



## Knowing your patient with type 1 diabetes: the transition to self-management

Living with type 1 diabetes is challenging, particularly as a young adult who is trying to balance the new freedoms of living independently with the transition to self-management. By understanding their experiences primary care can provide better support for these patients. This article incorporates the perspectives of two people, Brendan and Ruby, who were diagnosed with type 1 diabetes at age 10 and 14 years, respectively, and are now in their thirties. Brendan and Ruby provide insight into the challenges faced by young adults who are living with and managing this chronic condition.

### KEY PRACTICE POINTS:

- Transitioning from parental or caregiver control to self-management can be a time of high risk for young people with type 1 diabetes, particularly in terms of adherence to insulin and maintaining glycaemic control
- People with type 1 diabetes are usually under the management of a specialist diabetes team but primary care is also an important source of support
- Establish the patient's preferred point of contact for treatment advice and prescriptions, and ensure that a diabetes review is undertaken each year, including assessment of micro- and macrovascular complications
- Emotional distress is common among people with type 1 diabetes due to the burden of self-management and concern about long-term health; this is a risk factor for depression and worsening diabetes control
- Acknowledge and discuss any mental health concerns with patients and ensure that appropriate management strategies are put in place
- Other issues for young people with type 1 diabetes that may be discussed and managed in primary care include contraception, pregnancy planning, safer use of alcohol and other drugs, and smoking cessation

## Living life with type 1 diabetes

There are an estimated 15,000 to 20,000 people in New Zealand living with type 1 diabetes, many of whom were diagnosed as children or adolescents (see: "What is type 1 diabetes?").<sup>1</sup> A diagnosis of type 1 diabetes is life-changing for most people and their families/whānau. There are many day-to-day challenges, such as learning how to manage an insulin regimen and how to prevent hypo- or hyperglycaemia, as well as longer-term anxieties, such as complications of diabetes and how the illness may affect education, future employment opportunities, activities, sports, social life and relationships. A person with type 1 diabetes is never able to forget their illness or take a

day off from their responsibilities for maintaining their health. Primary healthcare professionals can help to share this burden by knowing the stories of their patients with type 1 diabetes, providing education and advocacy, ensuring patients have access to the best treatments and devices available to them and providing "whole body and mind" health care to support them to live their best life.

**Ruby:** "I wish I'd been connected with other people with type 1 diabetes (I thought I was the only child in New Zealand with type 1 diabetes) so I would have realised sooner that I was still 'normal!'"

## What is type 1 diabetes?

Type 1 diabetes is caused by the loss of pancreatic beta cells, resulting in insulin deficiency. This may occur rapidly, or over months or years.<sup>2,3</sup> There is currently no approved intervention to prevent the loss of beta cells, however, research is ongoing.<sup>3</sup>

Type 1 diabetes can manifest in people of any age, however, it is typically diagnosed during childhood or adolescence. In most instances, the loss of pancreatic beta cells is driven by an autoimmune response, triggered by genetic and/or environmental factors.<sup>2</sup> Multiple genes have been implicated in the development of type 1 diabetes.<sup>3</sup> Family history is a significant risk factor, however, less than 15% of children who develop type 1 diabetes have a family history.<sup>3</sup> The environmental triggers of pancreatic beta cell loss are largely unknown, but may be related to infection, nutrition or chemical factors.<sup>3</sup> Viral infection, particularly enterovirus and congenital rubella,\* have been linked to the development of type 1 diabetes.<sup>3</sup>

\* Unlikely to be a significant contributor in New Zealand or other countries with rubella immunisation programmes

In New Zealand, Type 1 diabetes is most commonly diagnosed in people of European ethnicity; in 2009, the annual incidence per 100,000 people was approximately 33 for New Zealand Europeans, compared to 14 for Māori, 15 for Pacific peoples and 14 for people of other ethnicities.<sup>4</sup> The incidence of type 1 diabetes is increasing in New Zealand, reflecting trends internationally.<sup>4</sup> An Auckland-based study found that the incidence of type 1 diabetes in children aged < 15 years more than doubled between 1990 and 2009, from 10 cases per 100,000 to 23 cases per

100,000.<sup>4</sup> The reason for this increase is unknown, however, it is likely to be multifactorial.<sup>3</sup> Type 1 diabetes accounts for 5–8% of all diabetes diagnoses in New Zealand.<sup>1</sup>

## Diagnosing type 1 diabetes

Diagnosis of type 1 diabetes is based on the presence of characteristic symptoms and a fasting plasma glucose concentration  $\geq 7.0$  mmol/L or a random plasma glucose concentration  $\geq 11.1$  mmol/L. N.B. a repeat measurement is usually required for confirmation unless the initial reading is very high.

