

World Diabetes Day
14 November



Diabetes is a word Don't make it a sentence!

A personal journey towards empowerment

Lis Warren

 @liswarren

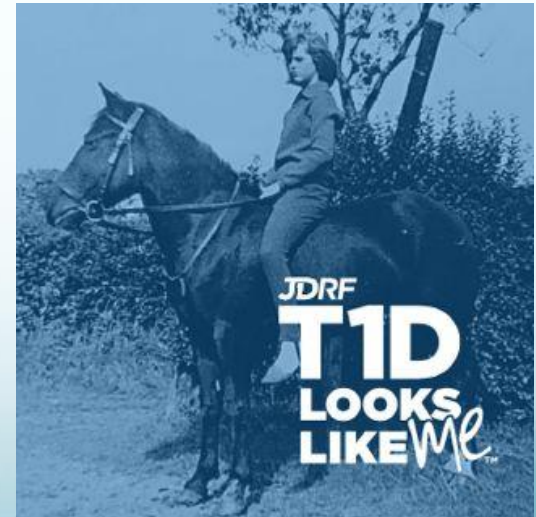
Themes

- My type 1 diabetes story
 - Journey to Empowerment
 - How clinicians can best support
- Emotional aspects of living with diabetes
- Language Matters
- Observations, reflections and things to consider
- Questions / discussion



Diagnosis & early years

- 1965: 3 weeks in hospital
- “You’ll never be able to eat parkin or treacle toffee” – planted life long problem with food
- Little dread or fear – just got on with it!
- Totally self managed (13 yrs old)
- Carb counting and weighing food



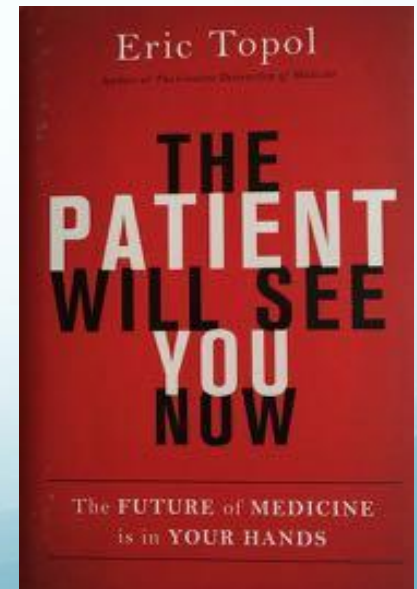
1960s



2018



Palmer Injector



Reflections

- Frightening threats of complications vs ‘the only thing you *may* not do is become an astronaut’
- Language Matters: **we** are going to manage this together in partnership
- Clinical **and** emotional support are key at and after diagnosis
- Education, empowerment & ownership: a *family affair*, for young, old, all types
- **Structured learning = part of the treatment, not an add on!**

Diabetes UK Information Prescriptions

Dr Kevin Fernando, GP *“Hands down, the most useful patient resource encountered in my diabetes career to date”*

On Emis Web, Vision & SystmOne :

Blood Pressure	Keeping kidneys healthy
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Cholesterol	Kidney disease
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Contraception & pregnancy	Mood
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HbA1c	Feet (low risk)
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Feet (moderate/high risk)

Name:
Name of Doctor/Nurse:

Date:

Diabetes and mood

Information Prescription

Living with a long-term condition like diabetes has its ups and downs, it not only upsets your body but your mind too. One in five of us feel depressed at some point in our lives, and it's even more likely if you're living with diabetes.

What makes people feel low?

Physical reasons: Some people have lower levels of 'feel good' chemicals in their brain. So if people in your family struggle with mood, you're more likely to.

Emotional reasons: The way we think can impact our mood. The more we listen to and dwell on negative thoughts the lower our mood may become.

Life events: Life can sometimes be difficult to deal with. When you're diagnosed with diabetes, or lose your job, or get divorced it can impact on your mood – which can be made worse if you feel lonely.



When should I seek help?

