetes?”

A personal belief has always been that the key to improving care is perhaps not the technology – but the ability to support self-management, the ability to encourage peer support – and seeing us as HCPs as guides along the journey – rather than being the enforcer of rules or dictating terms and conditions as to how diabetes care should be improved.

“Language Matters” provides useful advice on things such as alternatives to commonly used phrases which may cause offence to some – it is a practical handbook for healthcare professionals, designed to be used and referred to in a clinical setting, rather than sit on a shelf.

As healthcare professionals, our words have huge impact – and over the course of time, it’s the relations we build, the mutual trust we create with our patients that can help to improve their care.

The journey of looking into this vital piece of work started in the Type 1 Diabetes space (Baaton hi baaton mein) and subsequently into the world of those living with Type 2 Diabetes- led by the sterling work of Dr Tejal Lathia and Dr Chitra Selvan.

The final piece of work is indeed commendable and hopefully it helps many healthcare professionals to pause a moment in their busy lives and think of the impact their words can have on the lives of those living with a chronic disease.

In the words of David Gaider, “Privilege is when you think that something is not a problem- because it’s not a problem for you personally”.

Diabetes is no different to that either.

Professor Partha Kar,
Diabetes Lead, NHS-UK



FOREWORD

Greetings with “Hello or Namaste” with “How are you?” makes a difference. As Health care professionals whenever we are diagnosing and examining, we have been taught to show empathy, but the reality seems to be different. Saying “People with Diabetes” has a better impact than saying Diabetics! There are two aspects of a coin. A mixture of confidence as well as concern and convincing people with diabetes about consequences and management is necessary whenever we are trying to make them understand the situation of chronic diseases.

We need to realize the importance of avoiding the use of some terms such as injection, complications, uncontrolled and impending doom when conversing with people with diabetes. Language matters is an initiative to bring empathy to science.

It is my earnest request to all Healthcare professionals across the world to understand the feeling of the people who are living with lifelong diseases which require constant decision-making on their behalf. Good quality of life is one major aspect of living with diabetes.

Language matters is one such place where we try to unite the ideologies and expectations of people living with diabetes with their respective health care professionals. I again wish every person living with diabetes to stay positive this festive season and lifelong, we stand together always!

I wish you a life full of happiness and good health.

Dr. Banshi Saboo
President, RSSDI



ACKNOWLEDGMENTS

We are grateful to the entire team who worked with us to launch the Indian edition of Language Matters for people living with Type 2 diabetes.

A big thank you to Dr Siddharth Warriar and Dr Beena Bansal for their poignant poems.
Thank you to Jazz Sethi for design and layout.



Dr Mahati Chittem,
Medical psychologist with
expertise in diabetes qualitative
research



Dr Reshma Nayak
Specialist in healthcare
marketing and patient
experience



Reenu Sharma
Clinical psychologist with
expertise in patient counselling



Dr Mohan Raju
Clinical Psychologist
Ramaiah Medical College
Bengaluru

Heartfelt gratitude to the participants of our focus group discussions who took time to help us learn about their experiences, both in Mumbai & Bengaluru. We thank the doctors who took the survey to provide us with precious insights into the doctor-patient interaction.

Unheard

*The hospital walls are gleaming white
I sit in the waiting room. And wait.
My heart beats loud, in quiet fright
As I look to the doctor to know my fate.*

*He starts to speak - he's sorry to say
I'm suffering from some multi-syllable word,
And I must be more careful from today.
I ask a question. I don't think he heard.*

*He's speaking still - I try my best
To interpret each and every line
He says he'll need to run some tests,
He'll take my blood. And he'll need my sign.*

*I'll have to take some pills from now,
They're for my sugar, or maybe my heart.
They'll save my life, I don't know how,
I must not have understood that part.*

*The meeting's over, he shakes my hand;
I must follow up after a couple of months.
There are things I heard and didn't understand
And I wish I could have been heard for once.*

Dr Siddharth Warriar, Neurologist

Indian context – Is it ONLY language?

When we began this journey, we conducted several one-on-one interviews, focus group discussions (FGD) and surveys to understand how similar or different the experience is for patients living with diabetes in India.