The characteristic presentation of type 1 diabetes includes polydipsia, daytime polyuria and weight loss, however, there are also a range of non-specific symptoms, including:<sup>5</sup>

- Nocturia and/or secondary enuresis, usually in children
- Excessive tiredness and/or lethargy
- Irritability
- Dehydration
- Failure to gain weight in very young children
- Recurrent candidiasis or urinary tract infections

All patients with suspected or newly diagnosed type 1 diabetes are usually referred to secondary care for further assessment and management. The urgency and type of referral, i.e. to the emergency department or to an outpatient diabetes clinic, depends on how unwell the patient is at the initial presentation (i.e. the severity and duration of symptoms) and may also be influenced by other factors such as the patient's age.

## The transition to self-management is often challenging

Parents or other caregivers often have a major role in a young person's diabetes management following diagnosis. The transition to self-management, usually as a late adolescent/young adult, can be a time when issues with adherence and worsening glycaemic control arise. Young adults are often dealing with significant changes in lifestyle which can make it more difficult to prioritise their diabetes care, e.g. leaving home, beginning tertiary education, entering the workforce, going travelling, experimenting with alcohol or other drugs.<sup>3</sup>

**Brendan** [on the transition to self-management after leaving home to go to university] *"I didn't manage my diabetes closely enough. It's not that I ignored the fact that I had type 1 diabetes, but I guess I just believed I would get by without having to pay too much attention to my blood glucose levels and insulin doses. I probably didn't prioritise my diabetes high enough. Lack of testing my blood glucose level and therefore correctly managing my insulin doses probably did have some impact on my wellbeing at the time. I do remember getting sick a few times and having a hard time keeping my diabetes under control."*

**Ruby** [on coping with the transition to self-management]: *"It's honestly a bit of a blur. My parents and I did the best we could with the knowledge we had. There was certainly a lot of trial and error which included multiple trips to hospital with DKA [diabetic ketoacidosis] as I took control of my diabetes management."*

### What can primary care do to support young patients self-managing their diabetes?

Most often, a person with type 1 diabetes will be under the care of a multidisciplinary team, but this depends on their location, specific health needs and preference. Establish with the patient who their preferred point of contact is, and what role they would like their general practice team to have in their care. The objective is to ensure that there is clarity around who takes responsibility for overseeing the patient's insulin regimen, diabetes-related health issues and wider health concerns.

Even if a patient is being managed by a diabetes clinic, primary care can still provide valuable support by "knowing their story", i.e. knowing their diabetes history and general details about their regimen and acting as an advocate for their care if required. The general practice should keep a record of annual diabetes reviews (see below) and complete any necessary assessments or investigations if this has not been done. Assessing mental health and wellbeing is a core aspect

of general practice, along with identifying and managing any health needs related to or impacted by diabetes or in general, e.g. contraception, pregnancy advice, safer use of alcohol and other drugs, smoking cessation.

**Ruby:** *"For years I didn't feel confident speaking to my GP/primary care team about my diabetes, instead calling the secondary care team every time I had a question or issue. I'm grateful that in the past few years the GP practice I attend now runs a LTC [Long Term Care] clinic with two experienced diabetes nurses. I feel confident to ask questions and know that if they are unsure they will reach out to secondary care. I do not expect my general practitioner to know all the details about my diabetes management, but it's awesome knowing that I do not have to explain my history every time I see him."*

**Brendan:** *"My last GP was hands off in regards to diabetes by his own admission. I had already developed a good association with the clinic at the hospital so it wasn't a problem for me. And I guess a part of it was that seeing my GP came at a cost whereas the hospital consultations whether that be in person, by phone, or by email were free. My current GP seems a lot better about diabetes but I've kept it the way it has been and prefer to consult the hospital clinic. I guess another part of it is that the clinic staff specialise in type 1 diabetes more than a GP might, meaning that there is an amount of trust there."*

### Make sure patients have a sick day plan

Ensure that young adults taking over the management of their diabetes understand their "sick day" plan. This should include:<sup>3</sup>