Whilst it is normal to sometimes feel down, watch out for some of these signs of depression or anxiety if happening daily for two weeks or more:

- not interested in looking after your diabetes
- feeling down or sad and tearful
- not being interested in or enjoying activities
- feeling hungry all the time or going off your food
- trouble sleeping or sleeping more than normal
- feeling restless or tired
- feeling useless, hopeless or guilty
- finding it hard to make decisions
- regular thoughts about hurting yourself.

My next steps

The two most important actions I am going to focus on are:

(Discuss and agree with your doctor or nurse. Think about what, where, when and how?)

1

2

How can I start to feel better?

It's normal for everyone to feel a little down from time to time and it doesn't always mean you're depressed. It's important to remember:

- ☒ It's normal to feel scared about having diabetes.
- ☒ It's normal to feel stressed about managing your diabetes and experience burnout.
- ☒ It's normal to feel nervous when your blood sugar levels are too high or too low.

Talk about your feelings

- ☐ Talking to friends or family can be a great help.
- ☐ Talking to other people with diabetes can help you learn how others manage when they feel low. Try our Helpline 0345 123 2399*, one of our local support groups or our online forum diabetes.org.uk
- ☐ Talking therapies can help you find positive ways to cope, eg cognitive behavioural therapy, counselling or psychotherapy.

Discuss medication

- ☐ Your GP may suggest medication to help improve your mood and help with anxiety.

Make small lifestyle changes

- ☐ Looking after your body can improve your mood and your diabetes management. This includes eating a balanced diet, getting plenty of exercise and having enough sleep.
- ☐ Make time for yourself.
- ☐ Reading a self-help guide, available free online and in libraries.

NHSE's *Language Matters*

“So much language used implies **blame** just for having diabetes, causing guilt & shame. I just want to run away”

“I was told to use the sides of my fingers for blood tests, to preserve my finger tips for reading braille...”

“My child has type 1 and is not ‘**a diabetic**’; would you introduce another child as ‘**a myopic**’? I doubt it!”

“Being described as ‘**non compliant**’ is awful and does not reflect that I’m doing my best right now. It’s impossible to give diabetes top priority 24/7 – life gets in the way sometimes!”

“I’m not **a sufferer** – I’m a person living well with diabetes!”

Depression with diabetes



My teens and twenties

- Annual hospital visit to adult clinic, went off rails...
- Chaotic management and stopped attending clinic
- Rarely saw a GP
- Used food to manage emotions: food struggles + diabetes = 'double trouble' *
- Neuropathy and Retinopathy
- Weight fluctuations/struggles lasted 40 yrs

* Estimated that 40% of type 1s have an eating disorder (Prof Janet Treasure)

Um... let's see.
67g of carbs, plus 8g of
fiber, plus 3.52 units of
Humalog still on board, plus
impending 30 minutes of exercise,
factoring in my current stress
level, Insulin:Carb ratio for
dinner, and the fact that
it's Tuesday...

...equals...

...um...

Brain
Exploding



$$\frac{62}{351} \times \pi(15.3) \frac{1}{h} \quad 0.75y = 2$$

TYPE 1 DIABETES EXPERIENCE SIMULATOR APP

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Objective

- One challenge clinicians face when treating people living with type 1 diabetes (T1D) is the difficulty to understand the burden associated with self-management.
- The aim of the Type 1 Diabetes Experience Simulator (TIDES) is to simulate the experience of living with T1D for people with normal glucose tolerance and, in particular, for healthcare professionals.
- We hope that simulating the experience of having T1D will encourage greater access to helpful medical devices and therapies.
- The application has been developed in collaboration with INPUT Patient Advocacy (London, UK) the UK diabetes technology advocacy charity.

Method

- The Type 1 Diabetes Experience Simulator (TIDES) consists of a smartphone application developed in Android which includes a validated T1D simulator incorporating a glucose-insulin model [1], sensor noise, realistic intra-day variability on insulin pharmacokinetic, insulin sensitivity and uncertainty on meal estimation [2].
- TIDES provides a set of graphical user interfaces (GUI) that allow the user to visualize glucose levels emulating continuous glucose monitoring (CGM) or self-monitoring blood glucose (SMBG).
- In CGM mode, the TIDES app alerts the user about low and high glucose events. The GUI also allows the user to manually input information about meals consumed and exercise taken.
- The user has to estimate the insulin doses needed to control glucose levels and cover meal intakes.
- TIDES incorporates an optional bolus calculator to assist to the calculation of insulin doses.

