

## Survey results:

# What would you like health professionals to know about living with Type 1 Diabetes?

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This research was conducted by the Type 1 Diabetes Network. Users of the Reality Check forum and subscribers to the monthly Yada Yada newsletter were invited to participate in this survey, with the introduction that the data would be used to help develop an eLearning module for health professionals. All respondents self-selected into the survey. Results were collected in Survey Monkey, and analysed at a basic level only. The survey was open from mid-December 2010 till early February 2011.

## Demographics of respondents (278 people)

Female: 78.4%

Male: 21.6%

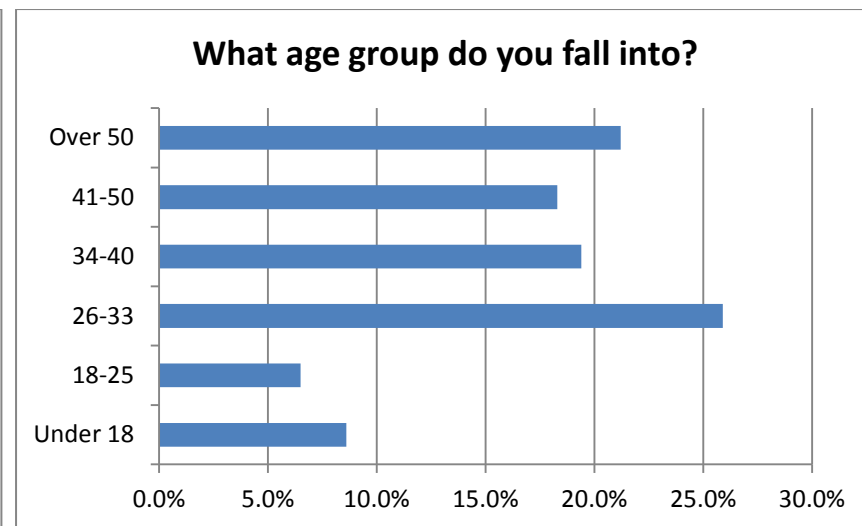
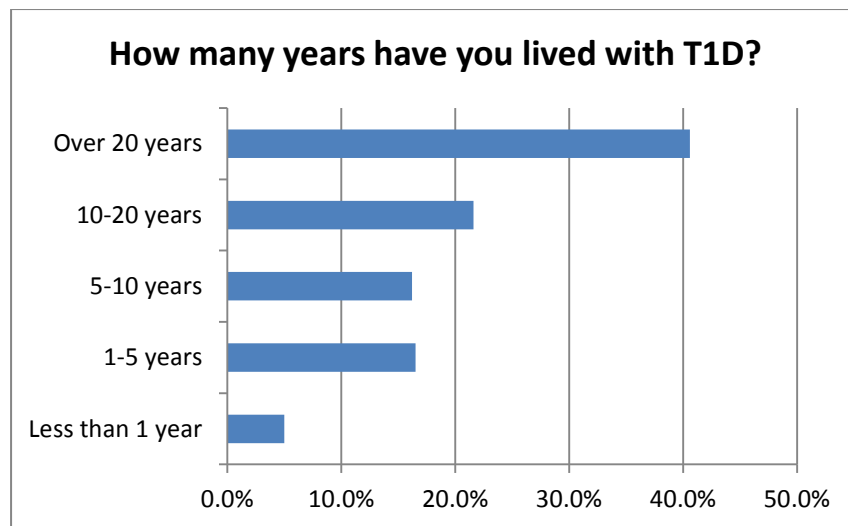
Rural: 11.2%

Regional: 27.3%

Metropolitan: 61.5%

Diagnosed under age of 18: 44.6%

Diagnosed over age of 18: 55.4%



## Question 1

Please select the health professionals who are involved in your health care (i.e. whom you have seen within the last 2 years).

Answer Options	Response Percent	Response Count
General Practitioner	97.1%	270
Endocrinologist	93.2%	259
Diabetes Educator	70.5%	196
Ophthalmologist	60.4%	168
Pharmacist	65.8%	183
Dentist	61.9%	172
Podiatrist	35.3%	98
Psychologist or psychiatrist	26.6%	74
Dietician	42.8%	119
Exercise physiologist	6.5%	18
Nutritionist	4.0%	11
Naturopath	7.2%	20

### Other (30):

Chiropractor (2)	Physiotherapist	General Internist
Optometrist (3)	Paediatric neurologist	Paediatrician
Periodontist (2)	Renal Physician	Massage Therapist
Osteopath (2)	Neurologist	Accupuncturist
Chinese medicine Dr/acupuncturist (2)	Rheumatologist	Dental Hygienist
Gynaecologist (2)	Specialist physician (for blood pressure issues)	Bariatric surgeon
Nephrologist (2)	Plastic surgeons	Bariatric dietitian
Obstetrician (2)	Radiation oncologists	Paediatrician
Dermatologist (2)	Respiratory physicians	Men's Health
Therapist	Allergy physicians	Insulin pump specialist; herbalist
Diabetologist	Physical Training Consultant	Massage therapists – rehabilitation
Personal trainer	Gastroenterologist	

## Question 2

Of these health professionals, how would you rate each person's general understanding of T1D? Please answer for every health professional you've seen in the last two years (as you listed in Q1). For health professionals not applicable to you, select NA.

	Excellent	Quite good	OK	Patchy	Low	Practically non-existent	N/A
General Practitioner	10%	<b>36%</b>	32%	15%	5%	1%	0%
Endocrinologist	<b>71%</b>	19%	5%	1%	0%	0%	3%
Diabetes Educator	<b>59%</b>	16%	7%	2%	0%	0%	15%
Ophthalmologist	20%	<b>31%</b>	20%	7%	1%	0%	20%
Pharmacist	6%	20%	<b>38%</b>	14%	5%	1%	16%
Dentist	3%	16%	<b>30%</b>	15%	11%	5%	20%
Podiatrist	10%	22%	17%	3%	3%	1%	<b>44%</b>
Psychologist or psychiatrist	6%	8%	13%	12%	3%	6%	<b>53%</b>
Dietician	20%	23%	11%	4%	4%	0%	<b>38%</b>
Exercise physiologist	4%	4%	4%	1%	1%	1%	<b>85%</b>
Nutritionist	4%	4%	2%	0%	1%	1%	<b>89%</b>
Naturopath	1%	4%	4%	4%	1%	2%	<b>85%</b>

[See full-text responses....](#)

### Question 3

How would you rate each person's understanding of the day-to-day challenges you experience in living with and managing T1D? i.e. not the clinical side, but the 'real life' side. Please answer for every health professional you've seen in the last two years. For health professionals not applicable to you, select NA

	Excellent	Quite good	OK	Patchy	Low	Practically non-existent	N/A
General Practitioner	7%	20%	<b>30%</b>	22%	14%	7%	1%
Endocrinologist	27%	<b>34%</b>	23%	7%	4%	2%	4%
Diabetes Educator	<b>35%</b>	29%	13%	5%	2%	1%	15%
Ophthalmologist	2%	13%	<b>28%</b>	16%	9%	7%	24%
Pharmacist	1%	10%	<b>23%</b>	22%	12%	12%	20%
Dentist	2%	3%	18%	19%	15%	18%	<b>25%</b>
Podiatrist	2%	12%	18%	9%	7%	4%	<b>47%</b>
Psychologist or psychiatrist	5%	7%	14%	10%	4%	5%	<b>54%</b>
Dietician	9%	18%	15%	8%	5%	4%	<b>39%</b>
Exercise physiologist	1%	3%	1%	6%	1%	1%	<b>87%</b>
Nutritionist	0%	5%	3%	1%	2%	1%	<b>88%</b>
Naturopath	0%	5%	1%	3%	3%	2%	<b>85%</b>

[See full-text responses...](#)

### Question 4

**How important to you are the following aspects of your health professionals' attitude to T1? First, answer this question about health professionals you only see because of Type 1 (e.g. Endo, Diabetes Educator, Ophthalmologist).**

	Very important
Clinical knowledge of the condition	238
Supportive attitude	226
Up-to-date knowledge of T1 treatment options	224
Respect for your judgment	218
Listening to your concerns	217
Keeping up with the latest T1 research	206
Understanding of your day-to-day issues	203
Willingness to try new things	148
An analytical approach to decisions	140
A directive approach to what you should do	110

[See full-text responses...](#)

