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DIABETES

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For newly
diagnosed
adults.



TYPE 1
diabetes
network

A Starter Kit for Australians Diagnosed with Type 1 Diabetes — 4th Edition

Published by the **Type 1 Diabetes Network** (Australia) — Support, Information & a Voice for the Type 1 Community. Developed through the time, efforts and contributions of dedicated volunteers.

Disclaimer

Information contained in this publication does not ever take the place of professional medical advice. Please ensure that you consult your doctor or health professional prior to making any changes to medications or treatment regimes.

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Section 1

introduction



The Type 1 Diabetes Network 1.1

Vision

Our vision is that all people living with type 1 diabetes in Australia should have access to the necessary support and information to make effective decisions about their self-care. They should also have the world's best treatment that is informed by evidence, tailored to meet their individual needs, timely, proactive and responsive.

Mission

It's our mission to create opportunities for Australians affected by type 1 diabetes to allow them to attain an optimum quality of life through:

- building an empowered and active type 1 diabetes community;
- offering support and encouragement;
- facilitating access to resources and information; and
- advocating and raising awareness on issues relevant to people affected by type 1 diabetes.

What is the Starter Kit? 1.2

There are heaps of diabetes resources out there, but ours is designed to be a little bit different. Firstly, the Starter Kit has been written by people who either live with type 1 diabetes or are parents of someone with type 1 diabetes. Further, it is specifically designed for people who have been newly diagnosed. We know that diagnosis can be a tough time, and this guide is made specifically to support you.

1. it is not your fault

Type 1 is not your fault, your parents' fault or your grandparents' fault. Type 1 diabetes is an autoimmune condition, NOT a lifestyle condition. Your immune system decided that the precious islet cells in your pancreas that produce insulin were foreign and killed them. This removed your ability to produce insulin. We still do not know exactly why, but we DO know that it has absolutely nothing to do with what you ate, where you live (except that T1 is much more common in Finland than in Japan!), who you are or whether your mum stood on her head during pregnancy. Likewise, you can be diagnosed at any time, not just childhood.

There is a genetic component to T1, but it's only one piece of the puzzle – even if your mum or dad had type 1 diabetes themselves, you only have about a 5% chance of getting it.

2. T1 IS A JOURNEY

Understanding how to live a happy and healthy life with type 1 diabetes is a journey, not a destination. You will always be learning new things and new ways to manage the condition. Every day will have ups and downs, both in your blood glucose levels (BGLs) and your emotional wellbeing.

Be patient, be open to new ideas, and don't put too much pressure on yourself.

When I was first diagnosed, I wish I was told that life can still be fun, and that you can still live it to the full!

Kait, Age 23, Diagnosed Age 8

3. PEER SUPPORT IS AWESOME

If you ask us, peer support is as important and influential as professional healthcare. Most leading diabetes organisations have acknowledged the importance of peer support for people living with type 1 diabetes.

This is why we feel so strongly about our Reality Check forum (for people living with type 1 diabetes – www.realitycheck.org.au), Munted Pancreas forum (for parents of people living with type 1 diabetes – muntedpancreas.com) and our T1DN Facebook and Twitter (@T1DN) pages. These online resources allow you to post questions, complain about bad hypos, read other people's experiences, ask how to carb count for fish and chips, and really tap into what it's like to live with diabetes 24/7.

4. the debate continues

There is an ongoing debate about what is best: Coke Zero, Diet Coke or Pepsi Max. **The good news is that 'diabetes-friendly' products are becoming more common** – if you enjoy soft drinks, most shops, cafes, pubs and restaurants provide sugar-free options. You will soon become an expert at identifying if a soft drink is not diet!

Don't bother with sugar-free chocolate. It is not good. At all. No one deserves that kind of torture!

5. PEOPLE SAY CRAZY THINGS

People will say dumb, ridiculous, ignorant, rude or just plain strange stuff. Most people do not understand the differences between type 1 and type 2, and only know about diabetes from a four-second clip on the news. People will say: "You don't look like you have diabetes!", "Are you sure you can eat that?", "Will you grow out of it one day?", "It's a shame you can't eat cherries." (you can!), or "It's okay, I heard a cure is coming – I saw on the news that they are trialling it with mice.

Of course, this is frustrating, but you will soon discover that you cannot totally understand type 1 diabetes unless you live with it. You will find your own way to deal with these comments – it might be perfecting your "ah-huh, ah-huh" and making a fast exit, or taking the opportunity to inform and educate people about their misunderstanding to ensure they do not say crazy stuff to anyone else they meet with T1!

6. everyone manages differently

There are many ways to manage type 1 diabetes and, as you will see throughout the Starter Kit, a lot depends on personal circumstances and preferences. We ask that you respect the fact that other people manage their type 1 diabetes in a different way to you. People's bodies are different too – comparing yourself to others with T1 is not always useful because T1 is experienced differently. Different is not necessarily wrong, just different. Everyone has their own stories, habits, feelings and ideas regarding their condition.

One of the best things about meet-ups and peer support is learning about how others live with their type 1 diabetes and that you are not the only one who does.

7. THE POWER OF THE INTERNET

The internet is your friend. The Diabetes Online Community (or DOC for short) has grown massively over recent years, with a range of blogs, websites, forums, tweet-chats, Facebook pages and YouTube channels dedicated to life with type 1. Social media is fundamentally changing the way people with type 1 engage with the internet, which is really exciting.

Explore these options and you will find friendship, information, guidance, understanding and, if you are lucky, a recipe for some awesome muffins!

8. YOU ARE IN CHARGE

You will probably only see your healthcare team a few times a year, complemented by phone or email contact. While this is important, **it is you who lives with the condition 24/7 and therefore you are in charge of the decisions relating to your diabetes.**

Most people report great relationships with their diabetes healthcare teams; however, this is unfortunately not always the case. Be assertive and prepared, and be aware that you can change healthcare professionals if you feel your needs are not being met.

9. DON'T LET IT STOP YOU

Don't let type 1 diabetes stop you from achieving your goals. Listen up troops. People will often try to tell you what people with type 1 diabetes CAN'T do. Well, we reckon that attitude is rubbish!

There are Olympians, fire-fighters, elite sports people, musicians, actors, politicians, TV hosts, doctors, mums, dads, chefs, police officers, diabetes educators and people in many other professions who live very successful, happy lives with type 1.

Sure, type 1 diabetes can bring some tough days. It's hard work, but it does become manageable. So whether you want to climb Mt Everest or have other goals in life, keep persisting and don't let T1 stand in your way. Let it be a partner on your journey, and celebrate the awesome, inspiring things you accomplish.

10. the balancing act

T1 is a continual balancing act. Balancing food with insulin, balancing insulin with exercise, balancing your expectations with your BGLs and balancing your physical health with your mental wellbeing. This can be exhausting, frustrating and difficult, there is no question. But it can shape who you are as a person and be immensely satisfying. Type 1 diabetes is not doom and gloom, and for every bad hypo and nasty high, there is usually something you can be thankful for!

We hope our Starter Kit helps inform you on your own balancing act. Best wishes.

What is diabetes?

Diabetes is a condition in which the body cannot sufficiently convert food into useable energy. This is caused by a lack of insulin – a hormone produced by a gland called the pancreas – or by a failure of the body to respond normally to insulin. We all rely on insulin as the key that moves glucose from blood into cells.

When many foods are digested, they break down into glucose, which builds up in the bloodstream. Insulin controls the level of glucose in the blood by helping glucose go from the bloodstream into the body's cells. Once in the cells, glucose can be used for energy or stored for future needs. In some people, the above process fails to work properly and results in diabetes.

Different types of diabetes

The common factor in all types of diabetes is the need to keep blood glucose levels in the optimal range. Doing this reduces the likelihood of long-term health problems or complications and means you feel better throughout the day. Diabetes is a chronic illness, and the treatments that exist now are not a cure. Until a cure is found, daily self-management must continue throughout a person's lifetime.

A large number of factors influence blood glucose levels, including the amount and type of food you eat, the amount of insulin you inject, all forms of exercise, drinking alcohol, and taking prescribed and recreational drugs. Many less tangible factors are also involved, often relating to the interaction of hormones in your body, such as those produced during periods of stress, anxiety and menstruation.

I went from being super healthy to diabetic in days. I had a rash coming up on my arm, so I went into the doctor to get it checked out – he gave me a blood test to make sure there was nothing in my bloodstream that was causing my rashes ... my sugar was high ... turned out I had type 1 diabetes. I had no symptoms at all.

Amia, Age 22, Diagnosed Age 20



Type 1

Type 1 diabetes involves an autoimmune response that destroys insulin-producing beta cells in the pancreas causing insulin production to stop completely. It is complex to manage and requires multiple daily insulin injections/insulin pump therapy and regular monitoring of blood glucose levels. Over 130,000 Australians have type 1 diabetes. The cause is not understood and there is currently no cure.

Type 2

Type 2 is commonly considered a lifestyle-related disease, and accounts for approximately 85–90% of all diabetes cases in Australia. In type 2 diabetes, the pancreas fails to produce enough insulin to meet the body's needs and/or the body is unable to respond normally to insulin (insulin resistance). Type 2 most commonly, although not always, affects older and overweight people. Rates of type 2 are increasing in young people (and older people) in Australia.

Latent Autoimmune Diabetes of Adulthood (LADA) – (aka slow-onset type 1 diabetes or type 1.5 diabetes)

Like type 1 diabetes, LADA occurs when the immune system destroys insulin-producing pancreatic beta cells. The main clinical distinction is that the onset of type 1 is almost always 'rapid' – over days or weeks, and insulin is generally required immediately at diagnosis and thereafter. LADA may be more subtle in onset, is sometimes initially diagnosed as type 2 and has a clinical phase where insulin is not 'essential'. Like other forms of type 1 diabetes, people with LADA eventually require insulin injections to normalise their blood glucose levels.

Gestational diabetes mellitus (GDM)

The hormonal changes in a woman's body during pregnancy sometimes cause insulin resistance, and if the pancreas fails to respond adequately, blood glucose levels rise. All pregnant women should be tested for gestational diabetes. Women who have had gestational diabetes have an increased risk of developing type 2 diabetes in the future. A famous case of this is Olympic gold medallist Cathy Freeman.

So, you've just been diagnosed with type 1 diabetes. We're sorry you had to find us. But what now? A million things are probably running through your mind, and it seems you have a million things to do to rearrange and organise your new life with diabetes. It's hard to know where to start.

Relax. We've made it easy (easier!) for you. Following is a quick explanation of the top 14 things we think are important to organise after diagnosis. Tick them off as you go, and worry about the other thousand things at a later date.

In the first few days after diagnosis

1. Organise emergency contacts and support.

Why

Trust us. Random hypos (hypoglycaemia – low blood sugar), hypers (hyperglycaemia – high blood sugar), and BGL readings that make no sense affect all of us with T1. After a while, you'll become an old hand at dealing with all sorts of 'surprises' on your own (really truly) – but the first few ups and downs outside the safety net of the hospital or clinic where doctors and nurses are stationed a few metres away can often be frightening and quite challenging to manage.

What you need to do

- Find out who you can contact for urgent advice after diagnosis. Ask your endocrinologist and diabetes educator who you should call if you need help after hours – with any luck, they may offer you their mobile numbers. If you don't have an appointment for a while, call the clinic or office and ask what arrangements there are for after-hours support.
- If you can't set this up with your endo or educator, don't panic – most major public hospitals have an endocrinologist on call 24/7, so if you need help, you can call the hospital and have them page the endocrinologist.
- Program relevant contact numbers into your phone, so you can access support easily even when you're feeling unwell. You may want to put ZZ or AA in front of each of your health-related contacts, so they come up conveniently at the end or start of your contacts list without needing to search.
- Obviously, in case of a serious diabetes-related emergency, the best number to call is 000 for an ambulance.

2. Stock up on a stash for hypos.

Why

Hypos (especially some of the first few you experience) can often take you by surprise. They tend to happen when (and where) you're least expecting them. Once you've figured out what sort of hypo supplies work best for you (see page 16 for some suggestions), keep a stash of your chosen sugary substances in places you frequently visit so that they're close at hand (and mouth) when you need them most. It might be helpful to stash things others are not going to raid – it is amazing how many people love jelly beans when they're within easy reach!

What you need to do

- Stash sugary stuff:
 - beside your bed;
 - in your desk drawer/locker at work;
 - in your school locker or pencil case;
 - in your handbag/backpack/pocket when going out;
 - at your boyfriend/girlfriend/best mate's house;
 - in the console of your car.

When I was first diagnosed, I wish I knew that it's fairly common for adults to be diagnosed too! Pretty weird being diagnosed in my thirties with something more commonly thought to affect children.

Jackie, Age 41, Diagnosed Age 35

3. Get a blood glucose meter that suits your lifestyle.

Why

This thing will be going everywhere with you. Make sure you choose one that you find easy to use and carry around. It is often better to talk this choice through with a diabetes educator who can help you select the meter that suits you without having a vested interest (normally) in selling you a particular model. The educators also usually know all the different types of meters available (and often have demo models), making it likely you really will be shown a meter that is best for you. Many diabetes educators and endocrinologists have a supply of various meters that they can give you free of charge.