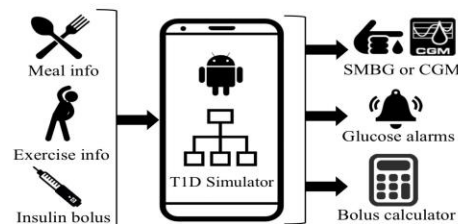


Fig. 1 – Inputs and Outputs of the TIDES app

Results

- Software specifications were gathered through focus groups organized by INPUT with people with T1D.
- The TIDES app went through several iterations before achieving a satisfactory result.



Fig. 2 – Home screen

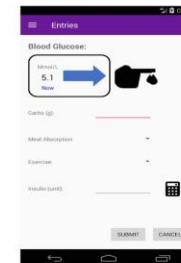


Fig. 3 – Entries screen

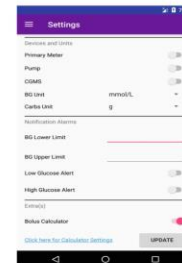


Fig. 4 – Settings screen



Fig. 5 – Calculator settings

Conclusion & Future Work

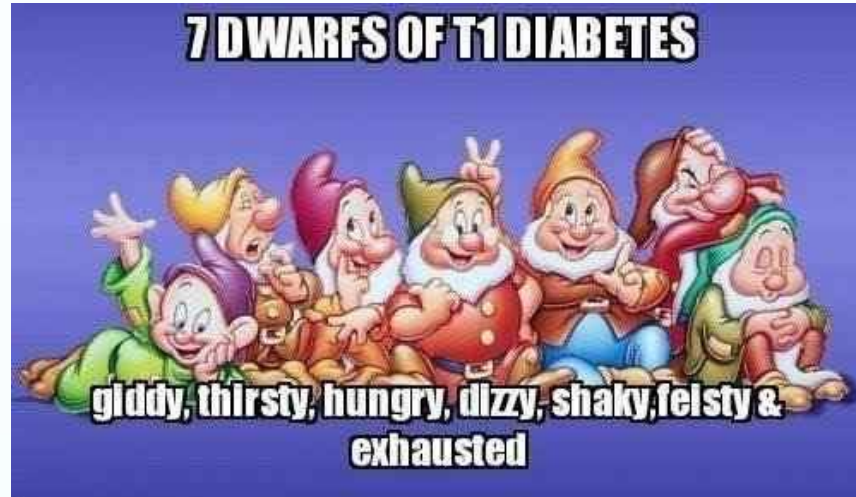
- A functional user-friendly smartphone application aiming to partially emulate the experience of living with type 1 diabetes has been developed.
- TIDES will be evaluated by a group of people with normal glucose tolerance over a prolonged period of time (e.g. 1 month).
- A semi-structured usability and quality of life questionnaire will be employed for this purpose.

References

- [1] Hovorka R Physiol Meas. 2004 Aug;25(4):905-20.
- [2] Herrero et al. Comput Methods Programs Biomed. 2017 Jul; 146:125-131.

Reflections

- Supported transition to adult services KEY



- On-going training/education necessary to stay motivated and well (annually)
- Ask 'How are **you**?' not 'How are your **numbers**?'
- Some have little appreciation of psychological support needed to ensure wellbeing and a healthy self-care attitude

Education & peer support

- Rarely spoke with others for 40yrs pre **DAFNE***
- Diabetes UK's **BALANCE** magazine: my only info
- Began meeting others - transformative
- Discovered Diabetes Online Community: #DOC #GBDOC
- Now attend huge number of social events and formal conferences
- With peer support, embrace diabetes!