## Question 5

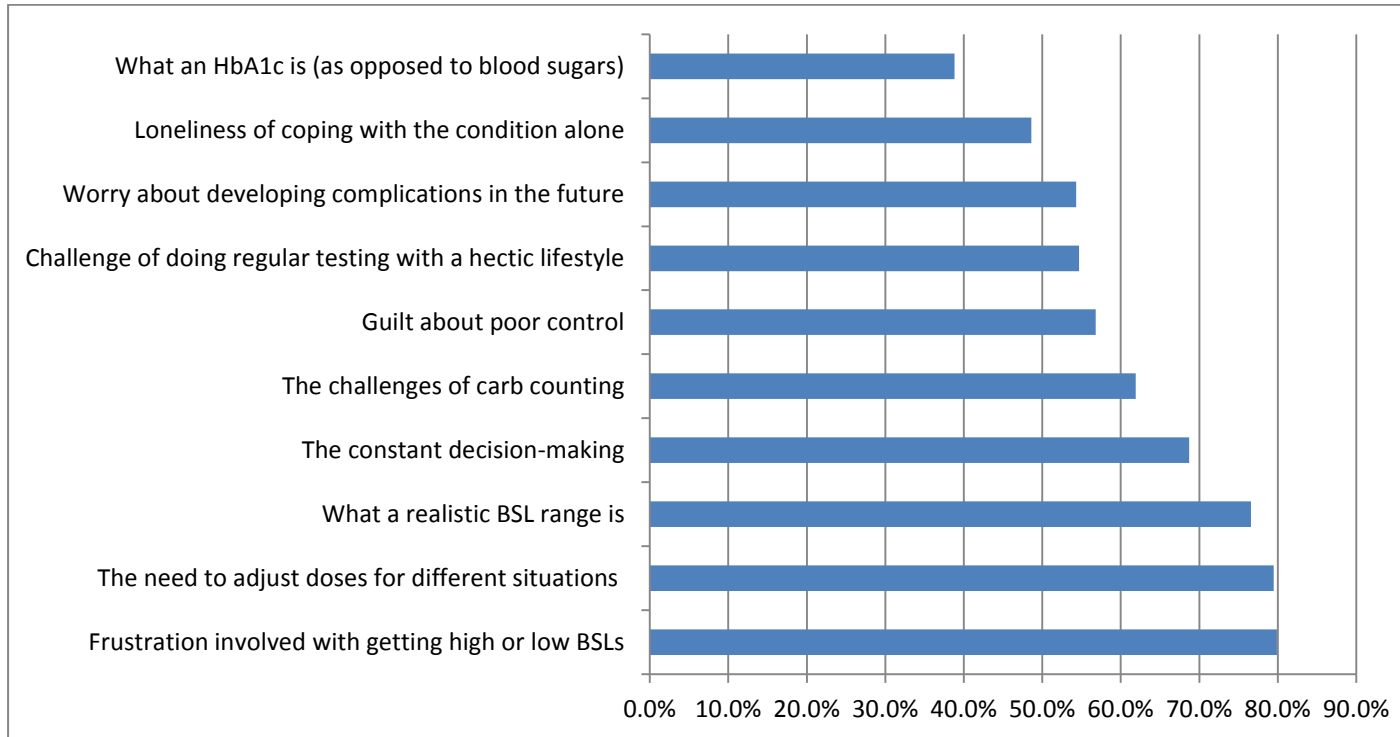
Next, answer this question about people you see for other things but who know you have T1 (e.g. GP, Dentist, Pharmacist). How important to you are the following aspects of your health professionals' attitude to T1?

	Very important
Respect for your judgment	163
Supportive attitude	147
Listening to your concerns	140
Understanding of your day-to-day issues	92
Clinical knowledge of the condition	86
Willingness to try new things	77
An analytical approach to decisions	72
Up-to-date knowledge of T1 treatment options	66
Keeping up with the latest T1 research	53
A directive approach to what you should do	36

[See full-text responses...](#)

### Question 6

For health professionals whom you feel don't have a very good understanding of what it is like to live with T1, what do you wish they understood?



[See full-text responses...](#)

## Question 7

If you could get ONE message to all health professionals about living with T1D, what would it be? (253 responses)

### Key themes:

It is complex, unpredictable, not a textbook condition and every day is different	(51)
It's 24/7 – constant – no break	(40)
Treat patient as an individual	(40)
It's not easy	(32)
Please listen	(26)
Understand the difference between T1 and T2	(25)
Respect the patient's experience	(16)
Don't judge	(14)

[See full-text responses...](#)

## Final comment field

Thank you for your input! If there's anything else you'd like to add, you can put it here. (67 comments)

[See full-text responses...](#)



## Full-text responses

**Q2: Of these health professionals, how would you rate each person's general understanding of T1D? Please answer for every health professional you've seen in the last two years (as you listed in Q1). For health professionals not applicable to you, select NA. ([Link back to question summary...](#))**

### Other: (46 responses)

- My dentist suggested I 'wait and see' what would happen to an abscess I had. A year later, I had the tooth removed. However, my sugar levels - because I had an infection - went through the roof. My Endo kept asking me if I had any infections. Obviously, I said no, because I really didn't understand that an abscess was an infection. Alas, my degrees are in law and not science.
- Therapist has increased their knowledge
- I choose to put together a team of specialist, it was the only way to create routine and trust for my son.
- Diabetologist - Excellent, Personal Trainer - patchy
- I have had some doozies of doctors over the years and plenty of them have made mistakes and said stupid things. The best Endo to see would have diabetes themselves!
- In fairness to my GP he admits he's not that knowledgeable about Type 1 Diabetes and thinks the Diabetes Unit is the best place for me to go for help, monitoring and any issues.
- Physio - quite good knowledge
- Renal- excellent
- Chin med dr/acu - understanding was good.
- I am basing this on my stand-in Dr...My original dr was absolutely brilliant when she went on maternity leave I saw a different Dr who thought I was actually type 2 not type 1, unfortunately I didn't know this is what she thought...She changed my insulin to different brand, did not go well!!! Luckily my original Dr is back and we are now trying to work out all the mess!
- They just don't have a clue!!!! I seem to know more than them... I know what to do... I know when i should do it... it's just hard to do and even when I do it I don't get the results I should be getting!!!!
- It's ok for hps to not know everything if they admit it and make the effort to try to learn.
- I don't have a problem with my GP not having excellent understandings - he always refers me to my endo for questions he isn't sure of.
- Rheumatologist — low specialist physician — patchy
- Obstetrician - Patchy
- I've searched high and low to get a good team around me - so this wasn't easy!!!! I've seen other dietitians etc whose knowledge has been 'patchy' etc.

- I also see a great physiotherapist who is quite good in his knowledge of Type 1 and very keen to learn! My dentist has Type 1 diabetes so this is probably not a very fair representation!
- Personally, a lot of professional opinion seems too black and white and is based on text book tertiary education as opposed to practical knowledge of day to day realities of living with type 1. "Living" means working in chosen field, exercising, travel, leisure, sleeping, interrupted schedules, etc.
- Depends on which GP as varies from one to another
- Nurses and hospital staff come in the "OK" criteria, I never feel safe when I am in hospital.
- I would like to be able to access an exercise physiologist that understands Type 1 and insulin pumps, but haven't had access to this service (I live in a rural area). I also find that my Endocrinologist has an excellent knowledge of the chemistry and biology of Type 1, but doesn't seem to recognise the impact of this on lifestyle and the psychology that comes with that - I often feel that she can't understand that my whole life can't revolve around my diabetes - there are other important things in my life as well. My GP purely knows the basics - I don't find consulting with him very useful.
- Often depends on individual and area of expertise.
- I have a new ophthalmologist so I don't feel I know her that well hence my quite good rating and not excellent.
- My dentist told me an hba1c of 7.3 was "terribly poor control" - despite my endo being fine with it, this is simply not true even. Will never see him again. Lecture me about my teeth which you know something about, not my diabetes.
- General Internist: Excellent understanding of how hard it is to manage T1.
- chiropractor - patchy
- Of the health professionals that I have said "quite good", they may actually know a lot more. I do not have real in-depth conversations about diabetes exactly. Psychologists may have some knowledge I have found but it can be quite patchy or non-existent. A psychiatrist I assume has some knowledge, but probably not the same depth as an endocrinologist but still quite good.
- I have noticed that general practitioners on the whole are more knowledgeable about diabetes and are able to assist me with diabetes management. I live in remote rural community and an unreal doctor practiced here but no longer does. She was wonderful and the best practitioner in regards to diabetes I had ever met. Since then I have noticed a big change in general practitioners' knowledge about diabetes.
- Very sceptical of alternative health practitioners, much as I would like not to be. Had too many really ignorant comments and suggestions made.
- nursing profession - not well informed about type 1
- Obs - Quite good
- I was diagnosed with Gastroparesis by my Endo and the Dietician at the local clinic had never heard of this T1 Complication. I was advised by her to eat higher fibre foods to help the digestive issues I have, little did she know that high fibre foods are actually what you need to stay away from with this complication
- Nephrologist - Excellent
- On one occasion I visited a different GP at my normal clinic. I had a sore throat, I told him I had been taking Butter menthol his response was that I had better be careful or I may induce Diabetes. He then looked at his computer monitor and realized I already had T1D.
- I feel like most people I meet...except for my Endo...there is a blur between T1D and T2D....