What you need to do

- Consider what factors are important to you in a meter:
 - Portability: size, weight, protective case;
 - Usability: screen/button size, type of strips and lancets;
 - Functions: testing time, memory storage;
 - Special features: backlight, PC adaptor, colour options.

You should also:

- visit your local Diabetes Australia shop/website (www.diabetesaustralia.com.au/en/Shop/) or local chemist;
- discuss meter choice with your diabetes educator;
- do some Googling. People with T1 are very proactive at reviewing meters.

4. Figure out where you're going to get your supplies.

Why

Consumables such as needles (which are free) and blood glucose/ketone testing strips have to be procured on a fairly regular basis. A lot of chemists are National Diabetes Services Scheme (NDSS) outlets – so to access supplies at the subsidised price, it's a good idea to know where your closest outlet is. See number 10 on this list for more information on the NDSS and how it can help you.

What you need to do

- Log onto www.ndss.com.au to find your closest NDSS outlet, or consider mail order by phoning 1300 136 588.

In the first month after diagnosis

5. Sort out your driver's licence.

Why

According to the national medical standards for licensing, being diagnosed with type 1 diabetes means you have to switch over to a 'conditional' driver's licence. Basically, this means you need medical assessments every two years to confirm that your diabetes isn't significantly affecting your ability to drive safely. It is your legal responsibility to organise this process, and if you don't, there is a risk that you may have problems with future insurance claims because you haven't been declared 'fit to drive'.

One of the key criteria for safety to drive is 'self-care behaviours' – that is things like checking your sugar before you drive and every couple of hours or so if you drive long distances, and having hypo fixes with you.

What you need to do

- Visit your local traffic authority office (or website) and find out which forms you need to fill out to report a medical condition/obtain a conditional licence.
- Have your endo (or GP) complete the national 'medical condition notification form' and any other required paperwork.
- Submit paperwork to the traffic authority as required.
- Expect to have to redo the medical certificate in two years.
- Check out the Diabetes and Driving booklet available from the NDSS website www.ndss.com.au (search for 'diabetes and driving').

6. Find and befriend your local pharmacist

Why

Be aware that insulin may take 24 hours for pharmacists to order in. Save yourself the trouble of two trips (one to drop in the script and another to pick up the insulin) and ask your pharmacist if you can phone ahead with your insulin orders and bring the script in when the insulin arrives.

What you need to do

Talk to your pharmacist. Find out how long it generally takes for them to order insulin.



7. Consider notifying your employer.

Why

You do not (by law) have to disclose medical conditions in job applications or interviews. However, even if you are not technically required to do so, it can be worth chatting to your boss and/or workmates about your diagnosis, just so they are aware of it in the event that something goes wrong. Some jobs require you to inform your employer of any prescribed medications you take on a regular basis. Insulin fits into this category, so if this is the case in your workplace you may need to let your employer know what's going on. It might also be useful from an insurance perspective.

We asked our Facebook followers how they approach the issue. The majority do tell their employer, do blood tests freely and inform colleagues about the fact their insulin pen or pump is not something carried around for fun – it's actually lifesaving! Some suggestions for telling your employer are: discussing the basics at the interview, developing an information poster for World Diabetes Day, sending an email to your boss and colleagues to tell them about the symptoms of a hypo, or even doing a presentation during a staff meeting.

It's important to note that you do not need to give the same level of detail to everyone at work – your boss might need to know what to do in case of an emergency, while your workmates might just need to know you that will do finger prick BGL checks throughout the day.

What you need to do

- Consider talking to your boss and/or a few workmates about your diabetes diagnosis.
- Consider giving the 'T1DN cheat sheet for family and friends' (available on the Type 1 Diabetes Network website, www.t1dn.org.au) to your employer.
- Check out the Diabetes Australia Victoria guides for employers and employees, especially to make yourself aware of discrimination laws (these vary by state). These guide are available from the DA Vic website www.diabetesvic.org.au (search for the 'Diabetes in the workplace' page)

8. Get yourself a medical alert talisman.

Why

A medical alert talisman lets paramedics and bystanders quickly identify that you have diabetes in an emergency. MedicAlert bracelets, bands and pendants are among the most easily recognised talismans, but there are other options (such as engraving your own jewellery or carrying a card in your wallet) if the official MedicAlert products are not your style.

What you need to do

- Visit www.medicalert.org.au or www.emergency.com.au to check out the range available.

9. Get ambulance cover in your state or territory.

Why

Everyone should do it, but now you're just a teeny bit more likely to need it – so save yourself the stress and join up.

What you need to do

- Every state has a different system for ambulance cover, so check what yours is! You might automatically be covered if you have private health insurance with hospital cover.
- In some states, your ambulance cover might be free if you're entitled to full cover under your state government scheme; in other states, you need to join your ambulance service separately from your private health insurer.

10. Join the National Diabetes Services Scheme (NDSS).

Why

The NDSS provides access to free syringes and pen needles and subsidises blood glucose and ketone testing strips. The NDSS is funded by the federal government, and it is free to register.

What you need to do

- Call 1300 136 588, visit www.ndss.com.au or speak to your diabetes educator and get a copy of the NDSS registration form.
- Fill out the form and have your doctor/diabetes educator fill out Section 3.
- Submit the form to NDSS and wait for your free registration card and starter pack.

11. Check if you are eligible for a Health Care Card.

Why

A Health Care Card lets you receive discounts on insulin and other supplies you need.

What you need to do

- Check out www.humanservices.gov.au or phone 132 468 to assess your eligibility.

12. Consider asking for 'special considerations' for your study/exams.

Why

If you're studying, you can consider applying for 'special consideration' during exams. Doing so usually ensures you will be allowed to take in food and other required supplies (e.g. blood glucose meter) into the exam room. Sometimes it also allows you to have extra make-up time if you have to take time out of the exam to manage your diabetes. It is well worth organising this as early as possible because it's the last thing you want to worry about in the lead-up to exams!

What you need to do

- Contact student services at your educational institution and ask them what special conditions you're entitled to and what you need to do to make sure your needs can be catered for.

13. Get your hands on some glucagon.

Why

Glucagon is an anti-hypoglycaemic hormone that releases stored glucose from the liver into the bloodstream. Glucagon can be injected in emergency severe hypo (low blood sugar) situations. It comes in an orange box and is the equivalent of an EpiPen for people with diabetes. You and someone close to you (family member, partner, friend or housemate) will need to be instructed by a health professional about how to use it in emergencies where you became unconscious and are unable to eat.

Glucagon is like an insurance policy – you need to have it, but hopefully never or rarely need to use it; when it is about to expire, you need to renew. Make sure you get a kit with a long use-by-date – generally at least 12 months, if shorter, insist on getting a new supply and leave the pharmacist to deal with the expiring product!

What you need to do

- Talk to your pharmacist, endocrinologist or diabetes educator about what glucagon is and how to use it.
- Explain it all to your family and friends – especially those you live with.
- Get a script for glucagon from your doctor.

14. Find a support network.

Why

It can be a good idea to make contact – either in person or over the web – with other people who genuinely understand what you are going through. There are so many questions, situations and experiences that are just not covered at hospital during diagnosis or with your specialist at regular meetings. Being diagnosed with type 1 (and managing it in the long run) is not always easy. Sometimes it can be downright scary, confusing and (despite the 130,000+ people in Australia with type 1 and the almost 2000 newly diagnosed every year) surprisingly lonely. Support groups help keep things in perspective and can be great to remind you that you are actually NOT alone!

What you need to do

- Talk to your diabetes educator about local support groups or check out what's available online.
- Visit the Type 1 Diabetes Network website (www.t1dn.org.au), which is run and visited by lots of interesting and experienced people who just happen to have type 1 diabetes and want to help each other out a bit.
- Consider joining the Reality Check forum (www.realitycheck.org.au), which is run by T1DN.
- Get Googling. There are blogs, Twitter accounts, Facebook sites and other websites managed by people with type 1. You are not alone!

The unfortunate truth...

Unfortunately, the costs of living with type 1 diabetes can add up. At a minimum, these costs include healthcare appointments, meters, batteries, insulin, consumables, hypo treatments and other supplies, and that is before you consider specialists you may need to see as well as trying to live a healthy lifestyle!

The good news – the NDSS

When you're first diagnosed, you will be told to register for the Australian Government National Diabetes Services Scheme (NDSS), administered by Diabetes Australia, which provides you with free or cheaper access to a range of supplies. To be eligible, you must be an Australian resident, hold a current Australian Medicare card or Department of Veteran Affairs file number and have been diagnosed with diabetes by a medical practitioner.

Our system may not be perfect, but it works effectively and is well-regarded internationally. Keep your NDSS card in your wallet. You never know when it might be handy!

Public versus private clinics

Public hospital diabetes clinics usually offer bulk-billed (i.e. free) or non-billed appointments with endocrinologists and diabetes educators, and generally give you access to other services (such as blood tests) that are free/bulk-billed within the hospital. The capacity of a public hospital to meet your needs may depend on its size and structure. Using these services saves on costs, but it may be difficult to access appointments as quickly as you might like. Some posters on Reality Check have noted that there can be a lack of continuity in terms of seeing the same healthcare professionals through the public system.

There are also many private endocrinologists, diabetes educators, dietitians and other diabetes health professionals who charge you for their services. This option gives you a bit more choice and certainty in making decisions on who you would like to assist you in managing your diabetes. You have to pay a fee for a private appointment, but you will get some of it back through Medicare. Ask when you book how much the health professional charges and how much you'll get back, as this varies between practices.

Private health insurance can be beneficial to the management of your diabetes and may help keep costs down. While private health insurance has an ongoing cost, this is offset by access to insulin pumps and private hospitals (if needed), as well as assistance with costs for some specialist services. Some private health insurance companies cover things such as gym memberships and blood glucose meter costs. For more information about private health insurance and to compare prices and benefits of all policies available, visit the Private Health Insurance Ombudsman's website www.privatehealth.gov.au.

Insulin

In Australia, the Pharmaceutical Benefits Scheme (PBS) covers a considerable proportion of drug and medication costs through Medicare. You can get insulin from pharmacies with a prescription (from either your GP or endocrinologist) using the PBS. One prescription is generally 3–6 months' supply, depending on your insulin needs.

The PBS ensures that the most you pay out-of-pocket for your insulin supplies is \$36.10 per script at the time of writing. This is even less if you are a Centrelink Health Care Card (HCC) holder – \$5.90 (at the time of writing).



Supplies and consumables

As noted above, one of the huge benefits of the Australian system is that supplies (blood checking strips, pump consumables or needles) are subsidised by the NDSS. Without the subsidy, these supplies would be much more expensive.

Blood glucose meters

Meters can cost anywhere between \$20 and \$100, depending on the features of each model. Private health insurers sometimes cover the cost of meters, and your diabetes educator may be able to provide you with a freebie. Companies who make meters often have specials with free or reduced-cost meters (they make their money from selling the strips) so keep an eye out for those! See the blood glucose meter section on page 20 for more information.

The trusty finger pricker

Lancing devices are usually provided with meters and you will probably end up with a whole bunch of them in a drawer. Unless it's an emergency, you are unlikely to need to buy one of these on its own. Lancets need to be replaced regularly though (usually when finger pricking starts to hurt!), and a new box of these generally costs \$15–20.

Insulin pumps

An insulin pump costs around \$8000–\$9500; however, recent changes to legislation support increased pump accessibility through private health insurance. This means that even with the most basic level of private health insurance with hospital cover, you should be eligible to receive an insulin pump with the full cost covered. Dealing with private health insurance companies can be tricky, but your diabetes educator can assist you in this process. Insulin pump consumables include reservoirs and infusion sets and cost fairly little via the NDSS.

The other option for subsidy assistance is the Type 1 Diabetes Insulin Pump Program (IPP) – an Australian Government program administered by the Juvenile Diabetes Research Foundation (JDRF) – which provides subsidies for insulin pumps for people under 18 years of age. More information is available from the JDRF website www.jdrf.org.au (search for 'insulin pump subsidy').

See the insulin pump section on page 18 for more information.

Tips

Stay organised!

- You can claim a tax offset of 20% (20 cents in the dollar) of your net medical expenses over \$2060 (at time of writing). If you call your state Diabetes Australia branch with your NDSS number, they can give you a list of your purchases for the year. More information is available at www.ato.gov.au/content/00313907.htm. Keep all of your receipts as this offset is for all medical expenses.
- When buying insulin and some other supplies, ask what the expiry date is. You don't want to spend your hard-earned money on supplies that expire before you have a chance to use them!
- Get a Health Care Card if you are eligible, which gives you substantial discounts on insulin and other supplies. Check out www.humanservices.gov.au for more information.
- Ask your GP about a GP Management Plan (GPMP) with Team Care Arrangements, which can provide access to Medicare rebates for up to five allied health visits per calendar year.

Section 2

managing diabetes



Managing blood glucose levels in the real world

2.1

From the instant you're diagnosed, there's a lot of talk about your blood and the amount of 'sugar' in it. Words like 'BGLs', 'hyperglycaemia', 'hypoglycaemia' and 'HbA1c' get thrown at you from every direction as part of the information overload you will later refer to as diagnosis. And several times a day (after your fingers get stabbed), a tiny drop of blood is placed on a check strip, and there's an awful lot of focus on the numbers that appear on the meter.

