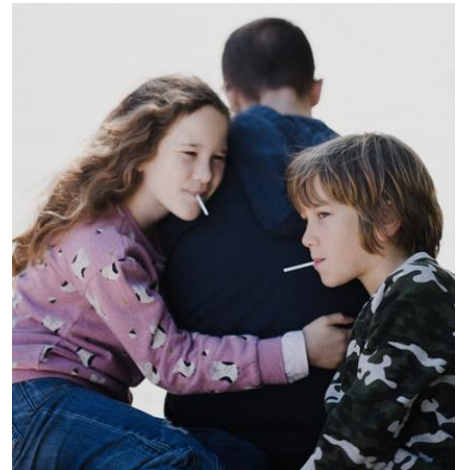


Suzi's story

Written and narrated by Coralie Wales for the launch of the Western Sydney Health Literacy Hub Launch 3 December 2018



Suzi is 45, married, with two kids. While she can speak English, she has difficulty reading and writing especially if she feels anxious or stressed. Her family speaks Farsi at home. She works full time as an office manager, her husband, Amir, is out of work.



Suzi has just been diagnosed with type 2 diabetes. She carries excess weight. She has been told she will need to manage this condition and she should go to a GP.

Now let's walk through a sliding door which shows Suzi taking one of two different paths to two very different places ...

Suzi attends the local medical centre. When she arrives, the receptionist looks busy and harassed, and doesn't look at her when she asks Suzi's name. The receptionist tells Suzi she will be called by the first available doctor. After 40 minutes she hears her name called. A doctor is standing in an open door looking down at some paperwork. She assumes she is meant to walk through the door.

- Suzi gives Dr the letter from the hospital.
- He seems very busy and appears to be doing many things at once
- When he does look at her he tells Suzi she is overweight and needs to lose several kilos.
- He tells her she will have to improve her diet and eat healthy foods.
- He prescribes some medicine and tells her to take two tablets three times a day.
- He tells her to go to the pharmacy and purchase a blood glucose monitoring kit
- He tells her that diabetes is serious but really common, and as long as she loses weight and takes the medicine she will be fine. He uses a lot of big words to describe the diabetes and she feels it must be a really bad thing.
- He gives her several brochures in English, tells her to read them, and to come back for a repeat when the medicine runs out.

The visit takes about 10 minutes and Suzi is not sure she understands what just happened. She feels fat and confused.

Suzi feels anxious as she didn't really understand what the doctor was saying. She is very busy juggling work and her family. Her health always seems to take second place. She finds it hard to lose weight – she has tried many times before.

Nevertheless, she gets a blood testing kit and asks the pharmacist how to use it. She hopes she is using it correctly but it's confusing.

She tried to read the brochures but she found that reading them in English is just too hard.

She is so busy she puts it all to the back of her mind.

She often feels unwell. She tries to take her medicine like the doctor told her but she is not sure how much to take or when. When she is feeling bad she increases the dose but some days she is too busy and forgets to take any medicine at all.

After two months Suzi feels really unwell. She has given up measuring her blood. One day as she drives to work something happens to her eyesight and she can't see where she is going. She crashes the car.

Next thing she knows she is in hospital.

Suzi has a hospital experience for which she is unprepared.

The injuries from the accident are slow to heal due to the underlying unmanaged diabetes. Her knee was pretty smashed up and needed surgery.

She still doesn't have a clear idea of what diabetes is or how to go about managing it.

Now she has been out of work too long, and this causes the whole family a lot of stress.

After this wakeup call, she realises she needs a good GP to help her learn how to manage this diabetes. She asks around and hears about a caring GP in her local area.

After getting out of hospital, she sees Dr New. He carefully explains diabetes so that Suzi understands. He refers her to a physiotherapist and a dietitian to support her as she learns how to manage her health.

Three months later she has lost 3 kilos.

It's twelve months since Suzi learned she had diabetes and she has lost 6 kilos. While she is now managing her diabetes, those months of unmanaged diabetes means she has not been able to manage her condition without medication. While Suzi and her family now live a pretty healthy lifestyle, she has been told

1. that she is likely to have eye problems in the future that may need surgery.

2. She will need to manage her blood pressure to avoid stroke, heart disease and other complications.

She now has chronic pain because her injuries after the car accident took so long to heal, and her GP tells her she may need a knee replacement sometime down the track.

While she wants to go walking with her husband most nights, her knee is very sore and sometimes swells up. This puts her off walking.

Let's go back to that sliding door, and see what happened to Suzi in a parallel universe where her choice of GP leads her down a very different path ...

Suzi heard about a local medical practice called a “patient centred medical home”. When Suzi calls, the receptionist is friendly and asks how the doctor can help her. When Suzi explains, the receptionist says she will book a long appointment for her. This kind lady says that Suzi will not have to pay anything, as the practice bulk bills.