- My GP reviews my Care Plans but I direct my questions about my diabetes to my Endo or Diabetes Educator or an Educator at DAV. I don't discuss my diabetes with my Pharmacist or Podiatrist (he just carries out the appropriate checks) I don't talk a lot about my diabetes to my Psychologist as I see him for other issues which contribute to my depression.
- Have also seen an obstetrician for a pregnancy. He specialises in high risk pregnancy so I would say his knowledge is quite good.
- My Endo is excellent on the physical things. Whenever I have 'wobbled' (mental stuff) he sends me off to see a mental health professional.
- Too much focus on T2D and not T1D. I'd be great to be with a Health Professional that understands the differences and treats you differently as well.
- bariatric surgeon - patchy bariatric dietitian - patchy
- I find some health professionals struggle with the difference between type 1 and type 2 diabetes, if I pick up on this and if I feel it affects my healthcare I move onto someone else.
- Paediatrician - is excellent, with a extensive knowledge of Type 1 - will be transitioning to endo over the next year.
- Exercise physiologist is type 1
- Gynaecologist - low to patchy (and he is a PCOS specialist!)
- I don't see an Ophthalmologist but I do see my optometrist annually and she has the ability to do Retinal Photographs in her clinic - I believe her understanding of diabetes (particularly regarding eye complications) is far better than other optometrists I've seen!
- My GP and my endocrinologist have an excellent understanding of diabetes by design, as I wouldn't be seeing them if they didn't. I was however impressed with the understanding of my dentist (periodontist).

**Q3: How would you rate each person's understanding of the day-to-day challenges you experience in living with and managing T1D? i.e. not the clinical side, but the 'real life' side. Please answer for every health professional you've seen in the last two years. For health professionals not applicable to you, select NA. ([Link back to question summary...](#))**

**Other (32 responses):**

- My dietician is so bad that I have refused to see her for over 2 years.
- Therapist has an understanding through sessions with me
- Diabetologist - Excellent, Personal Trainer - Low
- I have had type 1 diabetes for 55 years and have never had such poor treatment as now. Our local District Health Board is the most wasteful and have, as usual, overspent. I pay to see a private podiatrist and optician as the Hospital is unable to see me thanks to lack of money from the DHB. The waiting lists to see such places are far too long. Here in NZ it is shameful what the Health Boards do not do for diabetes.
- Physio - quite good
- Renal- excellent

- Chin med dr/a cup - low to ok.
- I am basing this on my stand-in Dr I saw!
- As above, they don't understand!!!!
- Rheumatologist — low specialist physician — patchy
- Obstetrician - Practically non-existent
- My DE is a Type 1 and she has children who are Type 1 - so.... she's more experienced in some ways than I am. However, more generally I'd rate some DEs as only be 'ok' with appreciation and understanding of the real life experience.
- Most of the above people do make an effort to understand. Also, I don't see these people just so they can tell me what I want to hear, their job is to challenge me on my diabetes maintenance, not pat my head and tell me how it's all going to be fine with out working hard to keep things on the level. Also, it is my responsibility to educate the above people with real life experience; the end result is our shared information being of greater benefit, not an us-vs-them attitude.
- Comments as above - also, I would like to be able to access a psychology service that understands Type 1 - I find the day to day mental challenges the hardest part of Type 1 and tis is the support that is very hard to find.
- chiropractor - practically non-existent
- I am not sure exactly how much the health professionals actually know about what diabetes is actually like on a day to day basis. I have had health professionals who have been rather clinical and not so relational. My current GP is good but I have seen GPs who have been a bit judgemental. Like once my blood sugar reading was 13 mmol/L. I am not perfect all the time and I didn't need the "looks" or the criticism.
- Both endo and DE are T1 themselves
- They tend not to understand how you have to compensate for daily events and activities that fall during meal times.
- I've never asked
- DE is a diabetic herself.
- My Optician fully understands my diabetes in regard to eye health
- As above. Re: day to day challenges of type 1 in pregnancy, would say quite good.
- High lack of empathy - Just tell you that you have to get your HBA1C down below this level...not how to do it and acknowledging how hard it is to maintain with all the stressors and influential things involved in day to day life that impact on sugar levels i.e. uni or having your period!!!!
- bariatric surgeon - practically non-existent bariatric dietitian - practically non-existent
- My gp blamed my recent aic result (7.4) on my "indulgences", when I have been dieting and exercising like a maniac! My endo commented that as I am coming out of my honeymoon that if that is as bad as it gets I am "doing a good job" - music to my frustrated ears on the verge of diabetic burnout. I don't think gps understand that sometimes no matter what u do, bsl management can be hard, they just assume you must be misbehaving!
- Paediatrician - very good understanding
- The Diabetes Educator has a husband with Type 1 so she understands what it is like to live with Type 1

- Pharmacists drive me nuts. Any time I have a non-diabetic reason for a pharmacist they like to tell me it's because my bgl are not in control (which is untrue). They also like to tell me how many supplies I should buy ('Oh you won't need that many' - when I'm preparing to go overseas. Why don't I be the judge of that.)
- Gyno - patchy
- If find that Endocrinologists can be particularly judgemental because while they're very good at the clinical/technical side of Diabetes, they have no real understanding of the day-to-day emotional implications of the disease. I find that many other practitioners have a better empathy of how it is to "live" with diabetes, even if they don't know the specific clinical details of the disease. However, over the years I've come across many doctors/practitioners who have little or no knowledge of the disease - still thinking that it's a "sugar" disease and this is very concerning for me.
- Again if they don't get it I won't see them.
- My DE is T1 so lives the 'real life' side but non-T1 DEs wouldn't have this experience so would score lower.

**Q4: How important to you are the following aspects of your health professionals' attitude to T1? First, answer this question about health professionals you only see because of Type 1 (e.g. Endo, Diabetes Educator, Ophthalmologist).** ([Link back to question summary...](#))

#### Other comments (19):

- Don't tell me what to do! I feel that my health is a collaborative project and decisions need to be jointly made.
- I had adverse reactions to NovoRapid and Levemir. The Endo and Educators didn't seem to be as worried about this as I was. One of the Educators said I was probably allergic to one of the preservatives, though I still don't know which 'preservative' it is and don't know if it is a product used in other medications. I contacted the company and I'm not sure if they pursued the matter because I didn't hear back from them. In all this I got the impression I was not believed. Interestingly, I had none of the same problems when I switched to Humalog and Lantus.
- While these are all very important to me, sadly, my team has difficulty displaying these qualities.
- The correct blood tests to request to ensure a correct diagnosis is made
- Don't know what the last one means
- It's important to listen and try to understand. We know what we need to do, it's just not easy to do and get the results we all crave. It's not like we don't try.
- The directive approach is interesting... I've had an endo which didn't tell me anything really. He was very supportive but that was it. He didn't give me any idea how to improve things. My next endo was great in that she provided some ideas and was directive in that she set goals. This approach worked well because it was combined with a high degree of knowledge and supportiveness. So, being directive can work but it needs to come from the right place.
- Re importance of a "directive approach": I want clear, reliable information and direct advice about what I should do, however that needs to be tempered by listening to my concerns, being open to analysing other options, and ultimately respecting my judgment (and the realities of life not always following our best-laid plans).
- We changed GPs and have found one who is knowledgeable and helpful at the same time
- I see my Endo for 5 minutes 3 times a year. In 28 years he has never allowed me to finish a sentence and deliberately interrupts me with a change of subject when I try to explain problems I'm having. There are other Endos around but they're so popular and fully booked that I can't get in to see them instead of my own Endo.

- I would appreciate if the health professionals I saw took a 'problem-solving' approach to my day-to-day challenges. This would involve them listening to my specific problems/goals and working with me to brainstorm solutions. I find health professionals are often too directive and are concerned about issues that are not a priority for me. I would like to take a 'functional' approach to goal setting with health professionals, e.g. help me brainstorm how to play basketball each week without hypo-ing instead of just talking to me about insulin adjustment for exercise in generic terms.
- I think the people who are treating directly because of diabetes should have up-to-date knowledge.
- I believe health professionals need to understand the challenges we deal with day to day and be supportive and helpful and not judgemental. I also believe it is important that they be knowledgeable of research and treatments of diabetes.
- Would love to know of an endo who also has type 1 diabetes.
- I see my GP only for the last 2 years for other things and she does not let me to forget about my D. I really appreciate her knowledge of the condition, even though I was seeing an endo 3 years ago, now I am not because I have too little money to see a private one and too little time to see one in a hospital, so my GP is just right at the moment.
- They are all important!!!
- There is a limited and unsure attitude toward behaviour and emotions related to glucose levels i.e. grumpy behaviour when "hypo-ing"
- What can I say? We pay a lot of money to see these people! We want the best for our healthcare!
- I have a very high standard for my health professionals. I also consider them to be consultants - I am paying them to share their expertise with me, not to tell me what to do or judge me.