- How to adjust their insulin dose to reduce the risk of diabetic ketoacidosis (insulin requirements can increase with illness, e.g. fever) or severe hypoglycaemia (with gastroenteritis and/or loss of appetite). Insulin treatment should not usually be stopped completely, however, in some circumstances, e.g. ongoing vomiting, insulin may need to be temporarily withheld for the duration of the illness.
- A reminder to increase monitoring frequency of blood glucose and blood ketone levels,\* e.g. every two to four hours, including during the night
- How to monitor and maintain hydration, including electrolytes

\* People with type 1 diabetes are eligible for a fully subsidised dual blood glucose and blood ketone meter. See the NZF for details: [www.nzf.org.nz/nzf\\_3767](http://www.nzf.org.nz/nzf_3767)

 Patient information for people with diabetes on how to manage sick days is available from: [www.healthnavigator.org.nz/health-a-z/d/diabetes-sick-day-plan/](http://www.healthnavigator.org.nz/health-a-z/d/diabetes-sick-day-plan/)

## Accepting the long-term health consequences may be difficult

Achieving and maintaining glycaemic control is a core component of type 1 diabetes management and requires significant and ongoing commitment by the patient, e.g. planning meals and exercise, monitoring blood glucose levels, and calculating and administering insulin doses. Young people taking over control of their diabetes management from their parents/caregivers are faced with the responsibility of how the decisions they make now affect their future health, i.e. their risk of micro- and macrovascular complications. This can be difficult for young people, especially when for many of their peers this is a time of spontaneous choices and lack of authority in their life.

**Brendan:** *"I didn't really look after my diabetes all that well in my early adult life. In my early to mid-thirties I developed diabetic retinopathy in both of my eyes. I ended up having surgeries in both eyes and I am no longer allowed to drive by law as my field of vision isn't wide enough."*

Primary care can provide ongoing education to patients with diabetes about the long-term health benefits of good glycaemic control. A discussion with the patient may reveal practical or psychological issues that are contributing to difficulties with adherence to their insulin regimen (see: "Patients require ongoing psychological support").

## Diabetes can significantly affect mental health and wellbeing

The unrelenting burden of self-management and the fear of short-term, e.g. nocturnal hypoglycaemia, and long-term complications, e.g. retinopathy, nephropathy and cardiovascular disease, can cause many people with type 1 diabetes to experience emotional distress, sometimes termed "diabetes distress".<sup>8</sup> Diabetes distress is a common and understandable response to living with and managing a chronic condition, and it can negatively impact diabetes management in some people.<sup>8</sup> Diabetes distress is a risk factor for depression and conversely, depression is a risk factor for diabetes distress.<sup>8</sup> The continual need to plan, monitor and make decisions, combined with unexpected or unsatisfactory outcomes even when doing everything "as recommended", can lead to burnout.<sup>8</sup> In turn, burnout can lead to further disengagement from self-management and worsening of diabetes control, which then exacerbates feelings of distress.

**Ruby** [on supporting young people with diabetes]: *"I wish I'd been told about the link between long term conditions and mental illness and how to build a strong, healthy and resilient mind."*

**Brendan:** *"... I have been through some tough times including a spell of depression. I feel better now, but I still believe that for me, diabetes can be a cause or catalyst of mental stress and at the same time mental stress can make it harder to control my diabetes."*

**Ruby:** *"My biggest challenge is random night-time hypos or high blood sugars, which disrupts your sleep, which then affects your mood and energy, which then goes on to affect how you interact with your loved ones and colleagues. It can sometime feel like a downward spiral. This can be hard to explain when on the outside you look 'so healthy', but you're exhausted from being knocked around by high or low blood sugars."*

Routinely asking patients about their challenges in managing their diabetes and how they are coping is important. Clinical indicators of sub-optimal diabetes control may also suggest that a patient requires more support, e.g. increasing HbA<sub>1c</sub> levels, infrequent blood glucose testing, hypoglycaemic episodes. This also provides an opportunity to discuss strategies to help improve diabetes control, e.g. using an insulin pump if eligible, and prevent further deterioration of mental health and wellbeing. Be alert for features of depression and initiate management early.