***DAFNE** : Dose Aadjustment For Normal Eating



Reflections

- Clinicians rarely put people together – WHY not?
- Youngsters get 'burn out', need support & motivation
- Ageing populations (inc clinicians!) get left behind, lose motivation, memory issues
- NHS budget time bomb if we don't educate & empower patients to self manage adequately

The #DOC

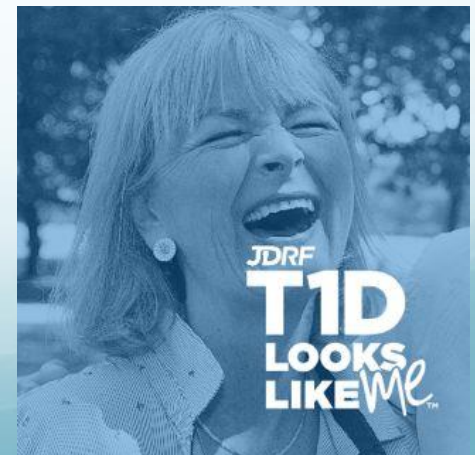


- Research participation spurred online search for info
- Dozens of diabetes Facebook groups, *every topic covered*
- My personal ‘education tsunami’
- Attended talks, meetings, Tweetchats
- Diabetes blogs
- Self regulating, clinicians also take part e.g. “TAD”
- Humour: promotes wellbeing & diffuses stress

Interactions motivated me...

- Membership of London Diabetes Strategic Clinical Network
- NHS & CCG procurement & advice
- Co-Chair NW London Expert Advisory Grp for diabetes and mental health
- Government's Diabetes All Party Parliamentary Group & Diabetes 'Think Tank' member
- Diabetes UK 'Service Champion' & Clinical Studies Group
- Started new Type 1 support group, a London Diabetes Walking Group & persuaded Diabetes UK to host Medalists' Facebook Group
- Active patient advocate
- Trustee of INPUT (Diabetes tech, now merged with JDRF)
- Research participation & PPI Research Reference Groups
- Training clinicians

and... LOOK AFTER MY OWN DIABETES WELL 😊



Diabetes UK Clinical Studies Groups

Identifying research priorities and
moving care forward

Tell Diabetes UK what you think
or get involved

CSGS@diabetes.org.uk

Diabetes technology

Continuous Glucose Monitors; Flash Glucose Monitors



Diabetes technology

- Continuous Glucose Monitor (CGM) & Flash monitors
- HbA1c masks *massive* glycaemic excursions; **time in range** now a preferred measurement
- GP out of depth, hospital had little experience
- Discovered **INPUT**, inspired and developed skills
- Pump benefits realised: began 2014
- Best HbA1c EVER!

My diabetes is managed -
it cannot be 'controlled'!



Reflections

- Judgement by numbers not helpful
- Factors that affect BGs:
 - Timing: eating, injecting, other meds
 - Glycaemic Index (GI) & 'food mix'
 - Weather
 - Illness or infections
 - Alcohol
 - Emotions, stress
 - Exercise – before and after (c. 24hr effect)
 - Hormones: dawn phenomenon, menstruation, pregnancy, menopause

REALLY, REALLY HARD managing blood sugar!