**Q5: Next, answer this question about people you see for other things but who know you have T1 (e.g. GP, Dentist, Pharmacist) How important to you are the following aspects of your health professionals' attitude to T1? ([Link back to question summary...](#))**

**Other comments (14):**

- All of the above only relates if the health professional chooses to comment on my diabetes management - I don't want a lecture on managing diabetes from a pharmacist who I'm buying Voltaren from...
- Don't expect these people to have the same in depth knowledge, but sometimes find these people are more likely to listen to some of the issues involved with diabetes, than the experts.
- I don't care if they're not knowledgeable about diabetes BUT it really irritates me if they start spouting nonsense with an air of authority. Keep your mouth closed and I'll think you're ignorant about type 1 diabetes, open it and you'll confirm you're a dangerous idiot.
- I feel like these health professionals are probably better off leaving t1 related things to the endo etc. I realise their knowledge base is quite large so I don't expect them to have much of a grip on t1 diabetes, but it irritates me when they know very little and pretend they know a lot.
- Also important that these health professionals are able to admit it when they don't have a strong understanding rather than given potentially conflicting and contradictory advice

- Working together is very important. Guidance, feed back and discussion are essential to my consistent motivation to stay on top of the condition.
- Basically, I want these practitioners to have a basic awareness of the daily issues raised by D that are relevant to their area of practice and to have a sound understanding of clinical issues that affect the safety of the advice or care they offer me. Over and above that, I just want them to be respectful, understanding of the fact that D affects how I manage all my other health concerns, and supportive when I present as being "burned out" on all things health-related.
- I don't expect health professionals I see who aren't directly related to my diabetes management to have up-to-date knowledge of Type 1, however, if that is the case I do wish they would listen to me. I have had GPs and nurses completely ignore knowledge I bring to a consultation.
- I think that all health professionals need to respect a diabetic's judgement (not necessarily agree with it), should be non-judgemental, and definitely listen to your concerns. If they cannot provide direct answers then they should be able to point you at least in the right direction to people who can.
- My treatment at a GP was appalling. I was told when diagnosed in hospital to get a care plan sorted with my GP - I asked him to organise me one - and he said he didn't do care plans. When first diagnosed we don't know what treatment or plans we need - the doctors should be giving us this information - but it doesn't happen.
- I get frustrated with well-meaning but misguided advice from healthcare professionals who aren't trained in type 1 issues. Unfortunately things aren't as quick-fix as some think... If it was that easy everyone would be doing it!
- This is a difficult question, as I would expect a GP to have knowledge of Type 1, but Dentists I would not expect to have as extensive knowledge etc.
- Up-to-date knowledge of research relevant to what they are treating me for is important, but I don't expect them to be across all areas that are not directly relevant to them.
- The most important thing for GPs and other general health professionals is to 'know what they don't know'. In other words, I don't mind if they know almost nothing about T1D provided they don't think they know more than they do. It's also very important that they understand I live with the condition every day and quite likely know more than they do. I've met a number of GPs who do very well at this - know the very basics, and trust me/refer me to my endocrinologist for the rest.

**Q6: For health professionals whom you feel don't have a very good understanding of what it is like to live with T1, what do you wish they understood?**

[\(Link back to question summary...\)](#)

**Other comments (50):**

- A BSL 'range' as opposed to one specific number - I constantly get asked 'what my sugar level is' - there does not seem to be an understanding that it can go between 2 and 20 on any given day (depending on circumstances). There is no one magic number that it stays at.
- My diabetes isn't the same as what they have read about in text books and won't be the same as the next person who walks through the door. AND I don't have type 2 diabetes...
- I also have Coeliac Disease. Yet to find an Endo who has any idea of the effect that Coeliac disease has on diabetes - mainly on Insulin absorbance times. They assume that they are the same or similar to those who just have diabetes, but there are different issues/times. But it is not just the doctors. None of this has been published anywhere, so doctors have no basis of how to act or what to say! So what does one do???
- Respect for "parents intuition"

- Trying to replace the pancreas's function is not easy. the emotional side of diabetes. change to a previous carefree lifestyle
- That t1 IS different to t2. T1 is a 24/7 regime, never to be forgotten at any time. Plus, at times can be unpredictable, we don't intend having high and low bsls, some days it just goes awry!
- The impact of things outside our control impacting on BSLs – e.g. illness, hormonal fluctuations, stress
- That BSL's are irregular on a daily basis, i.e. there is no "average" BSL, Hypo's and hyper's can occur daily; and that it is extremely difficult to maintain good control; and that the person with T1D knows more about living with the condition and managing BSL's than they do; and bring condescending about BSL control doesn't help; and it is different to Type 2 diabetes.
- Complications are not always the fault of the individual. I have had very tight control of my HBA1C and have experienced mild complications after seven years with IDDM. It should not be assumed by health practitioners that these complications have arisen because I have been a "bad diabetic" as I have often been told. This does not help with the management of the condition and only makes it harder to have motivation to keep up with rigorous testing regimes.
- The differences between type 1 and type 2 diabetes and to never, ever call me a "diabetic". I have type 1 diabetes.
- Especially the loneliness - I don't know anyone with T1 and I feel extremely lonely at times.
- Also that if I go outside of the 4 - 8mmol range, it really isn't the end of the world, nor will I necessarily remember what caused it! I've been virtually interrogated about "excursions" in the past by doctors. Sometimes we will go outside that tight range and that can be very normal! Maybe not ideal, but it WILL happen and it doesn't mean I have crap control, nor does it mean I don't care about myself.
- The more complicated it gets, the more room for errors and anxiety around control. Counting every carb is like counting every step on a 10km run, it's just not going to happen. Having BSL at 6.5 all day every day is a nice thought, kinda like patting a unicorn. Yes, it's an unrealistic fantasy. Bear in mind though, targets to aim at are required or there is no control. It's all about BALANCE
- That healthcare is about partnership between the person and all the health professionals they see i.e., they can talk to each other, & while I expect to be involved in decision-making, I shouldn't be expected to pass clinical information between them; I've had T1DM to have some idea of what 'mistakes' I can make; Challenges involved in needing to see multiple health professionals (if I had a dollar for all the time I've spent in waiting rooms for appointments!)
- What a realistic BSL range is for someone who works full time in a stressful profession, whilst trying to live life to the fullest.
- Sometimes I begrudge that my endocrinologist makes me feel guilty about my HbA1c. I don't think she means to but she does through inadvertent comments. When talking with medical professionals all the discussions revolve around medical targets and not lifestyle issues - it would be nice to be able to talk to someone about everyday issues/concerns.
- For me I appreciate that a professional will listen to my situation and approach but I still want them to present (and explain in layman's terms) their opinion and knowledge on their particular specialty without being judgmental
- Sometimes what works in theory doesn't always work in practice.
- All of the above are the daily reality, but I don't expect much (nor really care for THEIR opinion). I care for the people it encroaches on... like, my children, husband and close friends



- How exhausting (mentally and physically) T1DM is and how other problems sometimes feel like they are the straw that will break the camels back. They may only want you to do one extra thing but you already feel so overwhelmed with diabetes that it is so hard to do.
- That T1 is a constant balancing act, and that any solutions proposed must be practical and work for that particular person's situation.
- I think health professionals need to be non-judgemental. I am sure that there are diabetics who do not care about their health and do not make much effort, but there are people who are very health conscious and are dealing with issues all the time and cannot be perfect all the time. I think they should be encouraging and focus on positive behaviours. They also need to be realistic with the person, even if that means giving bad news. They should also treat a diabetic as a patient with diabetes and not focus solely on the diabetes but also on other concerns or possible causes for illness that are presented.
- That they should respect their limitations of knowledge and not try to give advice when it's not asked for or warranted
- Doctors are too busy slipping in patients for their 10 mins of support, which is not there.
- My GP still doesn't really know the difference between Type 1 and Type 2 (which he treats a lot). He still asks me things like don't I take any pills at all? He wants to treat me for Metabolic Syndrome, which most Type 2's have, but I don't have.
- The constant day to day, hour to hour, decision-making re BGLs, carbs, exercise, illness etc - not the big picture, but the everyday challenges. Extra supplies, travelling supplies, availability of hypo food, shift work issues etc. All the day to day stuff.
- They need to know that a lot of the time we know what is best for us and our bodies because we live with this disease day in and day out. So they need to be supportive of our treatment decisions, but be ready to help us if we have any questions or issues.  
The difference between type 1 and type 2 - the patient shouldn't have to explain that to a health professional
- Shouldn't act like they know everything because they did diabetes 101 at uni. Shouldn't patronise. They've got NO idea half the time. Be a bit humble. We do it hard, especially when our bsl's are hard to control.
- I wish people understood that you can try as hard as you possibly can but it sometimes still isn't enough! Some days are just DIFFERENT despite doing the same things as the day before
- Definitely what a realistic BGL range is. Most think it is extraordinary if you have a reading outside optimal range!
- Again most people I encounter they have no idea of what the "Ideal" BSL range is and how hard it is to keep on track...
- That diabetes is MUCH more complicated than any other condition and that taking your instructed dose of insulin and sticking to a diet is NOT enough to guarantee blood sugars between 4 and 8 all the time.
- What a tiresome pain in the ass it all is!
- That having no automated BSL control, i.e. type 1, makes consistent control very challenging. It is not type 2!!!!
- The immediate effects of having a hypo and need to have food asap
- That I understand how to manage my diabetes, even when things are a bit haywire.
- They assume it is your fault that sometimes your control goes out the window, and blame you, when all you are doing is trying your best. I wish they understood that it's not as easy as most treatments, i.e. 'take two pills twice a day with food' - this is much more complicated and just when you are getting the hang of it, your body can change the rules with no warning or explanation and you need to start working things out all over again!