**Ruby:** *"Managing stress and the effect it has on blood sugar levels can be a challenge. I'm definitely getting better at self-care and managing my stress levels, but the slightest thing can send them out of whack, e.g. a client meeting, running late...[or] a two-year-old that wakes 70,000 times in the night!"*

 For further information on insulin pumps, see: "Understanding the role of insulin in the management of type 1 diabetes", available from: [www.bpac.org.nz/2019/diabetes-insulin.aspx](http://www.bpac.org.nz/2019/diabetes-insulin.aspx)

## Communicating effectively

The way healthcare professionals communicate with people about their diabetes management can have a significant impact on how the person feels about themselves and their efforts to control their diabetes. Using language that is non-judgemental, encouraging, understanding and inclusive shows patients with type 1 diabetes that their primary care team acknowledges the difficulties of diabetes management, and wants to work with them to help find solutions.

## The annual diabetes check

All patients with type 1 diabetes should be reviewed at least annually to assess for micro- and macrovascular complications. If a patient does not usually attend general practice for their review, check that they are being reviewed in secondary care.

A diabetes review should include:<sup>3,6</sup>

- Body weight
- HbA<sub>1c</sub> (may be monitored every three to six months); stringent targets, e.g. 48–53 mmol/mol or lower, are recommended for younger people to minimise the risk of long-term complications if these can be achieved safely, i.e. without significant hypoglycaemia<sup>5,7</sup>
- Blood pressure; an angiotensin converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB) is recommended if blood pressure is persistently > 130/80 mmHg
- Urinary albumin:creatinine ratio (ACR) and estimated glomerular filtration rate (eGFR) calculated from serum creatinine; an ACE inhibitor or ARB is recommended if ACR is persistently > 3 g/mmol (albuminuria)
- Foot check – palpitation of pedal pulses, testing for peripheral neuropathy and assessment of skin and nail condition

- Assessment of cardiovascular (CVD) risk:\* a full CVD risk assessment every year may not be necessary for younger people, particularly if they have no other risk factors. However, lipid levels should be monitored annually. A statin is indicated for people with a total cholesterol: high density lipoprotein cholesterol ratio of  $\geq 8$ , familial hypercholesterolaemia, hypertriglyceridaemia or a five-year CVD risk score  $\geq 15\%$ <sup>6</sup>
- Retinal screening (every two years)

\* CVD risk assessment is an approximation for people outside of the age 30–74 years range, but may still be clinically useful. Further information is available here: [www.bpac.org.nz/2018/cvd.aspx](http://www.bpac.org.nz/2018/cvd.aspx)

👁 For further information on preventing the microvascular complications of diabetes, see:

- Diabetic kidney disease: [www.bpac.org.nz/2019/renal.aspx](http://www.bpac.org.nz/2019/renal.aspx)
- Diabetic retinopathy: [www.bpac.org.nz/BPJ/2010/August/retinopathy.aspx](http://www.bpac.org.nz/BPJ/2010/August/retinopathy.aspx)
- Diabetic neuropathy: [www.bpac.org.nz/bpj/2014/june/diabetic-peripheral-neuropathy.aspx](http://www.bpac.org.nz/bpj/2014/june/diabetic-peripheral-neuropathy.aspx)

👁 For further information on statins, see: [www.bpac.org.nz/2018/lipids.aspx](http://www.bpac.org.nz/2018/lipids.aspx)



**Ruby:** "For many years I thought I was a 'bad diabetic' because of the language doctors would use. A lot of it comes down to how 'good' is measured. For example, a high HbA<sub>1c</sub> is frowned upon and the instant focus is on how to fix it. And while I totally understand the health complications from poorly controlled diabetes, rather than focusing only on the bad, it would be great to know more about what's driving the increased blood sugars and celebrate the wins."

Communication strategies which may be beneficial when engaging with people with type 1 diabetes include:<sup>8</sup>

- Acknowledging the burden of living with diabetes and the patient's daily efforts to maintain their health
- Providing reassurance that managing diabetes is a learning process; it often involves a lot of trial and error and occasional "bad" days, weeks or months, but this is not a failing
- Celebrating successes, e.g. focusing on the fact that their HbA<sub>1c</sub> has decreased by 10 mmol/mol, rather than it still being above target
- Exploring ways to reduce negative feelings and improve coping mechanisms, e.g. consider a time when they felt more positive and what they did differently then, setting achievable goals, referring for additional support or education, e.g. with a diabetes nurse specialist
- Discussing the risk of complications using motivational language, e.g. complications are not inevitable and even small steps are beneficial at reducing the risks