Early on, we realised that using the word “Language” can be misleading in the Indian context. India, with its rich cultural heritage has 121 languages according to a 2011 census. One of the participants of our first focus group in Mumbai had this to say -



“When you say language, are you referring to Hindi, English, Marathi or the way doctors communicate with patients?” - SKS

However, it is more than just words alone. What emerged was that most patients were dissatisfied with the way they felt after a consultation and expressed the desire for a more positive experience. We realized that the entire doctor-patient interaction needs to be reexamined, not language alone. We extended the brief given to us by Dr Partha S Kar to encompass all of this. This was best described by another FGD participant...



“There is a therapeutic use of effective communication- verbal, non-verbal or paraverbal and this is to create a trustworthy and healthy relationship with the patient. Apart from the medicines, you need to enhance our manobal (will power)and this happens when the doctor talks nicely to you. And that too has a therapeutic impact on your disease.” - SKS

PARTICIPANTS SPEAK

“Not communicating with us is also a bad thing, the doctor should at least explain something, not just say take this medicine” - VT

“ Treat me like an adult, Present the options of treatment to me, and lead me to choose the one best for me. Don't just tell me, 'do this'" RM

“ The doctor already knows what to say to me, even before I've said a word and the prescription is ready” - S

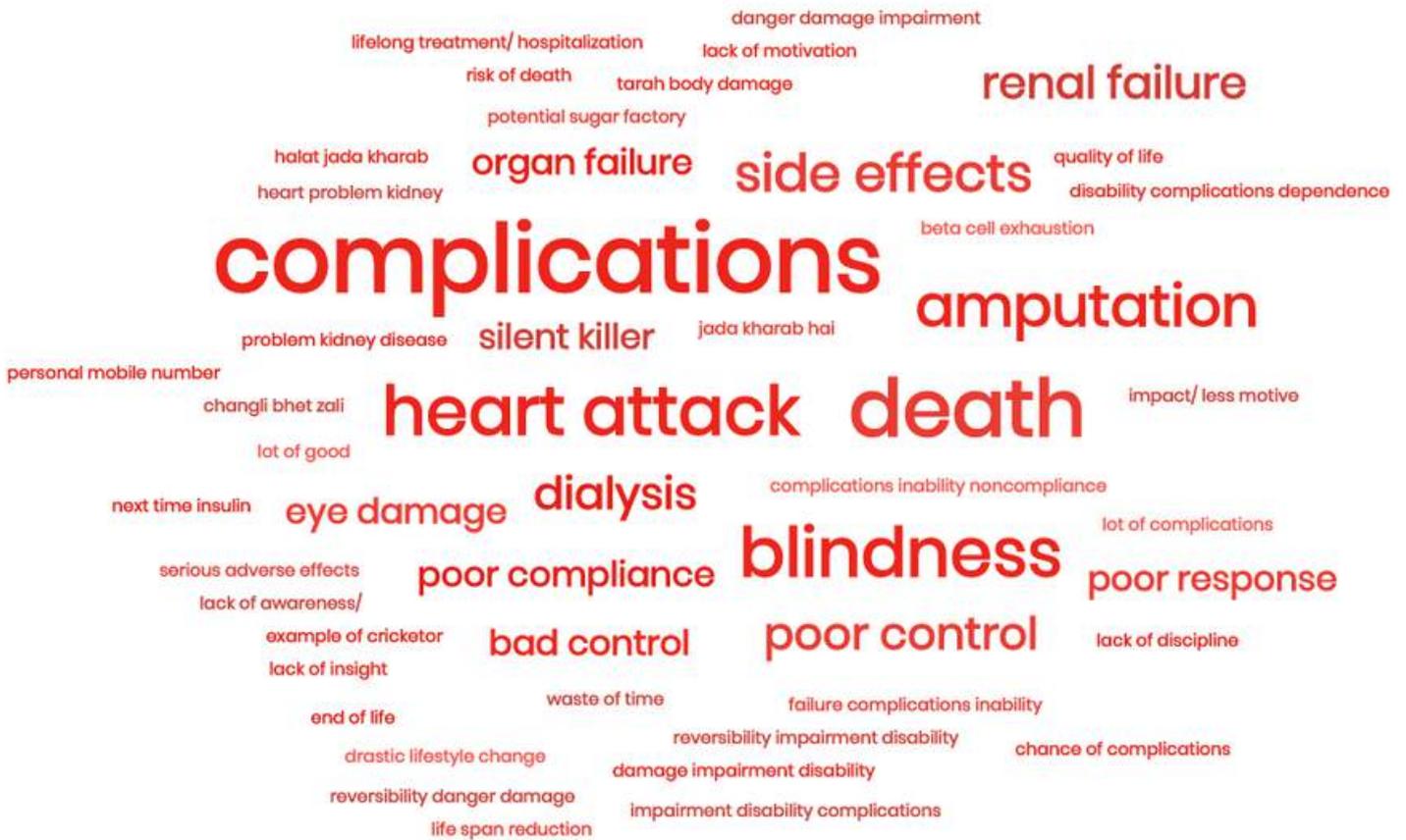
“The body language of doctors imply superiority, 'I know everything about you'" - AS