- The difference between type 1 and 2!!!!
- The amount of effort put in at all times to achieve good control.
- That getting an HBA1c under 7 isn't always easy.
- Please don't patronise me with simplistic info and explanations... I'm very familiar with the ins and outs of my condition - I have much more respect for your clinical position when you respect my level of understanding.
- How T1 diabetes can affect many aspects of health/how pervasive it is- for example, I have had problems with constipation, depression, difficulty with BSLs when ill, fatigue etc all very closely related to diabetes.
- Weight issue
- The difference between 'delayed hypo response' and hypo unawareness.
- My main frustration is when they ask "so what are your usual blood sugar levels?" And they expect you to provide a specific answer. So they are obviously unaware that they are CONSTANTLY changing. While my control is not perfect, it's also not bad, however I always have very variable BSL's. I should not be made to feel like a weirdo just because I can't answer their question with "Oh, usually between five and six" - AS IF!!!!!! I HATE having to answer that question with "They're always different, always changing, always going up and down – that's just the way things are!" I test > 10 times per day and constantly assess what I'm eating, bolusing, exercising etc, yet they are still constantly up and down - I think that's just the way it is. I also feel that anyone who does have BSL's mostly between 5 and 10 are more in the minority??? Many of us work very hard, but still have levels going up and down.
- Emphasis on what realistic BSL control is - many health professionals don't seem to get that even well controlled type 1 diabetics have regular excursions outside the ideal range and that this is basically unavoidable.
- The impact of other stressors and medical conditions on T1D
- Everything is Type II based with GPs and they have no realistic outlook on type 1 and the results you should be getting

**Q7: If you could get ONE message to all health professionals about living with T1D, what would it be? ([Link back to question summary...](#))**

### Comments (253)

- Improved management to avoid lows and highs
- That the patient is the one who knows their own diabetes the best and we are all individual in what works or doesn't work for us.
- We have to balance the challenges of living with type 1 diabetes and living our life to the best of our ability.
- Listen before you speak.
- Listen
- That I am not a number, but an individual and whose condition is exclusive to me.

- T1D is not a 'TEXTBOOK' condition. Every person's T1D is individual and you cannot fully understand the condition unless you HAVE it, and even then it's all a bit sketchy!
- Every one is different, please remember that when newly diagnosing someone :)
- It is hard to live with. And please, some positive feedback would be good.
- I would love them to have an understanding of the complexities involved with T1; that sometimes, no matter what you do, it can go wrong.
- That I have a pretty good idea of my knowledge base re me, and that their old textbook knowledge can be archaic and destructive
- It is constantly a concern and a fight every day even though you just get on with it.
- The sporadic nature of control
- Understand the difficulties of coping 24/7 with T1D1....
- It is a 24 hour condition and there is no perfect BGL.
- We are all different, and what works for some doesn't always work for everyone
- It's a constant battle - Not always able to achieve great readings there are so many variables which contribute NOT always our fault
- That although I need advise at times (especially with new drugs, needles, unusual circumstances, etc), I know what I need and am likely better at it than they are - I don't enter a hospital for example, and instantly forget how to test my BGL or when I need extra insulin for example - nurses get really shitty at this and don't realise it's the way I can actually be proactive and in control (so to speak) about this disease - doing it for myself! I do it every day for myself and by myself, so if I want to keep doing it myself in a hospital, I should be allowed to no questions asked. Its about a lack of respect I guess in general - not just in the hospital scenario - and sometimes I don't get respect from some professionals. Id like to! I know they have to deal with the lowest common denominator but really...if a type 1 D doesn't have some sort of grip after a few years...well they'd probably be in a gutter somewhere. I laugh when the chemist assistant (or pharmacist) asks me if I've used insulin before and do I know what does to give!!! I live in a [small] town ... and they know who I am (and I know they have to ask for some absurd bureaucratic reason) but I've often wanted to ask them..." no actually how much should I take"...it's bloody ridiculous. So my message is respect for self managing a tricky little condition!
- Any one can get Type 1 diabetes at any age.
- We need more support.
- Though T1 Diabetes is a common condition, it is also a very individual condition. No T1 is alike, similarities exist but you cannot generalise T1 management or treatment options. It requires tailored management to each person with T1DM. It also requires more than the support of a medical practitioner(s), other health professional with specialised expertise need to be strongly involved such as psychologist, podiatrist, diabetes educator etc.
- Listen and be patient
- On one hand they tell us to try not to be too obsessive about numbers (Daily testing) and on the other they tell us to have better numbers!(Hba1c)
- This is NOT Type 2 diabetes. This requires CONSTANT attention to every possible detail and it will not SETTLE DOWN!! Every day is a roller coaster.
- The saying " don't let it control your life " please refrain from using that B/s
- Everyone is different, and is affected in different ways. 1 rule can't be applied to ALL type 1's.
- It is never easy calculating 24/7/52 before any other of life's activities.

- No-one knows what it is like for each diabetic, every diabetic T1 is different and their bodies can behave differently. Just because you are over-weight does NOT mean you have type 2.
- Every person is different. What works for Bob, may or may not work for me.
- Testing young children for the gene
- That type 1 is very different to type 2 - and it can sometimes feel patronising when I'm given advice that I don't feel relates to me (ie: diet and exercise)
- Maybe some more experimental control options.
- Glucose control is affected by other factors than food and exercise
- I can eat some normal food, even have a coke at a dinner if I prepare for it. When staying in a hospital with an illness I don't eat as much and require less insulin. That is the most annoying part ... the diabetic can best regulate their insulin use and know how much insulin for types of food ... hospitals give you hypos due to over doing the insulin required. I have discharged myself from hospitals twice due to staff/doctors not listening to me and giving me hypos,, i mean does anyone like hospital food ?!?!? I would eat half what I would normally eat ..
- Everyone is different and DM is as much a personal condition as it is a medical condition. Listen first and hear what is being said before you make any judgement about T1D's approach to self-care.
- Every day is different (exercise & food) and requires thought and possibly different treatment.
- Learn more about type1 diabetes instead of type 2 diabetes as type 1 have more problems than type 2 diabetes
- That one treatment is not necessarily going to work for all. And, learn more about diabetes yourself. It is quite amusing to be told by the pharmacist, as I was recently, that insulin should be kept in the fridge except for the stuff you are using. Er I have had diabetes for 55 years so I already know that !!!
- To recognise that Type 1 is a difficult and complicated condition to manage.
- Lecturing me because you don't agree with my choices in managing my diabetes when you're not a part of diabetes care team will only make me never come back and tell all my friends with T1D to do the same!
- That EVERY person with T1D is different and every day for a person with T1D is different. What may work for you one day - or even one hour - may not work the next - you have to be open to trying different things.
- It can be a very individual condition – how your body reacts to factors (food, insulin etc) and how you personally handle the condition...
- Listen to the individual
- It is not always just the diabetes. Have some understanding of how much other diseases can affect diabetes. Diabetes by itself is quite simple. It is when it is affected by other diseases and situations that it becomes complicated.
- No two days are ever the same, a constant struggle to maintain 'normal?' blood glucose levels.
- It's an INDIVIDUAL disease - you are textbook experts, not experts when it comes to our children as individuals.
- The complications that come with having type 1 for a long time and to try to prevent some of the complications before they happen
- Try putting themselves in my shoes and understand the complex nature of living with a chronic illness.
- Be prepared to hear us. You know the theory... we live the practical.

- Listen to the person with type 1 and work together as a TEAM!
- There is a serious random element to T1D! Even if my behaviour is consistent, it doesn't necessarily mean that my BSLs will be.
- The reality of living with the condition.
- Now what you are talking about, keep up to date when you advising on Type 1.
- Imagine you had diabetes yourself
- Listen to the Diabetic, they know more about themselves than you do
- To treat each and every one of us as an individual, and realise that we are not all the same, regarding HBA1c levels, keeping records, etc., etc.,
- It is an endless, relentless journey
- That it's not just a matter of taking a prescribed dose of insulin and hey presto your bsls will stay within the desired range. It's not like treating hypertension. Every day is a challenge full of complex mental gymnastics just to get an a1c of about 7-8%. It's difficult!
- It is tough and we need HP's support not judgement. Judgement never encouraged me to seek help or got me a better HbA1c - support does!
- When the HbA1c creeps up, to assume or imply we are not trying hard enough or not eating healthily, etc. Nor refer to bsls over 7 as BAD.
- Please understand what a very difficult, time consuming and complicated condition it is to manage.
- Have respect for, and give serious consideration, to our views and experiences. We are the people who live with T1D 24/7 and know how our bodies react and how hard it can be to keep the condition under control.
- Type 1 DM is NOT Type 2 DM.
- In my case you should not go what the person looks like on your initial thoughts of what type of diabetes they may have.... Realise that it's tough and understand that we may struggle a lot.
- Try putting yourself in your patient's shoes... everyone is different and you have to be understanding / supportive and not upset the patient
- It is an extremely difficult condition to manage.
- It is extremely difficult to manage. Diabetes related complications are not always due to poor control and there are other factors often involved e.g. genetics
- It's not as simple as just taking your insulin and forgetting about it all other parts of the day. It's there all the time, you cant forget about it.
- There is more to type one than BSL & HBA1c
- To listen to what we have to say and to keep themselves open to new things
- It does control your life not matter what you do.
- That sometimes, no matter how hard you try, things just don't work and you end up with a blood sugar level of 2 or 17. It's not always because of something you did wrong.
- T1 does not always follow the rules, I live with it daily and understand it intimately and generally have good control yet it still has moments of intense frustration with unexplained Highs and Lows, for example.
- What works for one person does not necessarily work for the next.
- I can manage my diabetes with their help not them manage my diabetes with my help