 Further information for clinicians on supporting the emotional health needs of people with diabetes is available here: [www.diabetes.org.uk/resources-s3/2019-03/0506%20Diabetes%20UK%20Australian%20Handbook\\_P4\\_FINAL\\_1.pdf](http://www.diabetes.org.uk/resources-s3/2019-03/0506%20Diabetes%20UK%20Australian%20Handbook_P4_FINAL_1.pdf)

## Living life to the full: knowing how to stay safe while having fun

Part of learning about diabetes self-management is testing the boundaries of participating in enjoyable activities while avoiding hyper- and hypoglycaemia.

**Brendan:** "I believe that as a young adult there is still a need for education and support for those with diabetes. I think it's even more important for resources to be available in an organised way for young adults when they face the changes in their life brought on by study or work and the challenges brought on by the new freedoms available as an adult, such as alcohol and drugs."

## Discuss how to safely exercise

All people with type 1 diabetes should be encouraged to engage in physical exercise, however, careful monitoring and planning is required to avoid hypoglycaemia. Check that patients have knowledge of:<sup>3</sup>

- The type and amount of carbohydrate required for a specific exercise as this will vary with the intensity of the exercise
- How to reduce their insulin dose appropriately before and after exercise
- What to do if things go wrong, e.g. making sure they carry a cell phone and glucose/carbohydrate supplies

Discuss with patients the importance of measuring their blood glucose levels before, during (if appropriate) and after exercise, or to regularly check their sensor readings if using a continuous glucose monitor.<sup>3</sup> If they exercise in the afternoon or evening they may need to check their blood glucose levels during the night to detect nocturnal hypoglycaemia.<sup>3</sup>

**Brendan:** "I'm very physically active as I do competitive cycling as a sport. The training and racing can make management of my diabetes challenging. But with using a continuous glucose monitor and insulin pump I am able to monitor my blood glucose levels with a high density of data and I can alter my insulin regimen for different physical activity. It is still a learning experience and I don't always get it right. I just make sure I have contingency plans in place to manage any issues."

*For longer spells of physical activity I will reduce the rate of insulin delivery from my pump at least 30 minutes but preferably one hour before starting. This reduction will last the duration of the activity and for a period of time afterwards. For some races I will drop my insulin delivery by up to 40%. I also aim to have my blood glucose level slightly higher than my target level as I don't want to have a low blood glucose level during a race or training ride. I can always change my nutrition on the bike to drop my blood glucose level by eating foods or drinking fluids with less carbohydrates or even stop and take a small amount of insulin. I have developed a knowledge of what type of foods work for me during sports and how many grams of carbohydrates I need to consume per hour during physical exercise. I can alter my insulin regimen race by race if need be as some races might cause a spike in adrenalin which can raise my blood glucose level."*

 To read more about the challenges of juggling type 1 diabetes with competitive sports, check out Brendan's blog: [www.typeonecyclist.com](http://www.typeonecyclist.com)

## Dietary considerations

Decisions about what to eat and when to eat are often significant for people with type 1 diabetes, however, this can be difficult to negotiate when learning how to cook for yourself or not having control over meals, e.g. eating out or at a friend's place. Many people with type 1 diabetes use carbohydrate counting to optimise their glycaemic control by matching their insulin requirements to the carbohydrate content of their meals; this allows greater flexibility in terms of food choice and meal timing. Patients who are having difficulty with their diet may be referred to a dietitian.

**Ruby:** *"I describe myself as being 'carb conscious'. I am very aware of the effect carbs have on my blood sugar levels, and try to carb count as often as I can, but end up guessing a lot of the time. If my blood sugars have been stable I'm more likely to be spontaneous and am happy to eat out with friends/family or at restaurants. However, if my blood sugars have been all over the place, which affects my energy levels and mood, I'm more likely to take my own food to family dinners or be selective about the restaurants/cafes we go to, based on carb content and options."*

**Brendan:** *"There is definitely room for spontaneity and flexibility in my diet. I have gone through training with the diabetes clinic to count carbohydrates in meals whether it be by looking up nutritional information about a meal or food item or making an estimate. Using an insulin pump allows me to have flexibility in my diet as I can take insulin when and where I need it for meals or snacks. Foods higher in fat or having a low glycemic index can be challenging as I may need to take the insulin dose for the food over an extended period of time but this is possible with an insulin pump. While I do avoid sugary food and drinks I don't believe that I am all that limited in my dietary choices."*