Diabetes is a condition where a personalized approach to treatment is likely to yield better results. This begins with listening to that person's specific concerns. Communication with a patient starts from the time they enter the doctor's office till they leave - in words, in looks and in our expressions. People were hurt, upset and frustrated by much of their communication with their doctors and seemed to have lost hope that it could get better.

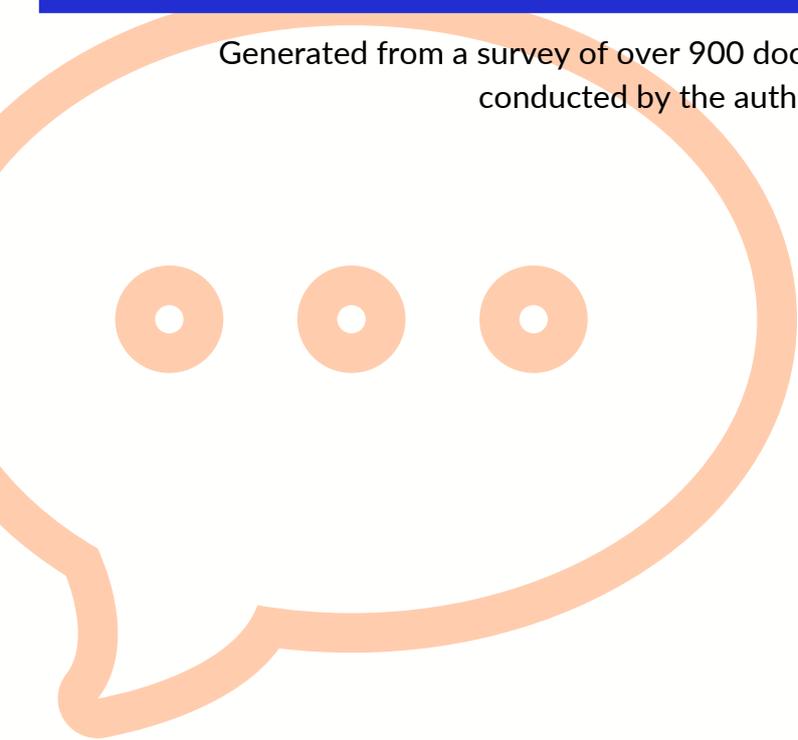
It would help us to recall a day when a loved one was taken ill and how we felt. There is a sense of helplessness, vulnerability, uncertainty and quiet desperation.

Many of us may think that if we listen but do not provide any solution to their domestic or emotional problems, then what is the point? However, empathetic listening is a therapeutic tool in itself. A recurring theme that emerged in our research was the need of the person to just be heard.

A doctor cannot fix all that is wrong with a person's life, but we can definitely communicate in a way which engenders trust, validates what a patient feels, motivates them and addresses their doubts and anxieties.



Generated from a survey of over 900 doctors treating diabetes across the country conducted by the authors in May - June 2020



DOCTORS SPEAK

I talk very less with patients

I always try to convince patients of the benefits of good diabetic control in terms of prevention of complications

I don't think I use any words that impact patients negatively

After we listened to the focus group discussions , we were dejected. It was difficult to accept that patients were experiencing such hurt and judgement during their interaction with doctors. This information was particularly jarring with our own intent to care which somehow wasn't evident.