Suzi arrives at the surgery with husband Amir. The receptionist asks Suzi what her preferred language is. Suzi confirms Farsi is preferred and the receptionist gives Suzi a form in Farsi to complete. After a few minutes another lady comes over to her. She introduces herself and walks her to the room.

- Dr Lisa asks her to sit down. She seems focused on Suzi, and asks how she can help.
- Suzi tells her she has been anxious since being told she has diabetes but that mostly she feels well.
- The doctor asks about Suzi & her family’s medical and social history. She seems interested in her life, including her work and her goals.
- She does a number of checks. She tells Suzi she is overweight and that regaining her weight in the normal range is one of the strategies for managing diabetes. She says that although her blood sugar is high her blood pressure is normal.
- Dr asks if Suzi would like her husband to join them to learn about diabetes and how it is managed. She says it can be helpful if her husband understands diabetes too. Suzi thinks this is a great idea and invites Amir to join them.
- Dr asks Suzi what she knows about diabetes, and then explains the condition. She emphasises that it is a serious condition and if not managed properly it has serious consequences, but that learning how to manage it is learning how to live well with it. After she explains each detail, she asks Suzi to tell her what she understands. She doesn’t use big words, and when she does she explains what they mean. Words like “insulin” and “pancreas”. She uses pictures too.
- She explains how diabetes is treated, and suggests that Suzi will benefit from seeing Jess who works in their practice. Jess is a specialised nurse/ coach who can work closely with Suzi to incorporate some of the diet and movement strategies used in managing diabetes into her life. She asks Suzi if she would like Dr Lisa to refer her and Suzi says yes.
- Dr Lisa explains that it will help her stay on top of her condition if she monitors her blood sugar. She suggests Suzi get a kit from the pharmacy and Jess will show her how to use it.

- Dr Lisa goes to a website on her computer and prints out a fact sheet about Diabetes in Farsi, and gives it to Suzi to take home and share with Amir.
- She asks Suzi to come back in two weeks after she has had a chance to see Jess, before she will prescribe anything, as changes in lifestyle alone can help many people.

Dr Lisa checks that Suzi has understood all that she has communicated during the consultation by asking her to feedback what she has understood. The consultation takes about 25 minutes.

Suzi feels that her doctor is interested in her and she feels confident she knows what she is talking about. There is a lot to know about diabetes, but she feels she understands what has been explained to her. She is looking forward to meeting the special nurse, and reading the brochure in Farsi with Amir.

Suzi purchases a blood sugar monitoring kit from the pharmacy. She makes an appointment to see Jess the next week.

Jess introduces herself, explains what she does, and tells her the session will take about an hour. She reviews Dr Lisa's notes with Suzi from the previous consultation confirming her family history, her work and her goals. She asks Suzi:

- What foods she regularly prepares to feed her family;
- what foods she enjoys;
- her family budget for food;
- What activities she enjoys and how often she does them; and
- About past efforts to lose weight

Jess asks Suzi to explain what she understands about diabetes and they have a conversation where some of Suzi's questions are answered including some of the side-effects of diabetes if not managed properly. She reassures Suzi that with adjustments to diet as well as regular exercise many people manage their diabetes without medication. They make an arrangement to meet every week for the next six weeks.

Suzi feels encouraged and wants to avoid medication if she can. With Jess, she has drawn up a shopping list and a daily plan of diet and activity. She has found out that most of the food she regularly purchases for her family are healthy, but she needs to avoid some fats and sweets and experiment with different ways of preparing the meals.

Suzi begins nightly walks around her neighbourhood with her husband. She is feeling better than she has in a while.

Suzi returns to Dr Lisa after two weeks for a check-up. She has lost 2 kilos, her blood sugar is in the right range, her blood pressure is normal. She is enjoying her lifestyle plan and is feeling well. Her husband also enjoys their evening walks and the kids come too. They all love the fresh and healthy food. She feels confident she can continue down this path and agrees to come back to see Dr Lisa in another six weeks

She is seeing Jess every two weeks now.

Six months after her initial diagnosis Suzi had lost seven kilos through diet and daily walking and feels terrific. At twelve months she has lost ten kilos and continues managing her diabetes with occasional visits to Dr Lisa and 6-weekly visits to Jess.

Having a GP and a coach who

- made sure Suzi understood her health information,
- connected with her and encouraged her (and her husband) to participate in the decisions that affected her
- means that Suzi manages her diabetes without medication, to stay healthy and happy.

From a consumer point of view, having the information and motivation to manage your health challenges is not just about great health professionals who are great communicators. It's about having systems behind those great health professionals. How people feel has an important effect on their health.

Let's go back to ENABLED Suzi. It's now two years down the track and she has done a lot of walking. She has a very sore knee.

Dr Lisa organises some tests, discusses the findings with her, and recommends a specialist.

The specialist, Dr Dave, explains that many people are able to avoid surgery if they strengthen her knee. He says that sometimes surgery is needed, but having a stronger knee means a better result after surgery.