 For further information on carbohydrate counting, see: "Understanding the role of insulin in the management of type 1 diabetes", available from: [www.bpac.org.nz/2019/diabetes-insulin.aspx](http://www.bpac.org.nz/2019/diabetes-insulin.aspx)

 Information on food and nutrition for people with diabetes, including recipes, is available from: [www.diabetes.org.nz/food-and-nutrition](http://www.diabetes.org.nz/food-and-nutrition)

## Provide advice on the use of tobacco, alcohol and other drugs

Adolescence and young adulthood are times when people often experiment with risky behaviours, e.g. smoking cigarettes,

using alcohol or other drugs. For young people with type 1 diabetes, the consequences of engaging in these behaviours can be particularly significant, both in the short and long-term. For example, alcohol increases the risk of delayed or severe hypoglycaemia by inhibiting gluconeogenesis, while cigarette smoking is a risk factor for developing long-term microvascular and macrovascular diabetes complications.<sup>3</sup>

Discuss strategies for avoiding excessive alcohol consumption, and give practical advice about minimising risks if they are drinking, e.g. checking blood glucose levels, maintaining good hydration with water and eating carbohydrate-based food before going to sleep to prevent delayed hypoglycaemia.<sup>3</sup> Advice about avoiding smoking or smoking cessation should be given. The use of cannabis or other illicit drugs should be strongly discouraged as this can significantly impact diabetes management by affecting decision-making and increasing the risk of mistakes with the insulin regimen, as well as altering eating and sleeping patterns.

 A HEADSSS assessment may be useful in adolescent patients to assess their mental health and wellbeing and risk-taking behaviour. For further information, see: [www.bpac.org.nz/BPJ/2015/October/wellbeing.aspx](http://www.bpac.org.nz/BPJ/2015/October/wellbeing.aspx)

## Discuss sexual health, contraception and pregnancy planning

The importance of using reliable contraception to prevent pregnancy and sexually transmitted infections (STIs) should be discussed with all sexually active patients; people with type 1 diabetes should be given additional information about how having diabetes can affect their reproductive and sexual health.

N.B. Patients may be reluctant to initiate discussion about sexual issues, therefore, clinicians should routinely ask patients questions about their sexual health, including sexual function, in a way that normalises the encounter.

### Most contraceptive options are suitable for females with type 1 diabetes

Most contraceptive options are suitable for females with type 1 diabetes, however, combined oral contraceptives are not recommended for those who have had diabetes for longer than 20 years, those who have microvascular or macrovascular complications, or additional cardiovascular risk factors; progestogen-only pills can be used safely if an oral formulation is preferred.<sup>3</sup>

 For further information see: "Contraception: which option for which patient?", available from: [www.bpac.org.nz/2019/contraception/options.aspx](http://www.bpac.org.nz/2019/contraception/options.aspx)

### Poor glycaemic control can lead to sexual dysfunction

Long-term exposure to hyperglycaemia can affect blood supply and innervation of the sexual organs. In males this can lead to erectile dysfunction and in females this can lead to vaginal dryness and reduced sexual stimulation. Pharmacological treatment may be indicated for erectile dysfunction, while over-the-counter personal lubricants may alleviate vaginal dryness. As diabetes is not the only cause of sexual dysfunction, other explanations, e.g. depression, should also be considered if patients report these symptoms.

N.B. People with hyperglycaemia are also more at risk of infections such as candidiasis, balanitis and urinary tract infections, as the high glucose concentration provides optimal conditions for fungal and bacterial colonisation. A regimen review may be indicated for patients with diabetes who have recurrent infections.

### Discuss the importance of pregnancy planning

Poor glycaemic control increases the risk of congenital malformations, miscarriage, stillbirth and neonatal death. Achieving and maintaining good glycaemic control prior to conception and during pregnancy significantly reduces these risks.<sup>3, 9</sup> Women with type 1 diabetes who wish to become pregnant should be referred to a diabetes specialist or obstetrician, ideally three months before they start trying to conceive, or as soon as a pregnancy is confirmed.<sup>9</sup> While primary care may have limited involvement in the pregnancy care of women with type 1 diabetes, clinicians should be alert to any wider health issues, including mental health and wellbeing, which may arise during pregnancy or while trying to become pregnant.