You may not yet completely understand exactly what different blood sugar numbers mean, the medical terminology used to describe them, or how you're supposed to make the numbers on the meter look good in everyday life. But you will.

Hypos and hypers happen – You always try to avoid them as best you can, but it's impossible really! Took me a long time to realise, but you just have to make the best of the situation and deal with it appropriately.

Kait, Age 23, Diagnosed Age 8

It has taken me a long time to accept that you cannot always control your BGLs, no matter how much you know, how hard you work and how much you're trying. Most days, despite my best efforts, I will have one mild hypo and one reading above 14. This is normal for me and even when I am trying really, really hard to get my carb counting right, things still go wrong so I have just accepted it, and I do not get too stressed about it.

I used to find it extremely stressful to get unexpected results and would get very angry with myself/the situation, or get upset. I still find it frustrating and sometimes feel a bit irritated, but not to the same extent. I have had to learn that I cannot always get it right, and it's not my fault! I deal with the situation and move on to the next thing. I do try to stick with my carb-counting methodology and keep track of my ratios (given they change from time to time) but I am not going to let it get in the way of me enjoying food and eating what I want to eat, when I want to eat it.

Natasha, Age 36, Diagnosed Age 28

Blood glucose levels (BGLs)

Essentially, a blood glucose level is a measurement of the amount of glucose in your bloodstream. In Australia, blood glucose levels are measured in mmol/L – millimoles per litre of blood. BGLs are often referred to as blood sugars.

When outside of optimal range, BGLs are classified as ‘high’ or ‘low’. ‘Hyperglycaemia’ and ‘hypoglycaemia’ are fancy medical names for high and low blood sugar. The origin of these words is Greek: basically, ‘hyper’ = high, ‘hypo’ = low, ‘gly’ = sugar/sweet and ‘haemia’ = blood. So hyperglycaemia = high blood sugar and hypoglycaemia = low blood sugar. In simple terms, you don’t want to be hypo or hyper for long periods of time.

HbA1c

HbA1c is a measurement of the amount of glycated haemoglobin in your blood, which reflects average blood glucose levels over the past 10–12 weeks. Since it reflects an average, and not daily ups and downs, health professionals like to use HbA1c to get an overall picture of your blood glucose management. For most people, it is recommended to aim for an HbA1c result of less than 7% (53 mmol/mol). Your GP/specialist should arrange for you to have your HbA1c checked approximately every 3–6 months.

For more information, check out the great HbA1c fact sheet T1DN has developed, available on our website, www.t1dn.org.au.

From July 2013, HbA1c will be reported in mmol/mol instead of as a percentage. Handy conversion tools are available online to help you get used to the different way HbA1c numbers will be reported. (There is one at www.nps.org.au, for example.)

I had a tough time after going into hospital with DKA once. It actually took a few years to get over as it made me really bad with anxiety, being alone, taking the proper amount of insulin. It made me scared as hell of lows, even though DKA is high. It was a horrible time and I only got over it in time, showing myself I can do this and with the help of friends and family.

Fiona, Age 27, Diagnosed Age 14

Diabetic ketoacidosis (DKA)

DKA is a serious condition that occurs when there is insufficient insulin to stop the breakdown of fats into ketoacids in the blood. This can occur if you are unwell and the stress increases your insulin requirements, or if you don’t give insulin for any reason. The result is a build-up of ketones in the blood and can be life-threatening and require urgent treatment in hospital. You may have had DKA when you were diagnosed. Usually high BGLs and high ketones go hand-in-hand.

A word on high and low blood sugar

In an ideal world, everybody’s blood glucose levels would be managed internally through a perfect, natural balance of insulin production and sensitivity. Whenever food is eaten, the pancreas would respond by releasing just enough insulin to transport digested glucose from the bloodstream to the body’s cells for energy, and blood sugar levels would stay somewhere in that golden range of 4–8 mmol/L all day.

Unfortunately for those of us with diabetes, the right amount of insulin doesn’t just magically appear in our bloodstream whenever it’s required. It’s up to us to try to balance our BGLs as best we can. Funnily enough, it’s no easy feat to mimic a complex internal bodily system from the outside – our blood sugars invariably change. High and low blood sugars happen – they are an unfortunate part of life. If we’re lucky, BGLs mostly sit in that close-to-optimal range, but there’s no denying that sometimes they will be too high, and sometimes they will be too low.

In the initial stages of diagnosis – and sometimes beyond – this concept can be a little scary and difficult to understand. The following sections on hypo/hyperglycaemia provide a breakdown of what that means and tips on what you need to look out for and do in each case.



What's low? (hypoglycaemia)

Generally speaking, a blood glucose reading of less than 4 mmol/L in adults is classed as low (hypoglycaemia).

What's just right or 'target range'?

No single set of numbers can be classed as 'perfect' for every person with diabetes. The truth is, everybody is different and the best numbers for you are the ones that work for your body and keep you safe. Your diabetes healthcare team will help you set individual targets.

Generally speaking though, it's usually best to try to keep your blood sugar level as balanced as possible, as long as you can do so without being constantly hypo. This means approximately 4–7 mmol/L before meals and around 5–10 mmol/L after meals. These are general guidelines only. Make sure you check with the specialists on your team for the range of levels that are right (and safe!) for you.

What's high? (hyperglycaemia)

Strictly speaking, any blood glucose reading higher than 8 mmol/L is above the average for a person without diabetes. Usually though, hyperglycaemia refers to consistently high readings or readings greater than about 14 mmol/L.

Hyperglycaemia

Hyperglycaemia – high blood sugar – is when your BGLs are above the optimal range. Hyperglycaemia can develop over minutes or be sustained over several days.

Causes

The following factors were identified by members of the Type 1 Diabetes Network as contributors to unexpected high blood sugar:

- skipping or delaying an insulin injection;
- eating too much carbohydrate in one sitting or incorrectly carb counting;
- sickness/infection;
- stress;
- anything that gets the adrenaline going;
- corticosteroids (prescription drugs);
- exercise;
- sleep deprivation;
- hot weather;
- some foods;
- hormone changes the week before a period.

Symptoms

Many people do not experience symptoms of hyperglycaemia until their blood sugar levels are extremely high. Often (especially in the early stages) the only way to detect hyperglycaemia is by checking your BGL. Symptoms of high blood sugar can vary from person to person, but some common early warning signs include:

- excessive thirst;
- frequently going to the toilet and passing large volumes of urine;
- feeling tired;
- blurred vision;
- nausea and vomiting;
- dramatic weight loss;
- chronic infections (e.g. thrush, cystitis, slow-healing wounds/infections).

What to do

- Check your blood glucose levels frequently and adjust with insulin.
- Contact your doctor or diabetes educator for advice about increasing your insulin doses if your BGLs are frequently high.
- Drink extra water to help replace fluid lost by passing more urine.
- Check your urine/blood for ketones.

You may need to contact your doctor or go straight to the hospital if:

- blood glucose levels remain high after insulin adjustment;
- vomiting stops you from drinking/makes eating difficult;
- moderate to large amounts of ketones are present in your blood or urine.

Remember

In type 1 diabetes, high BGLs can progress to a serious condition called diabetic ketoacidosis. This condition can be life-threatening and requires hospital treatment. See page 37 for more information.

Hypoglycaemia

Hypoglycaemia – low blood sugar – occurs when your BGL drops too low. For most people, a ‘hypo’ occurs at anything less than 4 mmol/L (although this varies in different situations and from person to person). It’s important to note that hypos can occur without symptoms, sometimes even when your BGL is very low – this is called hypo unawareness and risks developing into a severe hypo. It is crucial that you take care of any hypo whether you have symptoms or not. However, the cause of a hypo can be different every time and for every person.

In most cases, emergencies can be avoided by managing a hypo quickly, before the blood sugar level drops so low that unconsciousness occurs. If you are unconscious or drowsy to the point of being unable to swallow, glucagon should be administered (by someone else) and an ambulance called (see page 15 for more about glucagon).

Causes

Members of Reality Check reported some of the following as potential hypo causes:

- taking too much insulin;
- delaying or missing a meal (especially after administering insulin);
- not eating enough carbohydrate;
- unplanned physical activity/exercising more strenuously than usual;
- drinking alcohol;
- yoga/prolonged physical work (delayed hypo);
- cold or hot weather;
- sex;
- getting your period.

Symptoms

- sweating;
- weakness, trembling or shaking;
- headache, light headedness or dizziness;
- difficulty concentrating;
- irritability;
- hunger;
- tingling or numbness around the mouth and lips;
- confusion or altered level of consciousness;
- behaviour changes (aggression, tearfulness, crying, bizarre behaviour);
- slurred speech;
- marked drowsiness;
- seizures;
- and (eventually) unconsciousness.

What to do

- Hypos need to be taken care of as quickly as possible. As long as you are conscious, the treatment is to swallow quick-acting sugar/carbohydrate of any kind.
- Make sure you are safe (e.g. if driving, pull over to the side of the road and remove keys from ignition if you can).
- Check your blood glucose level (if time and circumstances permit) – a result less than 4.0 mmol/L indicates a hypo.
- Consume 15–20 grams of quick-acting sugar (non-diet soft-drink, fruit juice, jellybeans, glucose tablets).
- Wait 10–15 minutes and re-check BGL. If symptoms are persisting or BGL remains below 4.0 mmol/L, consume some more quick-acting carbohydrates.
- If your next meal is more than 15–20 minutes away, your diabetes educator may recommend that you eat some longer-acting carbohydrates (e.g. a sandwich, glass of milk, piece of fruit, biscuits, muesli bar).

What if I’m unconscious, drowsy or unable to swallow?

This is a hypoglycaemic emergency (sometimes called a ‘severe hypoglycaemic episode’) and some people go their entire life without experiencing a hypo for which they need assistance. Make sure people close to you are aware of these symptoms and know that if this happens they need to:

- place you on your side and make sure your airway is clear;
- not give you anything to eat or drink (if you’re unconscious, drowsy or unable to swallow, there’s a high risk you will choke on anything given by mouth); however, they can rub glucose gel inside your lips and on your gums;
- give an injection of glucagon (if available and they know how to administer it);
- call an ambulance (dial 000) and explain that it’s a ‘diabetes emergency’;
- follow instructions from the ambulance call taker, and wait with you until the paramedics arrive.

For me, the closest thing for a quick hypo fix is a glass of OJ. If I’m not at home and I go low, I find the nearest soda machine and buy whatever there is that’s non-diet.

Becky, Age 31, Diagnosed Age 10



Managing hypos on a day-to-day basis

Regular hypoglycaemic episodes that you can manage yourself are a part of living with diabetes, but you can do a number of things to prepare for and manage low blood sugar events, including:

- carrying a hypo pack and making sure you always have access to your hypo stash;
- wearing an identification band that says you have diabetes so people know you need urgent medical help if you have a severe hypo;
- noting in your monitoring book any lows you have and discussing them with your doctor or diabetes educator at your next visit;
- trying to determine the cause of your hypo after you've recovered so you can try to prevent the same situation occurring in the future; don't fret if you can't work out a cause as this is common too;
- checking your blood glucose before strenuous exercise or driving and eating to bump it up if it's around or below 5 mmol/L;
- eating carbohydrates if you are drinking alcohol;
- making sure your family, friends, co-workers and carers know how to recognise hypoglycaemia symptoms.

In the 17 years since I was diagnosed, although there have been many ups and downs, I've never had a hypo or a hyper I couldn't manage on my own. I'm lucky (so far) in that I've understood the reasons for my 'HI's and been able to correct them fairly quickly, and have still been functioning quite well even when my meter has read 'LO'.

Cassie, age 27, diagnosed age 10

Hypoglycaemic unawareness

Some people have no symptoms of hypoglycaemia. They may go severely low or even lose consciousness without even knowing their BGL was dropping. This is known as 'hypoglycaemic unawareness' and sometimes happens to people who have had diabetes for many years, or as a result of having a number of hypos in a relatively short period of time. It can be very dangerous as it can lead to unconsciousness without any warning symptoms.

Hypo symptoms can change over time, which may make low BGLs harder for you to recognise. No matter the symptoms, always manage low or dropping BGLs, even if you feel fine. If you find it hard to recognise hypos, you may need to check your BGL more often – including overnight – and make sure your friends and family know they need to watch for any changes. If your normal hypo symptoms disappear or begin to change dramatically, arrange an appointment with your specialist or diabetes educator to discuss what's going on. Hypoglycaemic unawareness is more common during pregnancy, especially in the first trimester. Hypo unawareness can often be overcome by carefully and diligently adjusting insulin and monitoring BGLs for a few weeks to avoid further hypoglycaemia during that time.

Glucagon

Glucagon is a hormone that raises blood glucose levels. For use in emergency, it is available as a 'GlucaGen Hypokit', which contains a powdered form of glucagon, a dilutant and a syringe for injection. It's almost like a diabetes answer to the EpiPen. If you become unconscious from a severe hypo, others can use glucagon to raise your blood sugar and bring you around. It would usually be kept at home if a family member, partner or friend is trained to use it. It is also useful to take on holidays or if you are away from emergency access (such as bushwalking or boating). Your doctor can organise the initial prescription and show you, your family and friends how to use it. For most people with good hypoglycaemia awareness, glucagon is never needed.