Almost all of us chose the profession for the good that we can bring to lives. But the skewed doctor-patient ratios and paucity of time handicap us, No one in medical school taught us how to communicate a diagnosis, educate about prognosis or how to encourage self-care behaviour. Most curriculum in medical college focuses on the theory of the disease and its' treatment while completely overlooking training in communication.

While it is considered imperative to discuss diagnostic dilemmas, doctor circles are not open to discussing difficulties experienced while communicating effectively or how to motivate a patient who does not prioritize their own health. No precedent has been set to think about the effect of our words on patients.

It is never too late to hone skills to make sure that doctors are trained for that most crucial aspect of patient care - communication and this journey begins with introspection.

This document is designed to draw attention to moments during a doctor - patient interaction for Type 2 Diabetes Mellitus and the things our patients hear us saying to them and the disconnect between what we intend to say and what is actually said.

The gap between doctors' intentions and Participant's feelings

DOCTORS' INTENTION

Using the blood sugar report to sensitize people about the importance of euglycemia

WHAT A PERSON LIVING WITH DIABETES FEELS

“(The) blood sugar report determines your image. If this person has not got a controlled blood report, she is a useless character.” S

“If I have a headache, I have a headache. It is not my identity. Why does it feel like high blood sugar is my identity?.” RM

“Taking a blood report is like an examination, no other illness has this type of lifelong exam, every quarter” VT

We often express our displeasure by facial expressions and words if HBA1C is not at target. The intention is to emphasize the importance of euglycemia for good outcomes. However, we quiz the person in a manner which presupposes that somehow the person is to blame for the result. Not only is it demoralizing when we reduce diabetes care to just numbers, but we assume people “don’t care” about their diabetes if blood sugars are high. But the fact that they are sitting there in front of you, implies they care!

We need to separate the report from the person. Discussing possible ways to tackle the problem together avoids alienating the person and does not deter him/ her from seeking help the next time their readings are above targets.

SOLUTIONS:

- Try to keep a neutral expression while looking at reports
- Use simple open-ended, non-judgemental questions to find out why blood glucose targets were not met like - "What were the problems you faced?" "How can I help you improve the reports?" "How will you fit exercise into your schedule?" "How can you modify your diet?" "How can we ensure you remember to take your medications?"
- Acknowledge that sometimes despite all best efforts, blood sugars may rise.
- Reiterate that you are there to help them bring the blood sugar down to target

DOCTORS' INTENTION

To explain that diabetes is a lifelong condition with limited possibility of reversal

WHAT A PERSON LIVING WITH DIABETES FEELS

"It baffled me that diabetes is irreversible, lifelong, there is no hope" - JD

Certain medical terminologies that we use regularly can have profound negative effects on the recipient. For eg - incurable, beta-cell failure, end-stage renal disease, morbidly obese. These words impact their ability to cope with the diagnosis of diabetes.

For doctors who routinely use these terms, it would seem inconceivable that these words would be seen as offensive. But, such words take away all hope and lead the person to believe that his / her body has failed them and they are somehow responsible for this. Truth must be told but in a compassionate manner. Discussing diabetes as a deficiency rather than a disease gives people hope that this is something they can manage.

SOLUTIONS:

- Make a conscious effort to avoid words with a negative connotation
- Present diabetes as a condition that can be managed, and not as an irreversible downward slope
- Possibility of reversal early in the course of diabetes must be explained.

What people need for a happy fulfilled life is hope, not just a thriving beta-cell reserve!



DOCTORS' INTENTION

Reprimanding people in an attempt to motivate them for better glycemia



WHAT A PERSON LIVING WITH DIABETES FEELS

"My dentist scolded me about how I have spoiled everything because of diabetes. I went home and cried because he blamed me!"

AS

"Treat me as an adult and tell me. Let me take my risks, you give me the information that I need to understand the risks" - R

"But that scolding, as if you have committed a crime!"

Often, a paternalistic approach is used in diabetes care. People are reprimanded as if they have not understood the importance of good glycemia or are willfully disobeying us. However, diabetes is one out of many challenges a person faces in their lives and inability to comply with treatment may often be as a result of circumstances beyond a person's control.

A patronizing tone can seem offensive and disrespectful to a person and apportioning blame can demotivate a person completely. It is so common to come across people who have not gone back to a doctor for many years due to a negative interaction with an HCP who used this approach.