- Stop treating us like numbers. If a cancer patient was trying to lead as normal a life as possible they are considered to be brave- why are diabetics labelled as naughty or non compliant or stupid
- It is a very mentally exhausting condition.
- LISTEN to me !!!!! Don't just tell me what I should do, explain why, in detail
- Don't assume that all diabetics are the same: we don't all respond the same to food, insulin, medication etc.
- Listen to the person who has Type 1. Not all diabetes is the same. I'm nothing like a T2 or GD
- Same as above.
- It's not Type II Diabetes!
- Diabetes is different for every person and can be different for that person every single day even if they eat or do the same thing on two different days.
- Appreciate just how difficult it is
- Listen to the patients. Sometimes we know our bodies and our T1D better than you do
- Don't be so set in your ways - think of other potential options for treatment (MDI's or pumps). Please don't be so patronising and blunt - a little more compassion and support would be great for my sense of self/self esteem.
- That diabetic control is an art as well as a science and because of this, it isn't always 100% predictable. T1Ds will go outside of the 4 - 8 mmol range despite their best intentions.
- Please be honest and say if you don't know or don't completely understand something, rather than give advice that is well-meaning but ultimately misguided
- That it is NOT Type 2! And that it is a constant battle... Even when I have perfect readings I am thinking about it every minute to ensure that they continue...
- I view Type 1 Diabetes as being under my control. The doctors are there to \*advise\* me but not to instruct me. I live with it 24/7 and I make the decisions, not them.
- It's hard - don't judge harshly be supportive
- Controlling D1 is like paying your taxes. As much as we don't want to pay tax, we have to every day or our world would collapse, so it's about acceptance and getting on with life with this in the back ground, but if we can get away with the minimum we will. Who pays extra tax? Also, does you tax define who you are? Neither does my diabetes, it's a small part of who I am, and I didn't ask for it in the first place but I've got it.
- It takes up a lot of time to manage diabetes and be healthy. It can't be done in 5 minutes.
- No one is exactly the same in how things affect their diabetes control. Listen to the patient who has the condition, don't just go off what is standard.
- Living with D1 is not the same as being a perfect clinical specimen, life is messy!
- It's a constant challenge to achieve balance between managing T1DM & trying to be 'normal'. At my workplace, it's not uncommon for people to miss meal breaks, and after-work drinks are one of our few social activities.
- Diabetes burnout is real and debilitating and requires assistance. When you are presented with a person who really truly seriously yearns for a holiday from T1D and laments their ability to keep on with the constant decision-making, consider whether they need some psychological support and help them get it. Yes, it's tiring and everyone gets sick of it sometimes, but PLEASE recognise the mental toll of this disease and don't expect that it will just come good on its own.

- Every one with type one is trying really hard to control there blood sugar levels but sometime they just get out of control don't put us down for this offer suggestions but do it with humility
- Listen and think what is she really saying, how can we support this life decision and consequently influence diabetic health and lifestyle in general.
- We live with it every day, everyone is different. Listen to us don't just judge us by blood results.
- The utter debilitation of hypo hangovers which can last anything up to two days and for which there is apparently no research and no cure. My current treatment for it is a strong cup of tea, paracetamol and to sleep it off - if and when possible. Often it isn't possible so it's necessary to go about your business feeling like DEATH itself, or to cancel your day altogether.
- Everyone is different be supportive to us all
- To know more about Type 1 and be able to really listen, advise, understand what they are being told about the feelings, frustrations and help their patient.
- T1D is not T2D!!!!!!!!!!
- It is a manageable disease BUT!!!
- I am not an idiot and rely on you to keep me up to date with what's new
- No one is perfect and sometimes BGL's don't make sense so please don't lecture me about poor control and complications, help me by listening and exploring opportunities.
- It is really hard to manage type 1 everyday - recognise that when you are talking to me and acknowledge that often Type 1 isn't the only thing in my life that I need to focus my energies on.
- No part of the moment to moment management is easy or straightforward, no matter how long I've had T1D
- We're not all the same. Life can't be lived from statistics written in a book.
- It is such a balancing act to get the right levels.
- The difference between type one and type two and not lumping us together! Knowledge of specialist services such as DEs that they can refer us to for more detailed support and advice.
- Living with diabetes is an art not just a science
- Frustration in getting high and low bgl's even if you do exactly the same thing each day i.e food intake, exercise, day to day work.
- We are all different! We don't fit into a box!
- Diabetes is everyday of my life, that's hard enough without you telling me I don't care enough or try hard enough. I do both and it's not even always enough - you try to do all the things you suggest and not get fired from your job or have a breakdown.
- Type 1 is not the same as Type 2, it is in no way related to poor lifestyle choices.
- Realize that we are doing the best we can with the limited tools that we have to replace a pancreas. It is the medical establishment who has failed us, we have not failed you. No other person with organ failure gets blamed this way.
- It is not easy to be T1 every single day, never to have a day off.
- Give us the facts as you know. And the information gathered from the wealth of other peoples experiences. Share the information

- Don't make assumptions - we are all different people, and T1D is a different challenge for each of us.
- To be supportive, let you know what your options are, and not to judge a person if they have poor control, to help them understand where they can make changes and improve their control without sacrificing their jobs, friends, hobbies.
- The person with diabetes lives with the condition and manages it 24 hours a day every day of the year. You must include them in decision making and respect their knowledge and experience. Diabetes is not a text book disease. Every diabetic is different and their bodies work in different ways.
- That it never stops.
- I've had this for 22 years - I'm not an idiot - don't condescend to me. While I respect them as professionals, in some instances, I know more about the technicalities of T1D than they do. LISTEN!
- Diabetes does not go by the text book and everybody is different.
- Don't judge harshly be respectful of people living with a chronic condition, keep it real.
- I once saw a new endocrinologist (I'd moved cities), and he spent 3/4 of an hour lecturing me on what I was doing wrong, but never once asked what I needed, or made any constructive suggestions for improvements in management techniques. This was despite the fact that I'd already been living with T1 diabetes for ~8 years. I never went back to that specialist. Lecturing doesn't help. Listening to your patients does.
- It involves constant juggling. Every hour of every day involves adjustments and decision making with variations in activity and diet.
- It is not a predictable situation 100% of the time, even with good attitude to diet compliance etc.
- Be humble, supportive, empowering, and not judgemental
- Keep looking at the WHOLE person, diabetes is just a part.
- Get with the real world of diabetes!(not all of us are textbook cases.....we're human beings!
- It is not easy. Overall control is not achieved with a standard dose of medication, it is affected by what we eat, how much we exercise, illness, stress and hormones. It is a complex disease and there is not guaranteed treatment that works for everyone, and one treatment may not work for the same patient all the time.
- The difference between a person presenting with T1D as apposed to T2D
- A T1 diabetic needs to lead as normal a life as possible, while never pretending he is normal.
- The difference between type 1 and 2. Type 1 being an auto immune response and that you are not type 2 on insulin.
- If 4.2 is about perfect and 3.5 is a technical hypo that leaves a very small margin of error when a bolus takes 6 hours to complete.
- What works for some people might not work for others
- Motivated positive type 1's make it look easy. Add some mental health issues and other chronic disease issues and you have a daily marathon!
- Please try to understand what we have to tolerate each and every day
- it is hard to have BSLS that are good all the time and we all try really hard to do the right thing , but lifestyle and our bodies are all different, which affects BGLS. A supportive, understanding and helpful approach is best.
- Treat the person not the condition
- I live with it every day, I know my diabetes, but sometimes I just need a little outside support. Don't treat me like I'm an idiot