Hypo pack

Keeping a hypo pack can be a handy way to manage hypoglycaemic episodes. You should carry it with you at all times and it could include:

- written description of hypo symptoms and instructions for how to manage a hypo (in case family, friends or bystanders need to help you);
- doctors' and hospital contact numbers;
- emergency contact details (nearest relative or next of kin);
- a stash of fast-acting sugar/carbohydrate (see the box right for suggestions) and slow-acting carbohydrate (e.g. muesli bars, fruit bars, biscuits).

In the box are some examples of handy things to carry around with you or store in your stash for when your BGL starts to drop. There are heaps of options out there, but these are some that have worked for us!

Some health professionals recommend following hypo treatment up with slower-acting carbs to stabilise your blood sugar and make sure it doesn't drop again. You're more likely to need this if you're on multiple daily injections than on a pump. Make sure you talk to your health professional about what hypo treatment plan to use for your diabetes management. If you are concerned your blood sugar isn't stable and your next meal is more than 20 minutes away, aim to consume about 15 g of longer-acting carbohydrate, for example, half a sandwich, a muesli bar, a glass of milk or a piece of fruit.

[To fix hypos] I buy lollies that I don't like – it saves me eating them when I don't need to! If I'm somewhere near a café, I'd rather buy something to save my emergency supplies for places where I can't access food.

Kait, Age 23, Diagnosed Age 8



Fast-acting sugars/carbohydrate

(for immediate use for low BGL – try to stick to 15–20 grams)

Jelly beans/jelly babies: about six per hypo should do the trick. Beware of them becoming sticky/goosey/furry in the bottom of your bag!

Small bottles of lemonade or other non-diet soft drink: usually available in packs from your local supermarket. Handy because you can swallow quickly without chewing, they have a lid for re-capping, and don't split open under pressure like cans and poppers sometimes do!

Glucose powder: easy to carry around in small containers while out and about – a great idea if lollies tempt you into snacking when you're not actually low!

Glucose tablets: available from your chemist/Diabetes Australia. They're easy to carry around, but can be expensive.

Glucose gels: can be good for exercise, especially in water, as glucose gel packs are waterproof and also easy to eat.

Strong cordial (undiluted): may taste sickly sweet, but it does the job in a hurry!

Lucozade, Stamina or other sports drink: make sure it's the type that has more sugar, not less! (Lucozade is generally the best for this.)

Milo: a generous scoop in a glass of milk is great as it gives you a short boost from the Milo and a sustained lift from the milk.

Sugar sachets: the kind you find on tables at restaurants and cafés. Generally about three sachets will fix a hypo, and they fit easily into purses and wallets. Just beware of splitting and spillage with rough treatment!

How, why, when?

Now that you've been diagnosed, we're sure you've been told that insulin is not a cure, but a treatment to keep your body functioning. Many newly diagnosed people with type 1 struggle with how to choose which insulin delivery method is best for them.

Insulin can be delivered subcutaneously just under the skin by syringe, by insulin pen with a fine needle or via insulin pump. There are pros and cons to each system, and ultimately you need to talk to your health professional and decide which one is best for you.

Syringes and pens

Delivering insulin via insulin pen or traditional syringe is still the most commonly used method. When using syringes or pens, you are likely to need different types of insulin – short-acting and long-acting – to try to replicate the way a healthy pancreas releases insulin. This combination will be determined primarily by your endocrinologist.

Using traditional syringes and vials of insulin was the only method available until the 1980s. The main advantages of sticking with syringes is that very little can go wrong – you can see the insulin you are drawing up and delivering, so you are unlikely to inject Lantus (long-acting) when you meant to inject Humalog (short-acting), and you can verify that you delivered the full dose. Syringes are extremely unlikely to malfunction or be damaged by being dropped or hit. In addition, you can mix certain types of insulin in a syringe (just don't change the order of the mix) and that may mean fewer jabs.

The downsides of syringes are that it can take longer to draw up the dose and the needle is very visible, which can be scary if you suffer from needle phobia.

Syringes have very fine needles and special coatings to make injecting as painless as possible. Your diabetes educator can assist you with fine-tuning your insulin delivery via syringes, especially if you experience bruising or soreness around sites.

Insulin pens are a more discreet and convenient way to carry and inject insulin. They look like a cartridge pen with a needle on the end. Users turn a dial, insert the needle under the skin and then press a plunger that delivers the 'dialled-up' dose of insulin. 'Dialling-up' a dose is quicker than drawing up insulin with a syringe, and insulin pens look a bit less intimidating than syringes. You only have to carry one item around (so long as you only need one type of insulin at a time) rather than the syringe and vial.

“Being a ‘fraidy cat when it comes to needles, I find the pens great. If I go out for dinner it is easy to slip into your pocket. I think it is fantastic.”

– Neal, Humapen road test

The downside is that pens can malfunction – albeit rarely – and they can actually be bulkier than a syringe and vial. However, most insulins are now available in disposable pens, as well as cartridges for re-usable pens, which many folk find more convenient and user-friendly.

Baz tells us: “They (pens) are much handier than syringes, but the things just won't work all of the time. I have been using Humapens for a while and in the past 12 months have had about four or five failures...”

[I use] MDI [multiple daily injections]. I'm not ready to have something attached to me 24 hours a day. I can't imagine sleeping with a pump as I am already a very light sleeper.

Natasha, Age 36, Diagnosed Age 28



Practical tips for pumpers

Allergic reaction at pump site

Some people have an allergic reaction to the insulin pump site adhesive. Putting a medical film on the skin first and then inserting the cannula through the seal so that the adhesive is attached to the film, not to the skin, can overcome this.

Pump getting lost or broken

Insulin pump warranties cover all breakages, but we advise including your pump under home and contents insurance as a specified portable item (for an extra premium) to protect it against loss.

Should you take time off work/study to get used to your pump?

Opinion is mixed about whether you should take time off work/school/uni when starting on a pump. Some people opt to take time off to fine-tune basal rates and establish their target BGL levels, while others feel it is best to road test the pump within the scope of their day-to-day lives.

Insulin usage and storage

Insulin scripts only last 12 months, and yes, it's annoying! You'll need to use a new insulin cartridge/vial about every four weeks. Insulin should be kept refrigerated until it's time to use it, but make sure your insulin does not freeze!

How does insulin work?

Insulin is generally defined and characterised by the way it works. Onset: the length of time until insulin hits your bloodstream and begins to lower blood glucose; Peak: the time during which insulin is at maximum effectiveness at lowering blood glucose; Duration: the length of time insulin continues to lower blood glucose.

Insulin pumps

That gadget many people with type 1 diabetes carry around is not a spy camera, pager, clock, mobile phone or mp3 player. It's an insulin pump! Insulin pumps deliver insulin constantly (basal rate) as well as on demand to cover food or correct a high sugar (bolus). Insulin is delivered through narrow flexible tubing that ends in a cannula just under the skin. The pump can be clipped onto a belt, carried around in a pocket or... well... it can be worn in almost a million different ways.

An insulin pump is a sophisticated way of giving insulin. Some newly diagnosed T1s are even put on an insulin pump immediately because of the benefits associated with pump use (see points below). If you have been on daily injections for some time, it is a rather large learning curve to change to a new way of managing your diabetes.

Kait noted on Reality Check: "I found it like being diagnosed all over again in that there is a lot to learn, and you don't learn it all at once. It took me a good couple of weeks to get the hang of it, but I was able to have my pump and play around with it for a couple of weeks before I got started on it, which was great as I knew how to navigate the different menus. There is also some overnight checking involved in the beginning – you have 24 hours to sort out!!"

The main advantages of using a pump are:

- A pump delivers a continuous, pre-set (basal) dose of insulin throughout the day and the rate of delivery can be customised to meet your needs, such as a lower rate late at night to avoid 1 am hypos and a higher rate in the early morning to overcome the dawn phenomenon (a well-known occurrence when sugars rise with the sun).
- Only rapid-acting insulin is used so it simulates a healthy pancreas more closely than MDI.
- One needle (to introduce a pump site) every 3–4 days, rather than 3–4 needles a day!

There was no way I wanted a pump initially. Then all of a sudden I woke up one morning and had to have one! Life or death! I think I just got that bit older and less worried about 'having something attached' and wanted to have better control of D [diabetes]. Although, when I first got it attached I broke down in tears and got it taken off. I came back the next day better prepared and have not looked back since. Many less highs and lows, easier to manage once you get used to it, and I hide it in my bra... no one would ever be able to tell. I love pumping!"

Fiona, Age 27, Diagnosed Age 14

So, is an insulin pump is for everybody? Not necessarily – some of the downsides of pumping include:

- The cost – however, recent moves by the federal government have improved this tremendously. The pump itself is covered by private health insurance (through basic hospital cover it is considered a ‘prosthetic device’ and paid for in full by the insurance company). If you don’t have private health cover, a pump costs approximately \$8000–\$9500. Many people sign up for health insurance just to get a pump, but be aware that there is generally a 12-month waiting period. Some pump companies offer a loan pump to cover those 12 months.
- The consumables required to run a pump – since September 2004, these have been subsidised through the NDSS. Prior to that consumables cost approximately \$200/month, whereas now they cost approximately \$25/month.
- The pump is connected to you 24/7 and can take time to acclimatise to having it Always On, however there is always the option to take a ‘holiday’ from your pump and use MDI for a while, giving you a break and a different perspective.
- As the pump delivers a constant stream of quick-acting insulin, if the pump malfunctions or you pull out the infusion site or run out of insulin, you are at risk of rapidly rising blood sugars and developing diabetic ketoacidosis (see page 37). To avoid this, you need to monitor your BGL frequently (minimum six times a day), have a well-developed emergency plan and always have backup insulin available in convenient places (work, school, car, bag) so that you can inject insulin the old-fashioned way if your pump stops delivering it for you.

Getting started on an insulin pump can be tricky. Firstly, it requires a bit of paperwork between your diabetes educator, endocrinologist and private health insurance company. Changing over to a pump involves a lot of learning as it is quite different from injections, and despite the many happy pumpers out there, it still requires a serious commitment and a lot of work. Accurate carb counting on a pump is very important, as the pump gives precise doses based on what you input, so knowing exactly what carbs you are eating will allow the pump to give a more accurate outcome.

I have used a pump for the last seven years. I have more flexibility and freedom despite being attached to something 24/7. It makes managing exercise and training a lot easier.

Susan, Age 37, Diagnosed Age 16



Coming ‘soon’... or is it?

News coverage often talks about new, fancy, whizz-bang, pain-free, trouble-free ways for delivering insulin such as inhalable insulin, insulin patches or implantable pumps. Diabetes technology companies are working furiously to provide new methods of insulin delivery, but at this stage, a satisfactory alternative to injections has not been developed, with insufficient clinical trials assessing the long-term effect of the different delivery approaches.

It is not all doom and gloom though. The most exciting potential development in pumping is the ‘artificial pancreas’, otherwise known as ‘closed loop’ technology. This technology combines continuous blood glucose monitoring with insulin delivery to automatically manage BGLs, effectively operating as a diabetes pump that doesn’t require anyone to ‘drive’ it. Realistically, this technology is still a while away, but exciting things are occurring in the world of insulin delivery.

Insulin pumps currently available in Australia

Accu-Chek Combo 1800 633 457
www.accu-chek.com.au/au/products/insulinpumps/index.html

Animas Vibe 1300 851 056
www.amsl.com.au/animas

Medtronic Paradigm Veo 1800 668 670
www.medtronic-diabetes.com.au

DANA Diabecare R, DANA Diabecare IIS,
Any DANA Android 1800 823 203
www.managingdiabetes.com.au

Checking blood glucose levels

By now you know that monitoring blood glucose levels is an essential part of diabetes management. Yes, checking BGLs requires a stab in the finger and a spot of blood – but we count ourselves lucky! Back 30–40 years ago the only way to monitor glucose levels in the body was with urine, a tablet and some urine-testing tape – or a trip to hospital. In the early days of blood glucose monitoring, the meters were brick size, blood had to be washed off the strips, results took 1–2 minutes and the meters had no memory! Nowadays it's a relative breeze – you can do it yourself with a blood glucose meter, test strips and a lancet device. Results are incredibly accurate and usually displayed within seconds – and no trip to the hospital or toilet required!

Your new friend – your blood glucose meter

By the time you're reading this, you're probably well acquainted with a blood glucose meter and know how they work. In terms of diabetes gadgetry and equipment, a reliable blood glucose meter is one of your most important tools as it provides you with information you need to make decisions about your diabetes. You should probably carry a blood glucose meter with you at all times. Some people like to use one meter and carry it around with them along with their other diabetes supplies. Others might have a number of meters and leave them at home or work, or in their car, bag or school locker. Choose what works for you.

Hopefully you received a meter at diagnosis, but if you didn't or you don't like the one you have, there are plenty of options out there.

The state and territory offices of Diabetes Australia offer a wide range of products including blood glucose meters. These can be purchased online or in the relevant state/territory store.