SOLUTIONS:

- Communicate about blood sugars not at goal in a neutral, non-judgemental manner
- Respect people's rights to be treated as an adult and their ability to understand the condition, its implications and treatment
- Compassionate listening and meaningful actions are the keys to good glycemia

DOCTORS' INTENTION

Insulin initiation for
better outcomes

WHAT A PERSON LIVING WITH DIABETES FEELS

"If you don't control, I will put you on insulin. Many doctors use this as a threat".

"A doctor told me pancreas is like a dead horse, What is the relation between the dead horse and pancreas?"
- LV (is an animal activist)

Using abstract analogies can offend or confuse people. Explaining the need for insulin should be done scientifically. Constantly re-emphasize that it is NOT their fault as often people see insulin therapy as a personal failure. Highlight how insulin is needed for them to stay healthy and live a productive life, free of complications of diabetes. Starting the conversation about insulin early in the course of diabetes gives time for acceptance. Highlight how insulin is needed for them to stay healthy and live a productive life with diabetes.



SOLUTIONS:

- Keep charts/pictures/models handy to demonstrate in a scientific manner about insulin physiology
- Train diabetes educators to talk with people with diabetes in more detail if you have time constraints
- Have a list/video of common misconceptions about insulin and their scientific explanations
- Refrain from using insulin as a threat. Portray it as an aid we might eventually need to use for better health.

DOCTORS' INTENTION

To make people aware of the gravity of the consequences of diabetes



WHAT A PERSON LIVING WITH DIABETES FEELS

“With these sugars, your kidneys will fail, and your life will be cut short by ten years” VS

“When I went to the doctor the first time, the doctors scared me. Every time I was told that you will have a heart attack” - NK

““Whatever patient has to face he has to face, but the scare tactics creates fear psychosis” - SKS

Every single doctor we know has done this at one time or the other (including us!). However, very few of us may have stopped to think about the impact of our exhortations and whether they are effective.

Through all our discussions, people complained of the constant threats of losing limbs and dire warnings they received and they were NOT conducive to better compliance but were often counter-productive. People needed to be given hope.

SOLUTIONS:

- Try substituting what will happen with what we can avoid

“If we maintain blood sugar levels close to normal, we can avoid a lot of unpleasant consequences of diabetes on heart, kidneys and eyes and lead a healthy life”

- Paint a better future

“If we maintain HbA1c below 7%, you may never have to face any complication of diabetes”

“I see so many patients with well-managed diabetes living a good life after 20-30 years of diabetes”.

- Fear most often leads to paralysis NOT motivation.

DOCTORS' INTENTION

To emphasize the connection between weight and type 2 diabetes

WHAT A PERSON LIVING WITH DIABETES FEELS

“A doctor once told my dad who was admitted with a heart attack to reduce 10 kg! When my dad responded that he doesn't eat much, the doctor mockingly asked him “ So did you get fat on inhaling air?” S

“The first thing they tell you is to lose weight, it doesn't matter if I have lost weight in the last 6 months . I am always told to lose weight ”.
AS

“In one consultation don't say Diet! Diet! Diet! a hundred times. Say it once, I get it, Don't harp on it!” RM

Obesity is a complex condition, far removed from the simplistic version of “calories in and calories out”, laziness or lack of motivation. We must understand that overweight people are continually reminded of their weight, it is helpful to seek permission to discuss weight before directly jumping to the numbers on the scale. Clearly stating that the conversation about weight is important in the context of their diabetes management might build trust in communication. There might be some implied judgement in our words or body language which may prevent the patient engaging fully with the healthcare provider. Above all, change is difficult for all human beings. Be Kind.

SOLUTIONS:

- Assess preparedness and seek the permission of the person to speak about the weight that day.
- Spend time to identify person-specific factors to address - For eg., binge eating, night eating
- Acknowledge small changes (For eg. one binge per week improved to one binge per month)
- Appreciate small but sustained efforts towards habit building.

DOCTORS' INTENTION

Optimal glycemia during pregnancy to ensure the best outcomes for mother and child



WHAT A PERSON LIVING WITH DIABETES FEELS

"I was on four injections and testing 4 times a day throughout pregnancy. When I delivered, my daughter went into respiratory distress. My doctor comments. "Had you controlled your sugars better, she would have been better". LA

'If you don't control your sugars, your offspring will get it earlier'.
Do you think I want the next generation to suffer like me?
I decided not to have a child after listening to my doctor."