**Ruby:** *"During my first pregnancy I never felt like what I was doing was good enough...it all felt so daunting and overwhelming. I was trying so hard to keep my blood sugars under control and doing everything I was told, but sometimes diabetes doesn't play fair. At 38 weeks I developed pre-eclampsia and my daughter was delivered by emergency c-section under general anaesthetic. It was a pretty traumatic ordeal. With my second baby I knew what to expect and therefore was more confident."*

### Preparing for travel

Overseas travel is an important "rite of passage" for many young New Zealanders. With adequate planning and preparation, people with type 1 diabetes can enjoy these experiences while retaining good diabetes control.

**Ruby** [on managing the change in routine when travelling]: *"I simply adapt. When I am in a different*

*routine or eating different foods I will make sure I test my blood sugars more often and correct with more insulin if needed. I also always make sure I have hypo supplies with me. I've been caught out too many times without them. I'm slowly learning."*

Check that patients undertaking travel which involves crossing time zones are confident in knowing how to adjust their insulin regimen. Depending on the patient's regimen, often only the long-acting insulin needs to be adjusted; the doses of short-acting insulin are given before meals and snacks as usual. Insulin, blood glucose testing supplies and carbohydrates should be transported in carry-on luggage and patients may require a letter for border security which states that they have diabetes and are carrying insulin and a delivery device, i.e. pens, syringe/needles, pump; insulin and any other medicines should ideally be in the original packaging with the labels from the pharmacy. Patients should also carry a second letter for a doctor should they require medical attention. This should detail their insulin type, doses and any other relevant medical information.

**Brendan:** *"I haven't had any problems [going through customs/security]. I carry a letter from the diabetes clinic which states that I have type 1 diabetes and need to carry medical equipment as well as a letter identifying the insulin pump and stating that it can't go through x-ray machines. I am upfront with airport security about having diabetes and carrying equipment and medication and have no troubles."*

 Patient information for people with diabetes who are planning on travel is available from: [www.diabetes.org.nz/managing-diabetes-travelling-2](http://www.diabetes.org.nz/managing-diabetes-travelling-2)



## Final thoughts

Everyone's journey with a chronic illness is different, and the support they receive from family/whānau, friends and the healthcare system will vary. Experience defines what we do now and how we react to challenges in the future. If you have a patient with type 1 diabetes at your practice, make it your mission to know their story. Be a constant source of knowledge and support, regardless of whether their diabetes care is mainly provided outside of general practice. Young people taking control of their diabetes themselves may find themselves at a crucial crossroad where finding the mental strength and discipline to maintain good diabetes control will reduce their risk of complications in later life; they need your help.

For the final word, we reproduce an excerpt from Ruby's blog, "Mastering diabetes", where she describes the feeling of being able to let go, if only for a moment in time:

*"...My blood sugars were sitting around 4.5 mmol, lower than I would have liked just before the headline act – Fat Boy Slim. I knew that things were about to be turned up a notch. With that in mind I removed my pump completely and let loose. Surrounded by great friends and thousands of avid Norman Cook fans, it was the right thing to do. There's also something extremely empowering and rebellious about removing your insulin pump (not something I do lightly). I'd love to say during his 90-minute set with my pump detached, I could almost forget I lived with Type 1 diabetes – but nope my CGM [Continuous Glucose Monitor] let me know I was dropping. So, there I was in the middle of the crowd dancing [like crazy], while eating a muesli bar. Doing my best to live well and truly beyond Type 1 diabetes."*

To read more about Ruby and her experiences with type 1 diabetes, see: [t1dmastery.com](http://t1dmastery.com)

To read more about Brendan and his experiences with type 1 diabetes, see: [www.typeonecyclist.com](http://www.typeonecyclist.com)

 Information and support for people with type 1 diabetes is available from: [www.diabetes.org.nz](http://www.diabetes.org.nz)

 Further reading:  
Bright Spots and Landmines: the diabetes guide I wish someone had handed me. Adam Brown:  
[www.brightspotsandlandmines.org](http://www.brightspotsandlandmines.org)



This article is available online at:  
[www.bpac.org.nz/2019/diabetes-self-management.aspx](http://www.bpac.org.nz/2019/diabetes-self-management.aspx)

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