Your diabetes educator or endocrinologist may be able to provide you with a free blood glucose meter. This can give you the opportunity to try a few options. Meter companies are often keen to get people using their products and sometimes give meters away as a promotion (they make money from selling the strips) so keep your eye out for these offers.

Most pharmacies provide a pretty good range of blood glucose meters across all price ranges. You should shop around, as there can be quite a price difference between pharmacies.

Your blood glucose meter generally includes a lancet device, case and a set of batteries. Some meters require coding strips to associate a particular batch of blood glucose monitoring strips to that meter, however this is becoming less common.

I only use one meter as I prefer consistency and know that I will get this from the same meter. Mine is easy to use in the dark – a bonus for testing at night (or in the movies) and not having to turn a light on. I find it fast and reliable – both important features for me.

Susan, Age 37, Diagnosed Age 16

I test around 6–10 times/day and correct for any highs. I am fairly strict with myself but try not to beat myself up about unexplainable highs and lows as they are an unavoidable part of having type 1!

Susan, Age 37, Diagnosed Age 16

Why check?

Regular checking is the best way to identify changes in blood sugar – which allows you to adjust your insulin doses to maintain good diabetes management and minimise the risk of long-term complications. Other benefits of regular self-checking include:

- better confidence in looking after your diabetes;
- greater understanding of how different exercises, foods and medications affect your blood glucose levels (everyone is different);
- faster detection of blood glucose levels that are too high (hyperglycaemia) or too low (hypoglycaemia).

When to check?

Generally speaking, the most common times to check are:

- before all meals;
- approximately two hours after each meal;
- before bed;
- before and after exercise (and during if it is a long exercise session);
- whenever you feel unwell.

In the beginning, your doctor, healthcare team or diabetes educator will help you decide when you need to check your blood glucose and the levels you aim for. They may also ask you to record all your BGL results in a diary, even though your meter may have an inbuilt memory. This is usually so trends in blood sugar can be monitored and insulin doses can be adjusted.

Times when you may need to check more often include when you are:

- experiencing hypo or hyper symptoms;
- sick, stressed or battling an infection;
- changing or adjusting insulin doses;
- travelling;
- changing your usual routine or eating habits;
- planning minor surgery;
- recovering from dental procedures;
- a female who is pregnant or trying to conceive.

What's the optimal blood glucose range?

Let us just put this straight out there – ‘optimal blood glucose’ for someone with diabetes varies. We generally don’t use the term ‘normal’ anymore, because let’s face it, no-one wants to be considered ‘abnormal’ just because their blood glucose is not within a particular range!

Everybody’s blood glucose fluctuates depending on various levels of eating, exercise and hormones (even people without diabetes). Fluctuations for people with diabetes tend to be more extreme. So, for example, if you eat a piece of chocolate cake and forget to inject insulin, you would expect the reading on your monitor to show up as quite high. If you run around the block before eating breakfast, your levels may go low. Between those extremes, you can expect your blood glucose level to fluctuate higher or lower at different times of the day. These numbers should not be perceived as good or bad, or as a reflection of ‘performance’. They are just an indication of what you need to do with your insulin dosages and eating patterns. Please do not judge yourself on these numbers.

Obviously, do your best to maintain your levels according to the targets set by your healthcare team and have your team help adjust your insulin doses to deal with regular fluctuations – but don’t beat yourself up every time your BGL is higher or lower than those targets. Diabetes management is not an exact science – it is pretty much impossible to be within target 100% of the time, and it is okay for your levels to vary!

What if the results don't seem right?

When it comes to diabetes management, technology is a wonderful thing. Usually, we don’t have to worry about it failing, but it’s best to be aware that many factors can affect the accuracy of your blood glucose check results. Some of the most common reasons for inaccurate results include:

- an issue with the strips (out of date or improperly stored);
- not washing hands prior to checking (food residue on fingers can give higher results);
- incorrect meter calibration or set-up;
- internal meter error.

If you get results on your meter that really don’t seem right, try checking the following things first:

- Have the strips passed their use-by date?
- Have the strips been stored correctly (lids closed, away from heat, light and humidity)?
- Does the calibration chip with the meter match the strips being used?
- Has the meter been calibrated with a change of strips?
- Did you place enough blood on the strip?
- Were your hands washed and dried before the check?
- Is the battery in the meter getting low or flat?
- Is the meter too hot or too cold?



Which meter?

Over the past few years, the range of meters available in Australia has increased hugely and is changing almost by the day, with new players entering the market. All meters provide you with relatively accurate blood glucose results, but each meter has slight differences. They vary in the size of the drop of blood needed; some can upload results to software; some have a light to test in the dark; some can set markers for exercise and food; some use cartridges of strips so you don’t have to carry test strips; and some can send results directly to your pump. One new meter on the market even plugs into an iPhone!

No meter is 100% accurate and it’s possible to get a 10–20% variance in results with two different meters, so don’t be too concerned if there is a difference between two meters. If you use more than one meter, discuss with your health professional how this could affect your pattern of results.

At the end of the day, choosing a meter is a bit like choosing a mobile phone. In fact, if you are ever in a room with other people with type 1 diabetes (remember many meet-ups are arranged through Reality Check), you will find a broad range of meters. As one poster on Reality Check once noted when asked about blood glucose meter recommendations: “What one person loves, another can’t stand!”

To get an idea what’s out there, have a look for information on your state Diabetes Association website or chat to your diabetes educator.

If all of the previous points check out and you are still concerned that you are getting inaccurate results, you can arrange to have your meter tested with a control solution (a solution with a defined concentration of glucose). Speak to your diabetes educator or local chemist. Alternatively, in not too long you’ll probably end up with two meters (or five...), so try testing on a spare meter and see if the meters agree.

What is a continuous glucose monitor?

Thanks to advances in technology, people with diabetes can now use continuous glucose monitors (CGMs). CGMs are electronic devices worn on the body, similar to an insulin pump site, that measure and display whether the glucose level in the body is rising, falling or steady. CGMs are useful tools that complement (but do not replace) blood glucose meters. Because a CGM measures blood glucose from the fluid between cells, rather than from capillary blood, there is a slight lag time for results. It is therefore safest to rely on a finger prick reading when making important decisions.

The costs of CGM technology are currently prohibitive for most people. There are efforts to improve their affordability through private health insurance or the NDSS. It may also be possible to borrow one through your educator to get an idea of what’s really going on in your body. While CGMs are costly (each sensor lasts 6–7 days and costs over \$70), it is clear that they will gradually become more common and important tools for the management of type 1 diabetes, particularly for those who use an insulin pump. An important step for type 1 diabetes management is to improve accessibility to CGM. This may take some time – keep an eye on the T1DN’s monthly newsletter Yada Yada for updates. (You can subscribe to Yada Yada at www.t1dn.org.au.)

Section 3

healthcare and Support



3.1 Doctors, nurses and choosing a good ‘team’

Type 1 diabetes is a complex condition that doesn't always play by the rules. The good news is you don't have to face off against it on your own – a range of health professionals are out there whose job it is to help you ‘win’ with various aspects of your diabetes management. These experts have trained their whole professional lives for this and have worked with many people who were going through the same things as you, so it's a good idea to keep them on your team.

Each part of your ‘team’ is responsible for different parts of your overall diabetes management (what they do is outlined in this section). It is important that you make sure every single one of them works for you. They may be the specialists on diabetes, but you are the specialist on your diabetes – they do not know more about your diabetes than you. A good team member should:

- make you feel comfortable, not nervous (they're on YOUR team!);
- be supportive, not judgemental;
- be open to and encourage questions;
- provide answers and explain things in a way that makes sense to you;
- help you make adjustments to your diabetes management so that diabetes fits into your life, not the other way around.

So... who's who and what do they do?

Endocrinologist

Also known as an ‘endo’, an endocrinologist is a doctor who specialises in the endocrine system and hormones produced by the body (e.g. insulin). Diabetes (all types) is the main condition of the endocrine system, but others include thyroid issues and Graves’ disease. You'll need to find an endocrinologist who specialises in diabetes – preferably one who mostly sees people with type 1. Endocrinologists can help you adjust insulin rates, solve problems and get major blood tests ordered. They can be seen publicly at major hospitals or privately in individual practices. Endocrinologists generally recommend that you see them 2–4 times a year. Your GP can organise a referral. You may be lucky and find an endo you get on well with as soon as you are diagnosed. If not, definitely hunt around – there are good ones out there! If you're not happy with your initial endo, a good place to start is the Type 1 Diabetes Network's list of recommended professionals (at www.t1dn.org.au) or ask on Reality Check.

Endocrinology registrar

An endocrinology registrar is a fully trained doctor who is finalising specialist training in endocrinology. They might not (yet) have the experience of a long-standing endocrinologist, but on the up-side, having just finished med school and compulsory research, they should be right up-to-date with the latest and greatest in technology and management strategies!

Diabetes educator (aka diabetes nurse educator or credentialed diabetes educator)

When you are first diagnosed, it was most likely a diabetes educator who ran through the basics with you on things like how to use your blood glucose meter and how to inject insulin. They may be an experienced nurse, dietitian or podiatrist who has also completed a post-graduate degree specialising in diabetes. They will also be your first port of call for all the niggling questions that pop up along the way. A diabetes educator is also usually your primary supports in accessing and learning about an insulin pump. They are found at most major public hospitals, as well as many private ones, and are usually easier to get hold of than the endocrinologist or local doctor – especially in cases of emergency. Your diabetes educator will be a long-term gold-mine of information and suggestions about carb-counting, how to check your ratios, effective ways to treat hypos and heaps of other tricky issues.

The most helpful and understanding person I deal with is my educator. She is fantastic, both emotionally and [with] practical information.

Maureen, Age 49, Diagnosed Age 48

Dietitian

Dietitians can take you through the ins and outs of things like understanding the glycemic index and carbohydrate counting of food. Managing food is a big part of having diabetes, so make sure you ask lots of questions and get plenty of answers about anything you can think of that's food related. Be honest about your favourite foods and eating habits, and ask for ways to incorporate these into your diabetes-friendly diet, even if it's not as regularly as before.

I was surprised how helpful the diabetes dietitian was in helping me with better BG [blood glucose] control and healthy eating to live longer and stronger.

Sally, Age 47, Diagnosed Age 12

Although I have struggled with depression quite a bit since my diagnosis, I try not to let it [diabetes] get me down. All I can ever tell myself is that while today might just full-on suck, there is always the possibility that tomorrow might be better.

Becky, Age 31, Diagnosed Age 10

Counsellors

It's no surprise that getting your head and heart around the daily challenges of diabetes can be exhausting, and recent studies have proven that people with diabetes are more likely to be affected by mental disorders such as anxiety and depression. Unfortunately, counsellors and psychologists specialising in diabetes (especially type 1) are fairly thin on the ground. If you're stressed out and need someone to blurt at, ask to see a social worker or health counsellor at your big local hospital. In some cases, they can identify management strategies that may help you cope better. Otherwise, a specialised online service is available at www.diabetescounselling.com.au.

Podiatrist

Podiatrists specialise in all things related to feet and ankles. Feet are commonly affected by circulatory issues that can occur in people with diabetes, so regular checks with a professional who can investigate and identify any issues early on is... handy. For people with diabetes, these specialists generally check blood flow, feeling and reflexes (circulation and nerves). The tests are painless. Your GP can provide you with a referral and recommendations.

Ophthalmologist and/or optometrist

Clinical guidelines state that people with type 1 need to have their retinas checked annually, through a dilated pupil by either an optometrist or ophthalmologist. ('National evidence-based clinical care guidelines for type 1 diabetes in children, adolescents and adults', available at www.nhmrc.gov.au/guidelines/publications/ext004.) Normally with type 1, you won't need to see one for the first four to five years. A good optometrist can do a full diabetes retinal eye check, send the results through to your endo or GP, is often easier to get into and is more likely to bulk bill. An ophthalmologist is the next step up from a regular optometrist – they have a medical degree, extra experience and advanced medical training. Ophthalmologists are trained to diagnose and treat all eye problems and conditions, and are licensed to practise medicine and conduct eye surgery. Ask your GP or endocrinologist for a referral when required.

Reality Check was my first port of call for recommendations [in setting up my 'team']. I found a GP, diabetes educator and a mental health nurse all in the same practice. They also work with an endo locally who runs a pump clinic. Bonus!

Jackie, Age 41, Diagnosed Age 35

Peer Support

They may not have a specialised degree, and you won't need a referral to see them, but getting in contact with other people with type 1 diabetes is definitely recommended. Just knowing that there are others out there who really know what it's all about can do wonders for your outlook, understanding and management of diabetes. Talk to your diabetes educator about local support groups or check out what's available online. The Type 1 Diabetes Network (www.t1dn.org.au) is a good place to start. It's a website run and visited by lots of interesting and experienced people who just happen to have type 1 diabetes and want to help each other out. It also houses the Reality Check forum (www.realitycheck.org.au), which is an honest, active online community that is a great place to vent, explore and ask questions. You can also check twitter for weekly chats with people with diabetes (both type 1 and type 2) by following the #OzDOC hashtag.