Planning to have a baby is a primal desire for most women .When we address a woman in her reproductive age about pre-pregnancy care, it is important to not paint a bleak picture but to choose words which convey hope rather than fear. In some instances it may deter them from planning the pregnancy at all. Care of diabetes in pregnancy often involves intensive insulin therapy and blood glucose monitoring which can be overwhelming and difficult.

A few questions about how they are coping amidst career and household commitments before we jump right into the numbers and risk is probably a reasonable approach to take.

Lastly, never ever blame the mother.

SOLUTIONS:

- Assess how aware the person already is of the possible risks involved and how detailed the explanation of risks needs to be
- Reassure them that we should be able to take care of the situation together. Acknowledge and appreciate their efforts
-
- Highlight how risk can be reduced by bringing down sugar levels to normal range
- Give examples of women who have been through a similar situation and have healthy babies now.

DOCTORS' INTENTION

To engage the caregivers to better support the person in diabetes care

WHAT A PERSON LIVING WITH DIABETES FEELS

“Once my doctor said your life is going to get cut short by 10 years. Can you imagine the effect on my children? I never take my children when I go to see my doctor”.

“When I am with my family member and you reprimand me, It cascades into fights for weeks “

“Stop eating sweets”. I know my wife is going to now monitor every festival” VS

Discussing the care plan and addressing areas that need improvement is a tricky conversation to have in the presence of a family member. The words we use could have a major impact on the relationship the person shares with their caregivers and could also be a reason for increased interpersonal conflicts.

People living with diabetes are often already judged for their condition by their own family members. Siding with family members to find faults in the person may result in disengagement from their diabetes self-care. Overbearing family members may be requested to take a step back.

SOLUTIONS:

- Be careful while providing ultimatums of life span being cut shorter or complications when children or grandchildren are in the same room.
- Try to engage the entire family in making healthier choices in eating and exercising together.
- Clarify that diabetes is NOT the person's fault.

DOCTORS' INTENTION

Caution children about the risk of diabetes and its consequences



WHAT A PERSON LIVING WITH DIABETES FEELS

“Look at your mother who is hefty and not able to move, you will become like that unless you take care.” - MD

“The doctor said - look at the condition of your dad, this is a hereditary disease and you are going to get it, that gave me a different kind of stress” - VT

In our attempt to caution siblings or children of people living with diabetes of their own risk, our words often convey a sense of inevitability...that there is no hope.

People react in different ways - they may heed your advice and start taking steps to avoid diabetes, they may be so paralysed with fear that they simply ignore your warning and go on with their lives as always or the warnings may have opposite effects and they may abandon any precautions they may have been taking. The doctor is not responsible for how the person reacts, but we are definitely responsible for how we phrase our warnings.

Here's what one of the participants in the FGD suggested:

“You are educated, so I am sure you will handle it in a much better way because you have the advantage of knowledge...when your mother got it there was no blood test, now we are much more advanced in science, things are going to be different for you...can be a much better future than it was before....” - MD



SOLUTIONS:

- Talk about RISK, not the inevitability of developing the disease
- Talk about the possibility of delaying diabetes with good lifestyle interventions
- Talking about scientific advances which allow people to live longer healthier lives even if they do develop diabetes.

ANATOMY OF A CONSULTATION

Visiting a doctor often forces people to face the potential consequences that they are at risk of and it is unsettling. Much of the fuss about the wait, comes from a place of uncertainty and fear about their future. And 'difficult' people are probably the ones who are the most scared.

It is important for us to acknowledge the trouble that a person goes through to rearrange their day to come down to your office and then wait to be seen. Time is precious for everyone.