- Realistic treatment by other medical professionals i.e. at emergency department at hospital where your reason for being there is dismissed and you are sent home still very ill from ketoacidosis and/or vomiting or other diabetic problem.
- If getting the HbA1c in the right zone means daily hypos and calls to the ambulance, there probably is a bigger problem. The cost of getting the right number sometimes outweighs the benefit.
- Stop worrying about your 300 dollars plus per hour
- Flexibility in managing day to day BSL's Just because my BSL right now is 9. something does NOT mean I have poor control.
- Hold some type of hope for us and a cure or better treatment, keep up with all the new research and just be positive about the outcome of the research. It's not easy depending on a couple of pens that you have to keep with you 24/7. I look at it like it's a temporary measure until a cure is found. My endo is a smug bastard that must sit in his lunch break counting his cash because he seems like that's more important than my hope and my condition. If they find a cure his just lost the majority of his clients.
- It's easier said than done.
- As much as you try, you'll just never understand.
- Type 1 and Type 2 are different diseases.
- Complications are not our fault, and not our parents' fault.
- Prioritise. I have too many medical things to try and fit in. give me the most important goal for the next 3 months and some understanding.
- Type 1 is NOT type 2!! It is very individual and very challenging.
- Understand the balance
- The patient usually knows how much more stress they can handle - help them learn to self-regulate
- That the juggling act of T1D is quite a challenge, it is not an exact science! Even on two consecutive days doing exactly the same thing will not get the same result, there is just too many variables in play.
- That T1D is a daily balancing act that can be tipped out of balance by absolutely everything. It is see-saw on top of see-saw on top of see-saw. To juggle all of that as well as normal life is a feat onto itself.
- Don't be so judgmental - unless you have walked a mile in our shoes
- Make sure they know what health problems the person is going through
- It's bloody hard work
- Every T1D is different so you can not group us altogether, our bodies all react differently.
- T1D doesn't run my life I make it suit around what I want to do
- T1 are not T2s
- It's not as simple as it may look
- It would be nice to feel like they were supporting you to make good decisions rather than judging you for having a high HbA1c or other difficulties and labelling with 'non compliance'

- Life happens and sometimes levels just aren't right and there is nothing you do fixes is straight away. The trial and error takes time.
- Be realistic about us doing the best we can in a challenging 24/7 situation
- See above.
- It's always a challenge, there is no set pattern but a range of different challenges
- Be honest - there is still a lot of unknown about type 1 - so don't pretend that you have all the answers. Also, consider that treatment is all day every day and many of us can't stop thinking about it. When BGL's go high or low - it is not always due to the food we ate or not counting the carbs/insulin correctly. Doctors need to listen to patients more.
- Never having a day off is that hardest thing of all
- Don't judge me by my BSLs and HBA1c
- EVERYONE is different
- Don't lecture. Offer advice, support and suggestions. Don't make orders
- It is different all the time
- Listen!!!
- ? everybody tells you something different.
- Type 1 and Type 2 are very different conditions
- Help us by being up to date and progressive in treating T1D. Don't treat it from an out of date knowledge base.
- To be less clinical as it is a daily decision making process
- Managing T1D is about getting a balance between reasonable management and everything else in life!
- Understand that the person who has T1D probably knows more about their condition than a GP who has read a book on the subject.
- We WANT to have control of this uncontrollable condition in OUR hands, please, empower us.
- As above...Knowing what the "Ideal" BSL range is and how hard it is to keep on track...
- It's complicated and don't assume you know more than you do.
- It is with me 24 hours a day - no break from it!!
- Anyone can get T1 at any age. (I was misdiagnosed for 6 weeks and as a result lost a lot of weight, was greatly fatigued and had blurred vision). When I returned and told her I had been diagnosed with T1 by a diabetes educator she still was in doubt.
- Even though I'm not a kid I HAVE TYPE 1!!!
- That living with T1D is not text book and what works one day may not work the next
- Even thin fit 50+year olds get it
- A continual challenge with daily fluctuations due to the many variables it's not just about insulin/carbs, many individuals with diabetes need support when reflecting on their concerns.

- It's harder than you think, harder than the textbooks say. Its constant, never-ending stress so don't judge us on what we do or how we manage until you have spoken with us thoroughly.
- It NEVER stops and it affects EVERY aspect of my life and if I have a melt down moment I need support & encouragement not lectures
- It's relentless and there is never any downtime. Try and imagine that!
- T1D is very challenging...I'm trying to do my very best but it's not always easy to get those perfect BGL's!
- Take cues from what we are saying. Don't have the same approach for all type 1s (or 2s, or LADAs)
- I can't think of one message that would apply to all health professionals but certainly the elements listed above in Q6. covers what I would like them to know.
- Each person with diabetes has different circumstances and therefore, should be treated differently based around the individual, rather than focusing on the condition. More connection between the health providers (i.e. GP and dentist, dentist and endocrinologist would also make life easier).
- It is really hard and I really do try
- It's not all about the number that appears on the screen that counts it's the number of times it appears on the screen.
- There is no such thing as perfect control and I do the best I can while still having a life.
- Diabetes care needs to be tailored for the individual - it can't be a text book approach.
- Glucose levels are not always aligned to food and exercise. Sometimes emotions/stress or some unknown factor can affect levels
- There is a difference between the ideal medical textbook world, and the real world of living with type 1 diabetes.
- Do NOT dictate to me.
- Practical solutions, tailored to one's lifestyle is the key to blood sugar control success.
- That it isn't easy and it can be very boring and monotonous
- I have been diabetic for 30 years, trust me, I know a bit about it!
- If you want to pass judgement or give advice, please make sure you are well informed, and if you find your knowledge lacking, please visit realty check!
- Keep up to date on new treatment
- Try it for a day when you have the flu or other ailment when your BGL just does it's own thing no matter how much you try to keep control.
- It is not as easy as a text book makes it out to be, you can do all the right things and still have BSL's out of range.
- I love it when they listen without being judgemental, and respect my understanding of my condition.
- We spend a lot of time managing our condition, so when we come to see you about a problem have the courtesy to value our input and help us find a workable solution. Please don't treat us like we don't know what we are talking about, because we live it everyday.
- Support me to manage this condition primarily myself.
- It's a juggling act with multi-factorial inputs. Only a well informed person with T1 has any long term chance at managing this well.
- Looking at BSL readings for the last "whatever" period doesn't allow you to manage things, because there are a host of contributing factors.
- Listen to me! As the patient, I live with it 24/7 so I'm most experienced in the day to management and understanding of my diabetes - Please don't underestimate the value of my experiences.

- That it is very difficult to remain an active self manager of this condition and meet their expectations as well as your own
- To offer support at all times with regular tests for everything to be done on a regular basis to help prevent the complications that are faced.
- That it's a constant battle and sometimes you just wish you could switch off and be "normal"
- That the psychological dimension of managing the condition warrants far more attention.
- I understand my responsibilities and necessary tasks associated being a diabetic. Please help me with the specific things I am coming to you with.
- Listen to, and understand, the person with T1D.
- Diabetes is a very fickle disease and you can never really fall into a pattern and relax because how your body reacts to insulin and your environment is always changing.
- That you are able to eat foods with sugar occasionally (ie chocolate etc) as long as you factor in to the insulin dose. The one thing I will never forget is my endo telling me "your chocolate eating days are over." To someone new to the illness that was terrifying. Also initially the dietician set up a meal plan that was so rigid and difficult to manage that again I was terrified. Professionals need to understand it as though they were faced with the illness themselves.
- The disease is extremely multifaceted. You do not just eat right or avoid certain foods and take your medicine and then you are fine. It is much more complex and no scientific formula or duplication of conditions will provide a replicable results, as to many variables are involved. It is also very time consuming and frustrating disease to handle.
- They should be helping get the message out that diabetes is not only a lifestyle disease. By lumping us all together ie type 1 and type 2 is it so misleading
- Everyday is different; Every occasion you leave the house is different; Everyone copes differently.
- Understand the fundamentals of the condition, listen to the patient and empathise.
- There are multifaceted factors affecting T1 control including time constraints; lifestyle issues; motivation issues and just being 'human'.
- They should try living with it
- It's nothing like Type 2 Diabetes.
- Know the difference between T1 and T2
- Listen first. Be sensitive and supportive.
- I'm trying to live as close to normal life as possible - it's not my fault that I have this disease, and it's very difficult to have perfect control every single moment of every single day. Please don't judge me or the choices I make. Oh, and T1 is NOT THE SAME as T2!!!!
- Insulin is no cure but a treatment. To achieve good control takes hard work and dedication along with support from others.
- Don't be legalistist with me about changing insulin levels if I feel I need to.
- I guess it's what I said above, that even though we may work our butts off to obtain good control, there is not even an answer to the question "what are your usual BSL's?"
- That type 1 and type 2 diabetes are two very different things!! Although both have many similar challenges when living with diabetes, I instantly feel alienated when they don't even understand the basic difference and assume my condition has somehow been caused by my lifestyle.
- Rather than frighten patients with the risk of complications - which is a real risk - Health Professionals should be encouraging their patients to think on the positive side and plan their future life.