After a lot of discussion with her GP, her specialist, and Amir, Suzi decides to do three months of physio. Her knee gets a lot stronger. Although she has managed to keep walking, the pain has worsened, it bothers her more and more. Talking it over with her specialist, her GP and Amir, she decides she will go ahead with the surgery.

Dr Lisa suggests that before the operation, Suzi brings Amir in so that they can talk about what to expect, and make sure that everything at home will be ok while Suzi is in hospital.

Dr Dave operates in a hospital which has a great reputation for good patient experience. The date is set, and Dr Dave has made the necessary arrangements. He confirms with Suzi that she prefers written documentation in Farsi and tells the hospital administration. He also asks if she would like her husband to be copied into communication from the hospital. Suzi says yes.

Suzi gets a letter written in Farsi communicating:

- purpose, place, time,
- how to get there,
- what to expect on the day and afterwards,
- how to prepare,
- important contact details

The letter also arrives by email to both Suzi and Amir. It has a link to the hospital website with a login. When she logs in, the website is translated into quite good Farsi. She sees the details of her planned surgery in straightforward language, simple images and a quality short video.

The website also has information about being a patient in the hospital. It explains what the REACH program is and what to expect while staying in hospital. Her husband finds this very interesting but hopes he won't need to use it. It's reassuring to know that they listen to the relatives of the patient. She sees a video about what pain to expect after the surgery and how

pain can be managed in hospital and later on. There is a video on a device called “PCA” which releases safe doses of pain medication that the patient can control. Using video they show her some exercises that will help her prepare for the rehabilitation she will have after surgery and after discharge back home.

She also finds out about the Patient Information device that is attached to the bedside. It provides information and entertainment and the video shows Suzi how to use it.

From this website she downloads an app to her mobile phone. It will help her find her way. It uses Artificial Intelligence technology to provide a virtual guide once she arrives at the main entrance.

She’s feeling reassured that she understands what to expect from the pre-admission clinic, the surgery, the recovery ward and what she can do to enhance her recovery. She reads that her diet and exercise routine is important to keep up as it will enhance her recovery.

Three days before the date of her procedure she receives a text reminding her of the hospital visit.

Hospital admin contact Suzi and check whether an interpreter would help during the initial consultation. Suzi confirms she is confident to communicate in English, now that she has reviewed the website and watched the videos.

Hospital admin also, knowing that Suzi lives with diabetes, asks her about her food preferences.

On the morning of the pre-admission appointment she opens the app and follows google maps to get to the recommended car park and with this guide she finds the main entrance in plenty of time. Following the instructions, she hovers the app scanner over the anchor point on a wall near the main entrance. This then provides her with a personalised guide, visible only to herself, who leads the way to the pre-admission clinic.

On arrival at the pre-admission clinic, the clerk welcomes Suzi. The clerk already has all of Suzi’s information but she checks to make sure that it is correct. The clerk explains that there won’t be a long wait before a nurse will come and get her and take her to another part of the hospital.

The nurse, Jenny, arrives in a few minutes, introduces herself, and walks with her to the appropriate unit. During their short walk the nurse seems friendly and interested in her. Suzi is feeling comfortable that she is in safe and caring hands.

Suzi wakes up in the recovery ward. She knows that her family won’t be visiting her here, but Nurse Jenny is with her. She has a friendly face and tells her the surgery went well. Jenny shows Suzi the PCA device that will give pain relief when she needs it. She encourages Suzi to rest and she drifts off to sleep. When she wakes, Jenny asks her how she feels, reminds her about the pain relief device, takes her blood pressure and other readings, before bringing her a cup of her preferred tea and a small diabetes friendly snack. Jenny later comes back and tells her she is ready to go to the ward. Jenny stays with her while she is transported to the ward by a porter. When she gets to the ward, Jenny makes sure Suzi is comfortable, measures blood pressure, blood sugar, and a couple of other checks and reassures Suzi that all is going well. She shows Suzi the bedside information screen and checks that Suzi knows how to use it. Suzi remembers the helpful videos she saw on the website before she came to hospital

but is glad to refresh her memory. Jenny introduces Suzi to Maddie, the nurse on the ward who is going to look after her. After Jenny leaves, Maddie sits in the chair next to her and explains what Suzi can expect in the next few days. Suzi is looking forward to seeing her husband and kids later.

While she is in hospital she chooses from a diabetic friendly menu every day and finds the food tasty and healthy.

Suzi does well in hospital and is discharged home with a brand new knee and a rehabilitation program while maintaining good blood sugar levels. She feels confident that she knows how to manage her pain, and she has a plan to see her physiotherapist in two weeks' time while doing the exercises she has been given in hospital.

Her diabetes is managed well, she knows what to do and looks forward to getting back into her daily walks and back to work.

Suzi had a total of four weeks off work, and then went back part time for two weeks before successfully upgrading to full time normal duties. She had enough sick leave to cover being off work.