I only stay with people I feel comfortable with, AND who provide what I consider to be 'good service', in a healthcare setting. I left my previous endo because she always ran extremely late with her appointments (1-2 hours)... and charged extra for an overtime appointment. I just approach it from the point of view that I am paying for something and if I am not happy with the service, I will take my money elsewhere. My current endo has a fantastic diabetes educator who works in partnership with him. At first, I was a bit reluctant to have an appointment with her, but she has turned out to be gold. She is very understanding of the difficulties associated with managing T1 on a day-to-day basis, and was fantastically supportive during my pregnancy, available for help and advice at all times... They are a great team and they treat me like a responsible adult, not a child.

Natasha, Age 36, Diagnosed Age 28



Tips

Whatever you do, when you're looking for your team, remember that you are entitled to the best. Don't settle for anything less. You need people and management strategies that work for you, and it's important that you're comfortable and confident in having them on your side. If you're not completely happy with the professionals you're with, hunt around until you find someone you like – there are a lot of health professionals out there, all with different personalities and approaches to diabetes management. Not all of them will be right for you. Some will be a great match – you just have to find them. It may take some time and a number of visits to several different people to find the team that works for you. But keep at it. The end result is definitely worth the effort.

Complications: a brief rundown

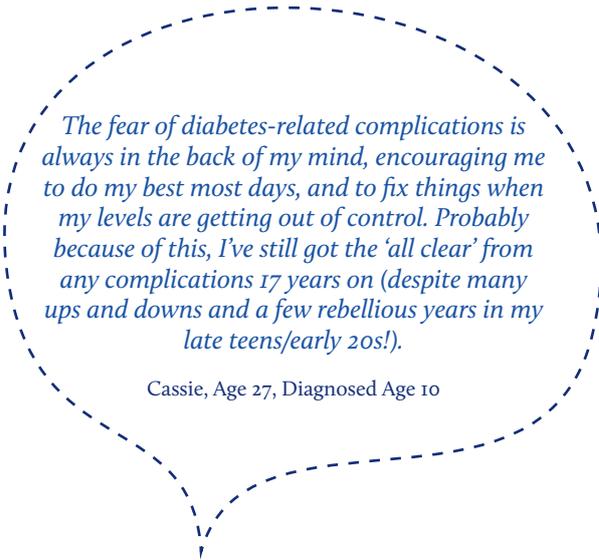
3.2

Complications. It is not a nice word, and they are not nice to think about. We know it might be a topic that makes you want to stick your fingers in your ears and go 'la la la', but we need to be honest and up front. Complications are a very real risk associated with type 1 diabetes and you'll probably hear it, a LOT, especially from people you've only just met. This is because there is significant evidence that both type 1 and type 2 diabetes can result in long-term complications. In particular, high blood glucose levels over a long period of time can damage the body's organs. It is NORMAL to feel anxious, nervous, worried, scared and fearful of complications.

It is important to think about complications in terms of risk. That is, there is a risk that having unstable blood glucose levels can lead to an undesirable outcome. You are not definitely going to face complications just because you have type 1 diabetes, but there is an increased risk due to the nature of the condition and the impact it can have on the body.

When I was first diagnosed, I wish I was told about potential complications. Being able to discuss this with an endo/educator would have been much better than hearing snippets of horrible sounding warnings from others (or TV, internet or whatever).

John, Age 31, Diagnosed Age 17



The fear of diabetes-related complications is always in the back of my mind, encouraging me to do my best most days, and to fix things when my levels are getting out of control. Probably because of this, I've still got the 'all clear' from any complications 17 years on (despite many ups and downs and a few rebellious years in my late teens/early 20s!).

Cassie, Age 27, Diagnosed Age 10

Why is your HbA1c important?

An HbA1c result correlates to an approximate average of your blood glucose levels over the past 10–12 weeks. Throughout the Starter Kit, we highlight that your HbA1c result is not an absolute measure of how you are managing your new diagnosis with diabetes. However, HbA1c IS a proven measure to assess the potential risk of complications, which is why it is monitored so closely. In regards to complications, HbA1c is your best available guide to what changes might be required in your diabetes management or lifestyle to reduce your risk of complications.

This section briefly covers the common complications those of us with type 1 can face. It is vital that you know about these complications and have an open conversation with your GP and other specialists about them. That said, with good management and regular checks there is no reason why you can't avoid these complications or have them addressed very early. Many people have lived with type 1 for 30, 40 or over 50 years without developing complications. Even if you do develop a complication, early detection and treatment is often effective.

The table on the following page covers some of the more common complications – it is not an exhaustive list and there are more rare complications, such as necrobiosis. You can find more information about complications on the T1DN website, www.t1dn.org.au.



Complications

Eyes (retinopathy)

Persistent high blood sugars can lead to damage of small blood vessels such as those in the retina at the back of your eye. This damage can cause problems with vision and lead to blindness if not managed. Damage to the back of your eye, or retina, can cause problems with vision and lead to blindness if not managed. If detected early, laser treatment can stop it progressing. To keep on top of this, get your eyes checked every 12 months at your local optometrist. Regular eye checks can usually be bulk-billed through Medicare at any optometrist who does eye testing for people with diabetes. Your endocrinologist may also refer you to an ophthalmologist.

Kidneys (nephropathy)

Prolonged high blood sugar levels, especially when coupled with high blood pressure, can lead to damage to the kidneys. Make sure your GP or endo does a microalbumin urine test at least once a year to check for the possibility of early kidney damage.

Nerve damage (neuropathy)

High blood sugar levels can lead to nerve damage throughout the body. Peripheral neuropathy is pain or loss of feeling in the hands and feet, and is a common complication of T1.

Cardiovascular disease

Damage to blood vessels to the heart and brain occurs more commonly in people with diabetes. This damage can be minimised by managing blood pressure, cholesterol and BGLs.

Feet (peripheral vascular disease)

Damage to blood vessels from high blood sugar levels can lead to restricted blood flow and delayed healing time. Blisters and sores, if not properly cared for, can develop into ulcers and become infected.

Teeth and gum care

High blood sugar levels, as well as lollies and sweet drinks used to combat hypos, can cause tooth decay and gum infection. Regular visits to your dentist will help you stay on top of things and keep your pearly whites in good nick. We suggest you go for a check-up and clean every 6–12 months.

Gastroparesis

High blood sugars can damage nerves connected to the stomach, leading to delays in stomach emptying and problems with digesting food. Drugs are available to help treat this condition.

It's important that you know about these complications and how to avoid them. Through good management of your BGLs and regular check-ups you can stay fighting fit and get the most out of life. A complications screen once a year can be arranged through your endo or GP. Getting the all clear is very reassuring, but if complications do start to develop, they are better treated early.

A heads-up for those who are newly diagnosed – you are likely to have Sally Do-Good minding your business and telling you how to manage your BGLs or how her uncle's cousin's sister's dog-walker has diabetes and proceed to tell you horror stories. Be prepared for this, politely tell them you have your levels well managed thank you and change the topic. Thankfully, these stories are not nearly as common as they once were. Technology is improving, insulin pumps are more widely available and there's more information to enable people living with type 1 diabetes to make informed choices about their lifestyle and management efforts.

For more information or to hear how others just like you deal with these situations, head over to the Reality Check forum (www.realitycheck.org.au) or check out the article about complications on our website www.t1dn.org.au.

Being diagnosed

If you've just been diagnosed, chances are that the word 'diabetes' conjures up a million-bazillion different thoughts and feelings. Many may be barely recognisable, as you try to wade through the information overload you're probably experiencing. There's so much going on around you and in your own mind that it can be hard to make sense of things. No kidding, it's a lot to get your head around. Hopefully some of what we've got to say helps.

As much as it may not seem like something to celebrate, welcome to the club. As daunting as everything is right now, the good news is that you are definitely not alone. There are 130,000+ people in Australia living with type 1 diabetes right alongside you – and almost 2000 more will be diagnosed this year. Whatever stage you're at right now, chances are others out there are in pretty much the same spot.

Also know that, whatever you are thinking and feeling, it's normal to think and feel that way given what you are going through. People react to diagnosis in many different ways. Some common feelings and emotions include shock, denial, anger, fear, helplessness, worry and sadness.

It's also completely normal to feel exhausted and overwhelmed. All the extra stuff you have to do right now, plus all the confusing thoughts and feelings your brain has to process mean that your body and mind are working overtime. This will improve! As you adjust, build habits, get some stuff sorted out and make sense of it all... you'll relax a bit. In the meantime, the key is to:

- **Manage this extra stress as best you can (with any support you feel you need).** This might mean ensuring you have opportunities to talk to and hang out with friends and forget about everything else for a while, have a massage or kick the footy. Basically do whatever gives you a physical and mental break from diabetes for a while. Not at the expense of doing what you need to do to manage your diabetes of course, but you will need some down time and a chance to unwind a bit.
- **Talk about what you're thinking or feeling (or write it down).** Getting it out of your head and into the open (even on paper) can help you process it. Talking to someone (whether a friend, relative or a professional) can be particularly helpful as you get the additional benefit of hearing their perspectives and feeling their support.
- **Be patient with yourself.** You're not superwoman/man and it's tough for everyone after diagnosis. Don't put any pressure on yourself to have everything sorted immediately, or expect yourself to feel any differently than you do.
- **Be persistent.** Just focus on one step at a time and keep wading progressively through all the stuff you're sorting out. Before you know it, you'll feel like you've made it through to 'the other side'.

When I was first diagnosed I felt like I had no future. I stopped dreaming of all the awesome things that I would be able to achieve and found it hard to get past all the 'might-happens' of diabetes. I know now that it is so important to look forward to things and maybe even to do them just to spite D!

Ashleigh, Age 22, Diagnosed Age 22

For some people, the expected stress and emotions associated with diagnosis take on a life of their own. All the stuff we've just mentioned is common after diagnosis and does make you more vulnerable to depression and anxiety. If you are prone to these issues or feel you are struggling mentally or emotionally, seek some help sooner rather than later. Very effective treatments are now available for depression and anxiety, and the sooner you commence treatment the quicker you'll feel better.

How can I tell if I'm depressed or anxious?

Feeling down is a very common human experience. We all feel low from time to time. It is okay to feel down when life throws challenges your way. However, there is a point at which low mood becomes a problem.

In everyday language, the word 'depression' is used to refer to feeling down, low, sad or disappointed. But 'major depression' (or clinical depression) is different from this day-to-day feeling down. When you have major depression, you feel down most of the time (for at least two weeks), and you lose interest in activities you used to enjoy. Other common symptoms include:

- change in appetite or weight;
- change in sleep patterns;
- loss of sexual interest;
- loss of motivation and enthusiasm;
- feeling restless, agitated, irritable or sensitive;
- feeling slowed down, sluggish or more tired than usual;
- feeling worthless or guilty, and low in self-confidence;
- having negative thoughts about yourself or your situation;
- having difficulty concentrating and making decisions;
- having thoughts of death or suicide.

Depression is very common and very treatable. If you feel you might be depressed, don't leave it too long before seeking support. The sooner you seek help, the quicker you'll feel better and more able to manage the other stuff in your life. The best place to go for help is your GP. Get onto it straight away if you suspect you need it.

Feeling anxious or panicky is also a very common human experience. We all get anxious from time to time, in fact some anxiety is essential for life. Anxiety is part of our body's alarm system, and it prepares us to either fight a threat or run away from it (flight).

Each of us experience slightly different symptoms when we are scared, and the situations that trigger our fears are also unique. When you experience fear or panic, you might notice the following symptoms: heart racing, shortness of breath, worrying, sweating, muscle tension, trembling or shaking, choking sensations, chest pain, dizziness or light-headedness, nausea or stomach pain, tingling or numbness, hot flushes or chills, blushing, dry throat and mouth and difficulty concentrating and making decisions.

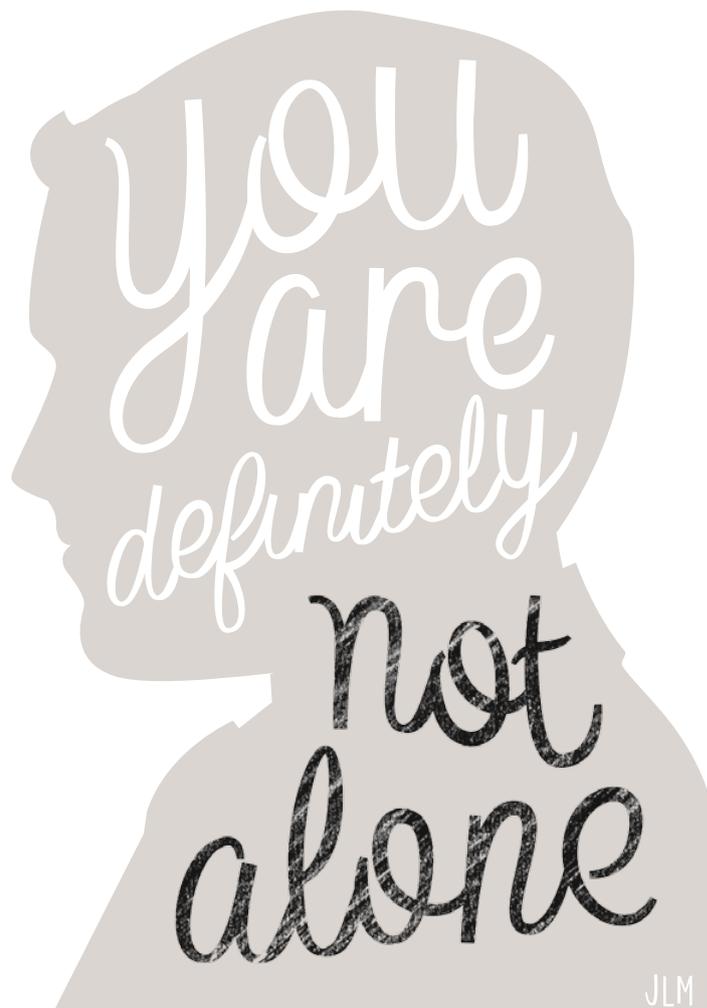
It is perfectly normal to feel anxious when life throws challenges your way. However, there is a point at which anxiety and panic become problems.