**“IT’S EXTREMELY
HARD TO
BE WELL-
CONTROLLED**

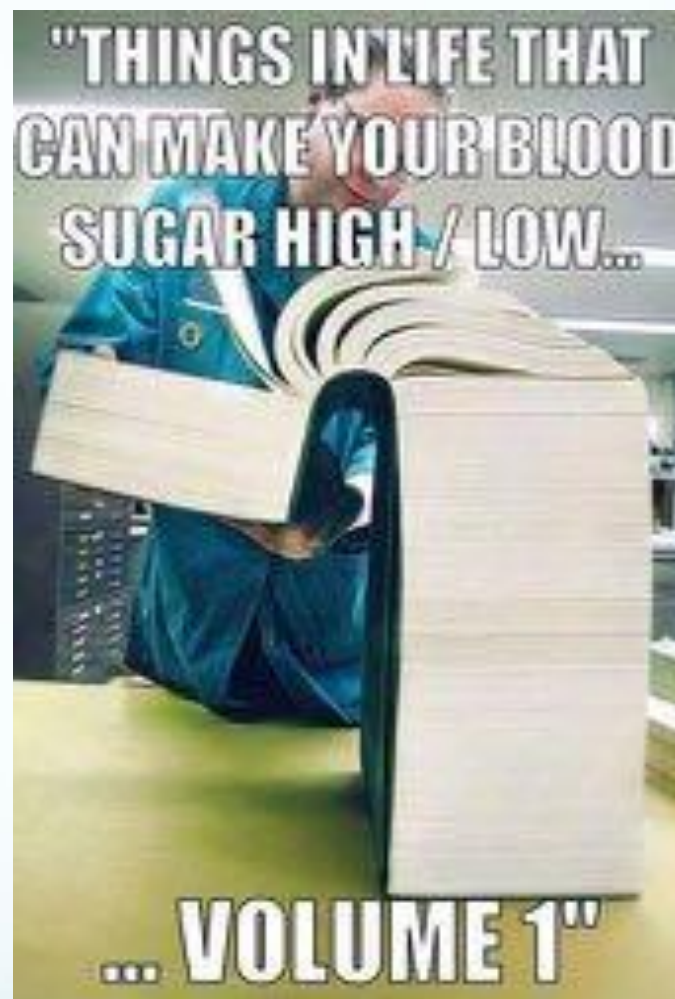
**...food, exercise, weather,
illness, temperature, stress,
injection sites. Don’t expect
me to have perfect control.
Life makes that impossible. ”**

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Factors That Affect BG

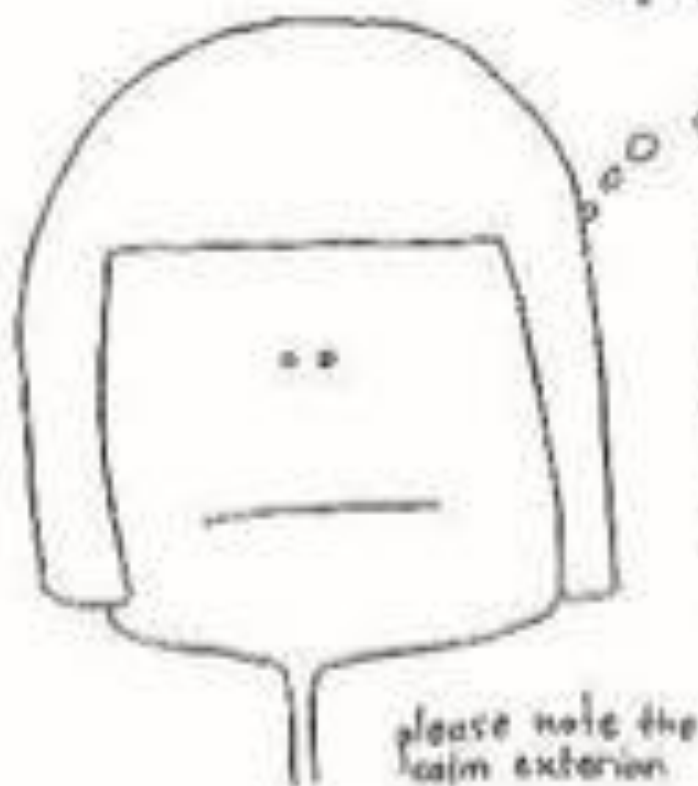
Food	Biological
<ul style="list-style-type: none"> ↑↑ 1. Carbohydrate quantity →↑ 2. Carbohydrate type →↑ 3. Fat →↑ 4. Protein →↑ 5. Caffeine ↓↑ 6. Alcohol ↓↑ 7. Meal timing ↑ 8. Dehydration ? 9. Personal microbiome 	<ul style="list-style-type: none"> ↑ 20. Insufficient sleep ↑ 21. Stress and illness ↓ 22. Recent hypoglycemia →↑ 23. During-sleep blood sugars ↑ 24. Dawn phenomenon ↑ 25. Infusion set issues ↑ 26. Scar tissue and lipodystrophy ↓↓ 27. Intramuscular insulin delivery ↑ 28. Allergies ↑ 29. A higher glucose level ↓↑ 30. Periods (menstruation) ↑↑ 31. Puberty ↓ 32. Celiac disease ↑ 33. Smoking
Medication	Environmental
<ul style="list-style-type: none"> →↓ 10. Medication dose ↓↑ 11. Medication timing ↓↑ 12. Medication interactions ↑↑ 13. Steroid administration ↑ 14. Niacin (Vitamin B3) 	<ul style="list-style-type: none"> ↑ 34. Expired insulin ↑ 35. Inaccurate BG reading ↓↑ 36. Outside temperature ↑ 37. Sunburn ? 38. Altitude
Activity	Behavioral & Decision Making
<ul style="list-style-type: none"> →↓ 15. Light exercise ↓↑ 16. High-intensity and moderate exercise →↓ 17. Level of fitness/training ↓↑ 18. Time of day ↓↑ 19. Food and insulin timing 	<ul style="list-style-type: none"> ↓ 39. Frequency of glucose checks ↓↑ 40. Default options and choices ↓↑ 41. Decision-making biases ↓↑ 42. Family relationships and social pressures