“Waiting in a doctor's chamber forces you to see a snapshot of what might lie ahead for you in your life with diabetes. You see somebody in a wheelchair with a toe amputated, another person struggle to walk after a stroke and the third has poor eyesight” VS



“The doctor has made you wait for an hour, and even if the courtesy smile is not there, it puts you off, you are angry but you can't do anything about it”



“When you enter, just looking at the doctor makes you scared, it is the doctor's responsibility to make the patient feel relaxed so that he opens up” - SKS

Every interpersonal interaction has a subtle hierarchy of power. When a person walks in to meet a doctor, he is vulnerable. Looking up when a person walks in, greeting them with a smile and addressing them by their name can go a long way in alleviating the fear and anxiety a person experiences while visiting the doctor and make them comfortable to communicate freely.

If there has been a delay, acknowledge it with a reasonable explanation -

“ I am sorry we are running late today, I had to attend to an emergency” or

“ I am sorry I was late, it was unavoidable”.

“ I was pointing to a patch on my leg and the doctor is looking at the computer, he didn't even see it!”
AS

“The doctors spent less than 15 min with us, they did not have the time to listen to my mother's feelings” -
JD

“Another issue is phone calls, the call is attended first, he has forgotten all that I have said and wants me to start again.” - MD

Looking at the computer, turning away from the person while conversing taking phone calls or checking messages during consultations may make the person feel alienated.

Not giving our complete undivided attention is perceived as a cue that their presence is not valued. Excusing yourself to attend the phone call or asking permission will help to minimize the disruption. Having a system in place where phone calls are attended by someone else and only important phone calls are passed on would be a good idea.

Address them by their name, so they know they are not just another face. Remember to ask them how they are doing and if they have any specific concern this visit. Try not to interrupt when they speak . Ask them about their usual day and how they cope with juggling work, home, family and diabetes. Share stories about journeys of others towards better health similar to theirs. It builds kinship and rapport. Watch their body language and facial expressions change in response to your words and actions and re-adjust your tone.

Make a small note about their native language, whether they are married or single and what they do professionally. Watch the person's face light up when you bring this up at your next visit!

Proactively soliciting questions from the person and their caregivers is important. Unanswered questions often leave people dissatisfied - “Do you have any questions for me?” is a good way to round off a consultation.

How the person feels - welcomed, heard or attended to is far more important than the length of the consultation.

What do people living with diabetes think of the importance of communication

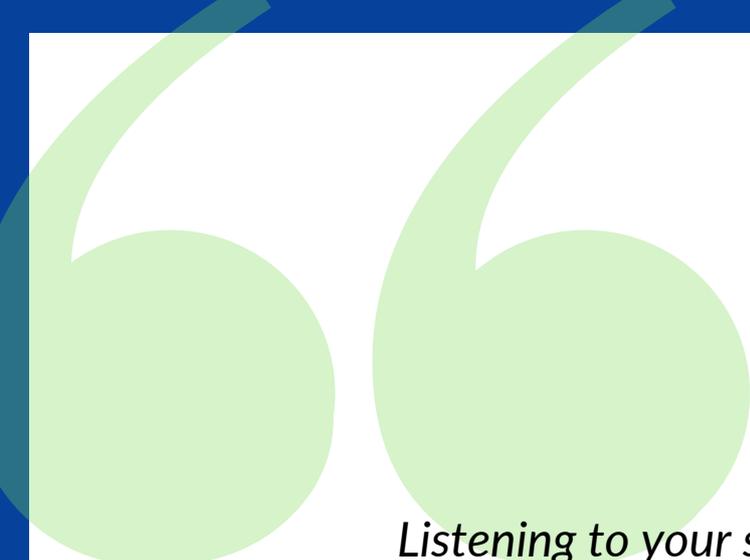
“

“Health Care personnel should be exposed to training in effective communication ”
- SKS

“

“ The art of listening must be included in the medical syllabus, the art of listening and compassion” - LV





Stories

*Listening to your stories, woven by your words
I don't have time for this, just tell me where it hurts
I may quickly "treat" it with my prescription
If it doesn't become fine, there are some tests to run*

*I am afraid, there is a job to do
It's not that I don't want to listen to you
I am scared that your words may reach deeper than my ears
And then I will not know what to do with my tears*

*I am trained enough to close my heart
I am terrified all this hurt can break it apart
So let's just wrap this up till you visit once again
After all I am only trained to use my brain*

*Once upon a time I loved the world of stories,
where I sometimes silently slip into
Till someone scolds me to get up,
because there is so much work to do.*

Dr Beena Bansal, Endocrinologist