The good news is that anxiety is very manageable, once you know how; so if you feel like anxiety or panic are causing problems for you, seek help! Seeking help will support you to control anxiety and free vital brain space to manage diabetes and other issues that life throws up. The best place to go for help is your GP, as GPs are now trained to identify and assess anxiety issues. We recommend that you book a double/longer appointment so you can explain what is going on and don't feel rushed.

Beyond Blue has developed a fact sheet called 'Depression and anxiety disorders in people with diabetes' that can be found on their website (see websites list, right).

I do find the incessant nature of the self-care very tiring at times. I think it's quite common for people to say that they just wish they could have a day off from it. There are no days off from it (or even half-days). That can be exhausting, mentally and physically.

Natasha, Age 36, Diagnosed Age 28



How can I get urgent help?

If you or someone you know is at risk of harming themselves or someone else, it is important you get help immediately. You can take the first step by:

- speaking to your doctor (GP or psychiatrist) who can explain your treatment options and (if you wish) refer you to a mental health provider for support; Medicare rebates are now available for mental healthcare;
- calling the psychiatric team at your nearest hospital;
- calling Lifeline on 13 11 14 or the Suicide Helpline (Victoria only) on 1300 651 251;
- calling the police on 000 (triple zero) if the person is threatening to harm you.

Burnout

Once you've lived with type 1 for a while, you might also need to keep an eye out for a quite common situation called diabetes burnout. Clinical psychologist Dr William Polonsky has written a book about it, and his research found that people may experience physical fatigue, low motivation, irritability, lack of interest and low mood. In some people, it looks a lot like depression, but 44% of people in the study did not experience low mood, so it is actually a different phenomenon.

If you're experiencing burnout, you might be feeling that managing your diabetes is too frustrating or annoying – it's just all too hard! You might feel mentally exhausted by having to manage the condition, or perhaps you're just tempted to completely ignore it for a while.

Burnout can be managed in a similar way to stress: with some rest and relaxation. Be kind to yourself! We also recommend talking to or venting with other type 1s, as burnout is something that many of us go through from time to time.



Resources

A variety of resources (books, websites, forums, support services) are out there with tips on how to process the head stuff associated with diabetes. You can do your own research in time, but for now, we've listed some helpful resources below.

Websites

Diabetes Counselling Online is an online counselling service for all Australians living with any type of diabetes. The website has a lot of great information and resources about living and dealing with diabetes. Founder Helen Edwards is a qualified diabetes educator.

www.diabetescounselling.com.au

Beyondblue is a national depression and anxiety initiative. Their website has heaps of information, resources and links about depression generally, but also some specific information related to diabetes. They also have a phone help line: 1300 22 4636.

www.beyondblue.org.au

The Australian Psychological Society represents psychologists in Australia. They have a 'find a psychologist' service that you can access online or by phone: 1800 333 497.

www.psychology.org.au

The Behavioral Diabetes Institute is run by Dr William Polonsky and offers evidence-based clinical programs to help people deal with diabetes.

behavioraldiabetesinstitute.org

Online networks, forums and support groups

Type 1 Diabetes Network forums:

Reality Check is an active forum for people with type 1 diabetes. A place to bitch, moan, argue or rejoice (yes, really) about having diabetes. Full of helpful people living with T1, and more stories, topics, info and support than you could poke a stick at.

www.realitycheck.org.au

Munted Pancreas is a place for parents and associates to discuss, learn, share and laugh about caring for children with diabetes.

www.muntedpancreas.com

Books

Eldelwich, J. & Brodsky, E. 1998. **Caring for your emotions as well as your health**. Perseus Books, Massachusetts.

Libberte, R. 2006. **Taking charge of diabetes: A practical guide to managing your health and wellbeing**. Reader's Digest (Australia) Pty Ltd, Australia.

Polonsky, W. 1999. **Diabetes burnout**. American Diabetes Association, USA.

Rubin, R. 1999. **Psyching out diabetes – A positive approach to your negative emotions**. Lowell House, Los Angeles.

Rural issues

3.4

Living in regional and rural parts of the country can put an added burden on managing diabetes. There is no getting around this, but with a bit of extra planning you can make sure that you always have what you need to keep yourself well managed. Here are some tips that may help:

- Check and see if your local chemist is an NDSS subagent – this is where you get your supplies. If so, make sure they stock the supplies you need. If they aren't a subagent, have a chat to them and see if they are willing to become one. Sometimes chemists carry a stock of supplies, but if they are not with the NDSS you will pay a fortune for them!
- Find out if you can order larger quantities of supplies from NDSS. Try ordering NDSS supplies through your state branch of Diabetes Australia – you can do this online, and they do free shipping. Often rural chemists aren't as well stocked, especially for pumps.
- Check that your GP and local hospital are aware of good diabetes management and make sure they know how to manage your BGLs in an emergency. A lot of specialists and diabetes educators are happy to be on call and can give instructions over the phone.
- Use check-up visits as an excuse to get to the city. Make sure you do something fun while there so it's not all about the diabetes. Talk to your GP about travel allowance.
- Try to book the specialists you need in the city for the same day. A lot of clinics will try to get you seen quickly if you explain you need to travel home and can't be delayed – this isn't always possible though, so make sure you have travel plans to account for these delays – especially if you've got a train or bus to catch!
- Excessive hot and cold temperatures can affect insulin or stop your meter from working properly. Some products on the market can help with this but otherwise keep supplies in the fridge or esky (not directly on the ice) when it's scorchingly hot; in cold conditions, keep your tester close to your body to warm it up. Never leave insulin inside a hot vehicle.
- People with type 1 can feel overwhelmed and isolated at times – especially in regional or rural areas. If you feel like making some connections with other type 1s, the web is a great place, for example the Reality Check forum (www.realitycheck.org.au) or you could catch-up with others when you visit larger towns/cities or volunteer at type 1 kids' camps.
- Some specialists can do Skype consultations, and there's a possibility this will increase with the introduction of the National Broadband Network. Ask your local hospital or community health centre if this is possible.

Hormones and diabetes

Diabetes is a disorder of the endocrine (hormonal) system, so it's probably not surprising to discover that various hormones have an effect or two on blood glucose levels. If you're a female of the species, you're probably already aware that hormones generally have a pretty big effect on our lives. From menstrual cycles to pregnancy and contraception, women's bodies (and emotions) are constantly affected by the range of hormones rushing around doing those things that girly hormones do. Unfortunately, girl hormones can also affect the way people react to insulin. So, you can expect some changes in BGLs around the times when your hormones are fluctuating.

Unless the specialist who diagnosed you was very cool (and probably female), it's unlikely the effects of hormones on your blood glucose levels and management of diabetes were even mentioned. Luckily, male endos have been trained in these things too, so while they don't 'know it' like you do, they should at least understand it and be able to help you understand and adjust!

Here we outline some of the more hormonal points of women's lives and how you can expect your blood glucose levels and diabetes management to be affected.

One of the only pros for me with T1 is that I get heaps of hypos right before my period is due – my diabetes lets me know I'm not pregnant every month. So I know as long as I have hypos it's all good (which in fact is bad, because who wants hypos?).

Ashleigh, Age 22, Diagnosed Age 22

That time of the month

Just as every woman's period is different, the way it affects blood glucose levels is different too. Some women hardly notice any difference in BGLs over the course of their cycle, others routinely deal with more dramatic highs and lows. Generally speaking though, changes are most common right before, and at the start of, each period.

Before your period starts, it is common for food cravings and premenstrual symptoms (PMS) to be triggered by an increase in the hormone progesterone. PMS is often worsened by poor blood glucose management, so try to keep your levels in check and (if possible) try to carb count what you do eat and manage accordingly.

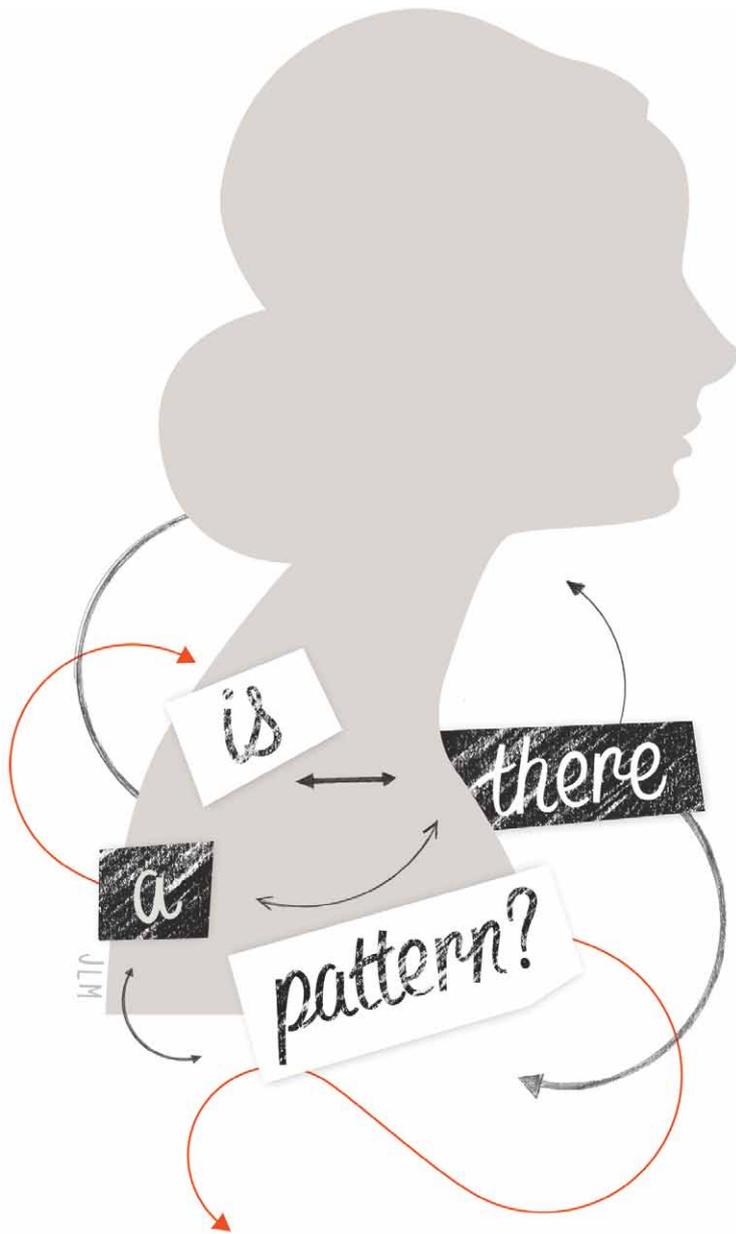
Closer to the onset of your period, it's the hormone oestrogen that affects your blood glucose levels. Generally speaking, oestrogen reduces the body's sensitivity to insulin, so higher oestrogen levels cause higher insulin resistance, which results in higher BGLs. Because of this, it is quite common to require more insulin for three to five days before your period starts (as oestrogen production increases), and lower once you start to bleed (when oestrogen levels drop). Sometimes the drop in oestrogen can be quite dramatic once you start to bleed, so be very careful to look out for more severe hypos on the first day or so of your period.

My control is ALWAYS better when I'm on my period. I guess loss of blood can be a useful thing sometimes, especially if the blood is sugary.

Becky, Age 31, Diagnosed Age 10

What can you do?

Everybody is different, but most women find that their own pattern of BGLs is similar from one month to the next. If you have erratic BGL changes in response to your hormones, you'll need to identify your body's unique pattern of changes and go from there. Try keeping a record of your blood glucose levels and premenstrual symptoms for the duration of your period and at least a week either side for a few months. Once you've established a pattern, have a chat with your endo or educator about adjusting your insulin doses around this monthly pattern. If your changes are quite dramatic, some forms of hormonal contraception (e.g. the pill) can be useful in smoothing out the hormones (and thus blood glucose levels) over the month – again keep a record and chat to your endo/educator/GP.



What about contraception?

Contraception is important for women with diabetes because of the risks to mother and baby in an unplanned pregnancy. Unfortunately, no single form of contraception is perfect for everybody – and having diabetes makes no difference to this. The same risks and conditions of contraception apply to every woman. There are, however, some extra considerations to keep in mind as a woman with diabetes. Some forms of contraception are better at smoothing out the effects of hormonal changes on blood glucose levels than others; some have been linked to increased insulin resistance (which will likely make your BGLs higher); and some are known to carry a higher risk of things those with long-term diabetes need to watch out for (such as increased risk of clots and high blood pressure). If you find your blood sugars reacting erratically to your menstrual cycle or current form of contraception, chat to your endocrinologist or a gynaecologist specialising in managing women with diabetes.