diaTribe®



“Please note the calm exterior”

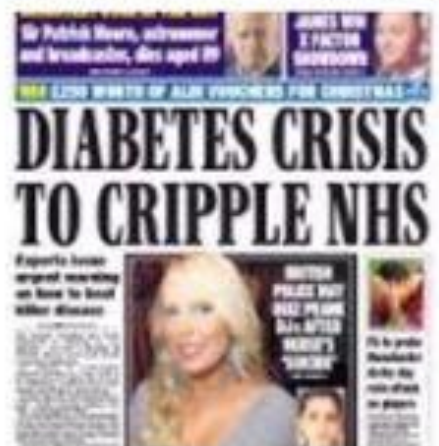
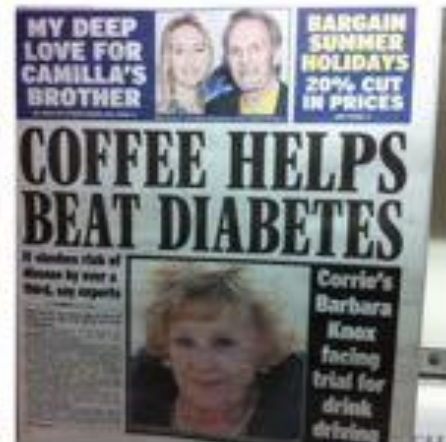
what goes on in a
diabetic's head:



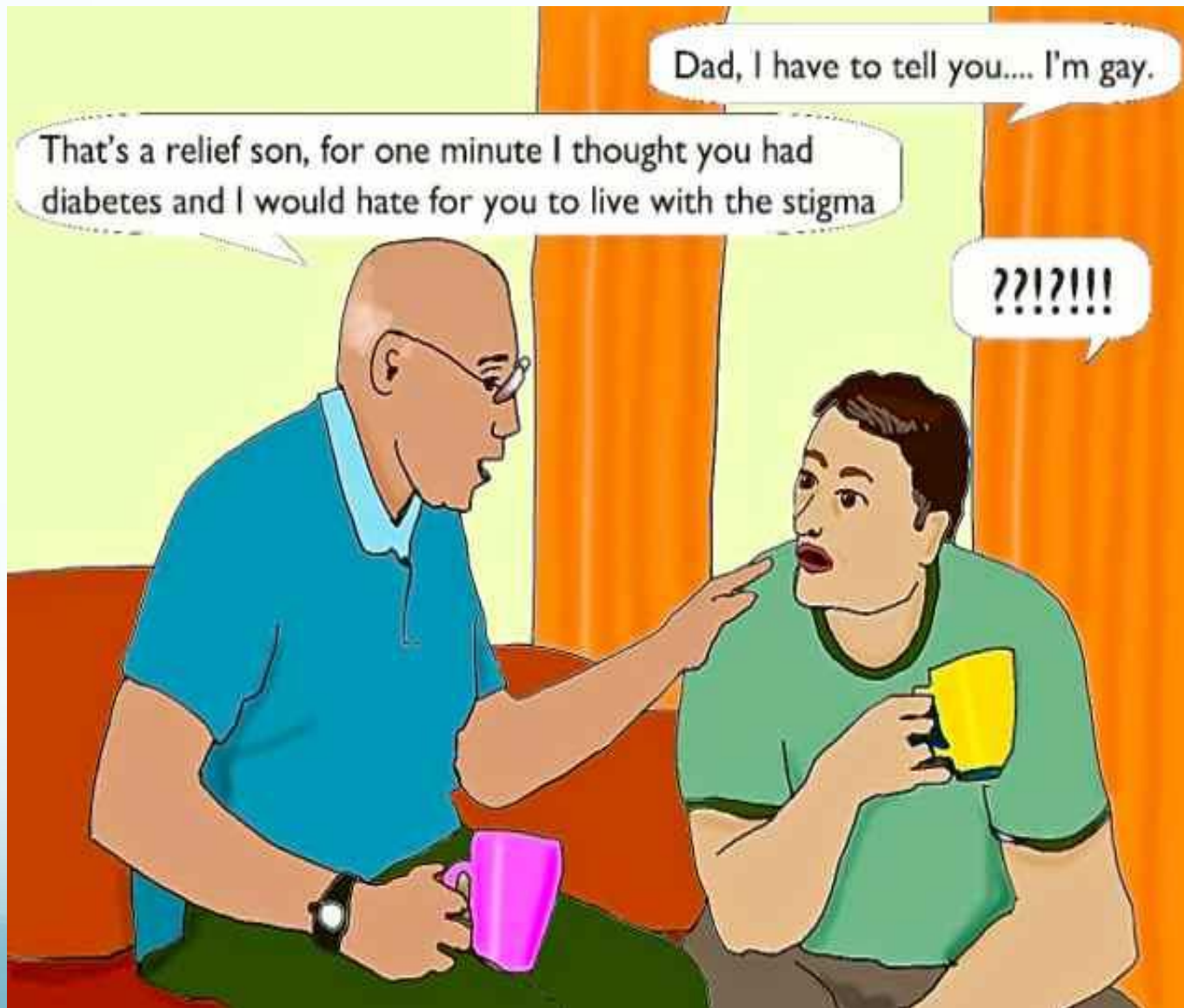
When did I last eat? Where's my
meter? What's my blood sugar? How
many carbs is that cookie? That
salad? Do I need to pee? Are my feet
tingling? How long until lunch? Who
will attend my funeral? How will
people know I died? Am I
doctor's appointments today? Forever?
Am I shaky? Am I nervous or is my
blood sugar low? Is my blood sugar
low or am I just a little? Is there
sugar nearby? Am I doing my best?
What does the clock say? What does the
meter say? What does the pump say? What
does the A/C say? What will my friends say?
Am I eating normally? Am I full? Can I make
it to lunch? Am I able to drive? Do I have enough
fuel strips? Does he know I'm diabetic?
Is he hungry or am I full? How many carbs
will I be sending? Do I have bad dentures?
Shouldn't I have a heart check? Why does my
leg hurt? What's that?

Diabetes & stigma

Causes guilt, is hurtful, misunderstands genetic components of diabetes.
Ultimately affects patients' self-care
so could be a cost to NHS...



Diabetes & stigma



Clinician & Patient support

- **Diabetes UK** diabetes.org.uk (*blue, not red logo!*)

Support for Professionals, all patients with diabetes *and those at risk*, research, campaigning

- **JDRF** jdrf.org.uk

Research, campaigning and support (only for Type 1) now merged with **INPUT**, diabetes technology advocacy and support inputdiabetes.org.uk

- **Know Diabetes** knowdiabetes.org.uk

NW London NHS Diabetes Transformation Programme
online information, **videos** and education hub



Diabetes is only a word
Please don't make it a
sentence!



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