- Please be helpful
- It's basically impossible to keep BSLs in range all the time, and even keeping them there most of the time is far more challenging than anyone without the condition realises.
- It's not a one size fits all condition so look at each case individually and work with the 'client/patient'.
- Its hard.
- Shadow/follow a T1D for a couple of days and listen to their constant thoughts on every decision and its ramification on the next BSL.
- That what is taught in books is very different to what happens in reality.
- Living with diabetes is hard work
- That there is a difference between type 1 and type 2 diabetes - omg, I can't believe how no one knows the difference!
- If it was all so easy and logical and measurable and controllable as many HPs think, we would all have perfect A1cs all the time!!
- It is NOT Type II, don't think the treatment is the same

**Q8: Thank you for your input! If there's anything else you'd like to add, you can put it here. (67 comments)**

- Thanks
- Keep up the good work.
- Great survey!
- It's a pain, but I'd probably be less healthy without it
- Oh for a cure !!!!!
- Great work - this is a bugbear of mine and needs addressing - thanks!
- I'm the mum - filling in the survey for my 7 year old son who was diagnosed when he was just 4 years old.
- By the way I think the system for Diabetics in Australia is fantastic, but..... When travelling it would be great if airlines could add a couple of kilo's to the allotted hand luggage weights for diabetics, so we can still manage spare clothes as well as all our medications plus the just in case spares, insulin, tablets, cooling (ice) etc. The hand luggage limit is 7kg. Bag weighs = 2.5kg 1month insulin, flask cooling pack and tabs = 1kg Spares the same = 1kg High and low GI foods = 1kg Itinerary and documents = .5 kg Not much left for any change clothes if the main case does not turn up for a while ! Thanks.
- I have had Type 1 [for over 40 years]. I have no signs of 'complications' eg heart/kidneys/eyesight etc are all OK and working well. I don't even wear glasses. I would like to know why that is, and why some younger friends of mine have tragically passed on. There must be some sort of genetic protection for some, like a gene; but alas nobody medical wishes to study it. If they could find out why I am relatively healthy and in one piece, perhaps they could solve the riddle of diabetes complications. NB remember, I have had Type 1 diabetes since pre blood glucose testing.
- Diabetes Educators need to work more closely with schools and the wider community in order to educate people about T1D and in particular the differences between T1D and T2.

- A national computer system that holds all your medical history, so if you travel interstate or need to see another doctor, they merely type in your name or number and all your medical history pops up.
- thanks hope this makes a difference
- Thanks
- Thanks for taking the time to investigate these issues, they are very important to my morale in managing what is often a challenging disease with little or no support.
- I have my ups and downs.... but my down days are awful. I feel so alone.... In 3 months, my parents have only asked how I am going with my levels about 3 times. It's like they don't care. I have very little support, and I feel like I can't really talk to my GP (as my parents see him too and I worry he will talk to them), or my Endo (as he is quite 'down the line' and not very compassionate. Online support groups, like RealityCheck, are awesome, but they're virtual, not real ppl in my life...I wonder if there are support groups around or if I could get subsidised counselling services??
- Excellent idea guys.
- Keep up the good work
- Caramello Koalas f&cking rule!
- I drive an hour each way to see my endo, diabetes educator etc. in the nearest regional centre. It usually involves taking a day off work. I have to prepare for the relief staff before I go and then turn around and prepare for the next day when I get home. Some visits are very unrewarding. It takes a lot of effort to get there and I want people to value my time and give me something awesome in return. I guess I just need a holiday from D!
- Thank you
- Keep up your good work, I appreciate your efforts.
- I have specifically found it hard to find medical professionals to help me with managing Type 1 and my plans for pregnancy. My Endocrinologist is very knowledgeable on the topic, but on the medical issues, not the guilt and the other factors that affect decision making. My husband and I have made the decision to try for children despite my HbA1c being above the medically recommended range. We made this decision because of our age, however, recent comments from my Endocrinologist made me feel guilty about this decision, despite her not asking me why we had made this decision. I also have difficulties sometimes with my diabetic educator recommending things that my Endocrinologist overrides. However, my educator shows more respect about my day-to-day challenges than my Endocrinologist. I feel constantly frustrated with my GP who often speaks to me about medical guidelines that are written for both Type 1 & Type 2 - he shows no recognition of the differences in managing the different conditions.
- Don't forget about older adults diagnosed with this condition.....yes, you can be diagnosed with it when you're over 40.
- Happy to do surveys. Thank you.
- Great Survey, very practical.
- Thank you for all the hard work you put in. It makes our lives better with every step/ advances you make.
- I haven't seen an endocrine specialist in over 3 years until just last week. I have to say that I now remember why I don't go to see them. He was rude, unhelpful and accusing. I went there to try and make some changes to my life, and left feeling awful, and guilty, about my life. I won't go back, and I hope that no-one else has to

experience that when they see a specialist. I hope that educating them in what actually LIVING with type 1 is like, will give them a bit more compassion and understanding. You cannot know about type 1 from a text book, you have to live it.

- Type 1 following total pancreatectomy. Managing well with pump. Find CGM soooo re-assuring when I can afford to use it. Wish is was more accessible cost wise.
- My diagnosis took from 1989 to 2000, with some bum steers on the way, until a GP and a D educator, with one objective test, got it right
- Nurses need a lot more education about the different types of Diabetes as there understanding is very poor.
- I feel I'm currently experiencing "burnout" after 26 years of living with T1D. I had gone to P.O.W Hospital (Diabetes Education Centre) to get information on "diabetes burnout" but they could only recommend a text to read or if depression was to increase I could make an appointment to see a psychologist at the hospital which may not have much experience in this area? I was disappointed to think that possibly a practitioner with diabetes or had studied this condition would have been invaluable.
- Thanks for conducting the survey
- My Mum filled this in.
- I hate having Td! and for me it is had to adjust
- Thanks so much for this opportunity.
- Thanks for doing this survey.
- I have been T1 for 41 years. I am well, fit and happy. I am a reg nurse but my big gripe is that many medical professionals do not understand the difference between type 1 and type 2. Type 2 requiring insulin is NOT a type 1 - but is an insulin requiring type 2. In a health care setting there are some similarities but the diseases and history are different.
- Just for them to be aware that we are individuals and what works for one person (or in a textbook) won't necessarily work for another. Also, not to assume that we are doing something wrong if our control suddenly goes bad, because it is very frustrating not knowing why your levels are whacky and having your GP/Educator be all "you need to start testing more and counting your carbs properly" instead of actually helping you!
- I have completed this as a parent of a diabetic for my diabetic child.
- I'm old - 54 - but I'm cool!! Lol.
- I wish there was specific diabetes doctors, a nice mixture of your general doctor and your educator
- I'm glad to complete this survey. I have only been diagnosed with type 1 for 6 months and I have been very disappointed at the standard of knowledge and care from nearly every health care prof I have had contact with. The standard of care and understanding needs to be lifted. I hope this survey helps in some way to do that.
- Support groups at more realistic times for the working individual would be awesome
- Keep up the good work...I love reading Yada Yada...
- Completed by a parent with a child T1, concerns reflected by child and parent
- Attitudes need to change.
- I really hate having to repeat myself to every health professional I meet especially if I have been to a clinic before and they just too lazy to take a moment to read my file. I don't mind clarifying or correcting if they made the effort.
- Thanks for the opportunity.

- There is still a lack of information re the difference between Type I and Type II diabetes. I often get asked why I have diabetes when I'm not overweight?
- Thank you for making a survey like this, it is so comforting to know that there is a recognition that type one diabetes isn't always understood by those who have involvement with people who have the disease. I hope the results of it lead to better outcomes, and more support and understanding in the future.
- Thank you & Merry Xmas :-)
- Too many health professionals are driven by numbers, rather than the actual experience of diabetes. The numbers ARE important, but there has to be a balance.
- Thanks guys for all your hard work! You have made such a difference to my t1d journey!
- Why do I need a GP to refer me to Endocrinologist and Diabetes Educator and Dietician. Why not allow my Endo to refer me to the allied health professionals who support me in my control of condition. Let GPs focus on T2 Diabetes.
- A great thing to ask about! Thank you.
- I had severe constipation for 2 years whilst I was on lantus and novorapid- I went to various GPs, Endocrinologists and diabetes educators and no one could offer me a reason as to why I was so constipated. I got an insulin pump and within months was not having any issues with constipation anymore. I put it down to tighter blood glucose control which has made me less dehydrated (though I was constantly drinking water before) and now allows my body to digest properly. I just want diabetes professionals to be aware of this, and suggest pumps as a solution to other constipated T1s on injections.
- I have a medical background so the health professionals approach me differently in discussions and inclusion than they do for many patients. I appreciate this.
- I truly hope this improves the basic standard of GPs. Their care across the whole spectrum of diseases is significantly lacking (generally speaking). Finding a good one is like finding a needle in a hay stack!!!
- Probable had T1 whole life
- I think this is a fantastic survey - I wish you well with getting the message out to other practitioners, not just those who specialise in Diabetes. Thanks so much for the opportunity to put forward my option!! :)
- Thanks so much for all your work in trying to make things better for those of us living with T1 - it really is greatly appreciated!!
- Great job!
- I have had to resort to taking a medical blood test results page with me to doctors and emergency, to prove I am type 1 - I have been flatly told that because I am 40yr and was diagnosed only 2-3 yrs ago, there is no way I could be type 1 - I'm definitely type 1! OMG!!!! Happy to provide more feedback anytime. This is so frustrating...