I found that the pill helped to minimise my hormonal blood sugar spikes and lows.

Kait, Age 23, Diagnosed Age 8

...and babies?

Women with diabetes usually have healthy babies – and this can be made even more likely – it just takes a lot of planning and dedication to tight management of blood glucose levels.

Pregnancy for women with diabetes is considered high risk, both for mother and bub. For this reason, it is highly recommended that pregnancies are planned, and that general health and blood glucose levels be very well managed prior to conception and throughout pregnancy. There are specific diabetes-related targets, checks and medications that should be addressed at each stage from pre-conception to the birth. If you are thinking about having a baby, chat to a specialist (ideally your endocrinologist or diabetes educator) before you start trying to conceive. They can give you tips and pointers – and get you started with the diabetes-related checks and goals you need to set and maintain.

Specialist diabetes and pregnancy clinics exist at all major women's hospitals in Australia. You can attend these clinics in both pre-pregnancy and pregnancy stages. Here you can see both diabetes specialists and obstetricians who specialise in working with mothers with diabetes.

What you need to do

Make an appointment for pre-pregnancy planning with your endo or closest maternity hospital six months before you plan to become pregnant.

For more information about diabetes and pregnancy check out the following resources:

- **Can I have a healthy baby?** This free booklet contains a lot of the information you need to know about pregnancy and diabetes as well as pregnancy stories from many women with diabetes. You can download the booklet from www.t1dn.org.au.
- **Having a healthy baby.** This DVD contains two short films about diabetes and pregnancy. Hear from women with type 1 and type 2 diabetes who are planning a pregnancy, already pregnant or already had a baby. It also includes health professionals providing clinical advice. Call Diabetes Australia on 1300 136 588 for your free copy.

Pregnancy was REALLY hard work. I had a lot of trouble controlling my BGLs, even though I was keeping very detailed records, testing every hour and weighing most of my food. My A1c was generally really good (under 6) and my fructosamine was lower than a person without diabetes, but I still experienced pretty big fluctuations between BGL readings most days. It was very stressful not being able to keep tight control over every reading, despite my best efforts, and I did worry a lot about it affecting my baby. She was born very big (5 kgs!) but other than that, we were both fine.

Natasha, Age 36, Diagnosed Age 28

Section 4

work, life and play



4.1

Exercise and T1

Can I exercise?

Yes! You can run, skip, jump, leap, throw, sprint, jog, swim, float and even skydive with type 1 diabetes. If you come across any dodgy old material that says you can't play sport with diabetes – throw it out immediately! There are people with type 1 who have competed in the Olympics, played elite sport, climbed mountains, run marathons or participated in community sport regularly.

People often ask if living with type 1 diabetes presents issues or barriers when it comes to exercise. Although you will come across the occasional activity that is much more challenging with diabetes (e.g. scuba diving), we are happy to tell you that type 1 diabetes is certainly not a barrier to most types of exercises and activities. However, you do need to plan ahead and vary your insulin and diet accordingly.

It's important to bear in mind that it may take you a long time to work out the correct strategy to prevent lows or highs during and after some activities. It's crucial to use your best judgement based on experiences and discussions with your diabetes healthcare team.

Safety first

It is recommended that you wear a medical alert bracelet (or similar) that states "I have type 1 diabetes". Of course, we hope that this bracelet never needs to be used, but it is useful to have just in case of emergency (see page 07).

Be prepared

As described in other sections of this kit, living with type 1 means you need to carry a range of supplies most of the time or at least have them handy for quick access. This is particularly important during exercise, because physical exertion can cause your blood glucose to fluctuate. This shouldn't stop you from exercising, but it's always important to have a meter and hypo gear handy!

It may be hard to believe, but thanks to smart phones, mp3 players and other gadgetry, there are a range of pretty cool exercise belts available that will keep your supplies safe. These are very handy for a packet of jelly babies or glucose tablets, a mobile phone, an insulin pump/pen and a blood glucose meter. Lots of accessories are available online but one we recommend that's available in Australia is SPIbelt who make a specific belt for this purpose.

Generally, whenever I exercise, it's swimming or riding my bike. I ALWAYS make sure to test my blood sugar immediately before I start, and if need be correct with insulin. I am never without glucose tablets in my pocket or purse in case of an emergency low.

Becky, Age 31, Diagnosed Age 10



Blood glucose monitoring

Different forms of exercise will probably affect you differently – low to moderate intensity exercise generally causes a drop in blood glucose levels, but vigorous exercise might in fact increase BGLs due to the release of hormones.

As a general rule, always check directly before and after exercise, and probably again an hour after finishing; however, hypos can occur six to eight hours after vigorous exercise. When you start a new type of exercise, it is important to check overnight that your BGL is not dropping too low. Some people like to check during exercise for peace of mind, but this is an individual preference. When in doubt about the effects of any form of exercise on your blood glucose, we suggest doing extra monitoring.

Disclosure

There is no legal requirement for you to disclose your type 1 diabetes before participating in any form of exercise; however, some sporting clubs, leisure facilities or competitions now ask if you have any medical conditions that need to be noted. We recommend disclosing your type 1 diabetes, unless you feel uncomfortable doing so. It's useful for your type 1 to be on record in case you do have a nasty hypo sneak up on you when you're in the middle of a mixed netball game or running at full speed on a treadmill.

If you are competing in a sport that carries out Australian Sports Anti-Doping Authority (ASADA) testing, you need to lodge a Therapeutic Use Exemption form that declares that your insulin is to manage your diabetes.

Don't just think of sport!

As Reality Checkers attest, sport isn't the only activity where you need to be especially aware of your blood sugar readings. Activities like vacuuming, cleaning the bathroom, getting intimate, dancing, gardening, shopping, moving house or walking the dog are actually exercise, and you may need to adjust your food intake or insulin dosage accordingly.

Shoes

Foot health is really important for people with type 1 diabetes (see page 23), and you need to have regular foot checks with your GP or endocrinologist. It is important for people with type 1 to see a podiatrist if there are risk features, which include neuropathy, foot deformities, vascular disease or previous ulcers. Almost all people with type 1 can safely purchase any well-fitting pair of shoes without any great concern. In terms of exercise, we recommend that you wear comfortable and well-fitting sports shoes.



The final score

Exercising with type 1 diabetes requires a level of planning and knowledge about how exercise influences your body. There is no doubt that an unexplained high after exercise or a tricky low just as you put on your gym gear can be really frustrating, but people with diabetes can achieve amazing things.

Through good management and assistance from your healthcare team, you can do whatever exercise you want. Don't let type 1 diabetes stop you from participating in life, because exercise is not only good for your physical health, but it's also tremendous for your mental health and wellbeing. Regular physical activity can also improve blood glucose management by increasing your body's sensitivity to insulin.

You may feel like a juggler from time to time, carrying your hypo gear, blood meter, cash, keys, insulin and so forth, but this eventually becomes the norm.

Go out, be prepared and get active!

Exercise is the single biggest factor affecting my levels – beware of hypos several hours later (potentially while you're asleep if you run at night, for instance), and eat low GI after you exercise.

John, Age 31, Diagnosed Age 17

Where can I find out more?

If you want to learn more about exercise and type 1 diabetes, the following resources are a good start:

- HypoActive (www.hypoactive.org) provides information, ongoing support and inspiration to participate in exercise challenges while learning from others with diabetes. The group is based in Melbourne with key links throughout Australia and New Zealand.
- The Australian Sports Commission (www.ausport.gov.au; search for 'diabetes and sports nutrition') has a page dedicated to diabetes and sports nutrition written by the Australian Institute of Sport in 2009.
- *Diabetic athlete's handbook: Your guide to peak performance* by Dr Sheri Colberg-Ochs, an Associate Professor of Exercise Science at Old Dominion University and a type 1 diabetes athlete herself, provides some useful information for managing diabetes around whichever exercise you may wish to do or continue doing.
- *Your diabetes science experiment* by Ginger Vieira, a record-setting competitive powerlifter with type 1 diabetes. This is a book for people with type 1 who want to gain a deeper understanding of how the basic science of the human body impacts their blood sugar levels and insulin needs.
- exT1D (www.ext1d.com.au) is a website developed by Allan Bolton, an exercise physiologist living with type 1 diabetes who seeks to inspire and help every person with type 1 confidently participate in regular physical activity, exercise and sport.
- *Diabetes monitor: 10 ways to get type 1 diabetes, exercise and you on the same page* by Scott K. Johnson (www.diabetesmonitor.com/healthy-living/exercise/10-type-1-diabetes-exercise-tips.htm) is a good introductory article for tips on how to successfully combine type 1 and exercise.

As a dietitian, I'm passionate about including exercise into my daily routine to ensure I stay healthy and don't develop 'double diabetes' as there is type 2 in my family too. To manage it depends on the type I'm doing. For my 40 minute walk/skip/lunge routine I just allow an extra 15 g carb without insulin, but when I play golf or exercise for longer than an hour I reduce my basal rate 2 hrs beforehand. Exercise is again about watching your own patterns/trial and error.

Sally, Age 47, Diagnosed Age 12

Most people with type 1 diabetes continue to drive with no problems, and some even hold a commercial driver's licence. We've already covered the need to arrange a conditional driver's licence in the first month after your diagnosis (see page 06). However, you need to be mindful of a few things when driving with diabetes, and there are some common sense precautions you can take to keep yourself and others safe.

Hypos affect both your thinking and your coordination, which makes it dangerous to be in control of a vehicle. Some simple things you should do to minimise the risk of going hypo while driving are:

- Always check your blood sugar before driving and don't drive if your blood glucose is below 5.
- Always carry hypo supplies in your car. Glucose tablets or gels work well as they last and won't be eaten by your passengers! But use what works for you. Check out the hypo pack section on page 16 for some other ideas.
- If you feel yourself going low, pull over as soon as you can, turn off your engine, check your blood sugar and manage your hypo if necessary. Don't start driving again until your blood sugar level is above 5.

A severe hypo is defined as a hypo where you were unconscious and/or needed assistance from someone else. These are rare for most people, but if you have a severe hypoglycaemic event, you won't be allowed to drive for a significant period of time. The minimum period of time before returning to drive is generally six weeks, because it often takes many weeks for patterns of glucose control and behaviour to be re-established and for any temporary lack of hypoglycaemia awareness to resolve. The non-driving period depends on factors such as the reason for the episode, specialist opinion and the type of motor vehicle licence. Discuss with your health professional when it's safe for you to start driving again. Although this may be very inconvenient, it'll be a lot less problematic than having an accident!

Hypo unawareness occurs when you don't feel any physical symptoms until a hypo is severe. This is very dangerous for driving, as you may go from feeling fine to semi-conscious very quickly. Scary, but also rare and it can be reversed! If you think you might have hypo unawareness, talk to your health professional about options, which may include running your blood sugars a little higher until your hypo awareness comes back.

Hyperglycaemia (high sugars) can make you feel pretty icky, but at present there is no good evidence that they affect your ability to drive. Use common sense – you wouldn't drive drunk, so don't drive if you feel like you can't concentrate.

For more information about driving with diabetes, check out the 'Above 5 to Drive' booklet available from the Australian Diabetes Educators' Association website, www.adea.com.au.

Diabetes absolutely does not need to kill the travel bug! Many people with diabetes travel far and wide, in style and on a shoestring, in a hurry for constant business trips and on long extended holidays around the world!

There are some extra things you'll need to do; however, these are mainly to keep the security guys off your back for carrying 'sharp objects' and to make sure you always have insulin by your side as you travel.

Before you go

- **Get a letter from your doctor.** Ask your doctor to write a letter stating your full name, address and date of birth, that you have type 1 diabetes and then listing the medications, insulin delivery devices (syringes, insulin pens or pumps) and blood glucose checking equipment you use, and that you must be allowed to carry these with you at all times. Make several copies of this letter; carry copies with your diabetes supplies and your valuables, and also scan and keep an electronic copy.
- **Check customs regulations.** Some countries have particular rules about how much insulin you can carry and what documentation they'll want to see. For example, in Japan you'll need to apply for special paperwork in advance if you are taking more than one month's supply. Look up the rules in advance so you aren't caught out.
- **Check your supplies.** Make sure you've got enough for the trip; if not stock up in plenty of time.
- **Think about food.** Stock up on hypo supplies and emergency snacks. There's no need to request 'diabetic' meals on planes though, as these can be a little unpredictable. Some people even report that their diabetic airplane meals have included not a scrap of carbohydrate. On a related note, for long-haul flights you can generally find out from the airline which meals will be served – but not exactly what the meals contain – which may be helpful in planning long trips. Packing some extra snacks is always a good idea.

Always always always carry your insulin with you, not in checked luggage. In a plane it can freeze, on the roof of a bus it can get too hot, and you can't easily replace it if you lose it or ruin it. Otherwise, carry jelly beans and do anything you like.

John, Age 31, Diagnosed Age 17



During your trip

If questioned at customs or security about syringes or other diabetes equipment that you are carrying, stay calm and simply state that you have type 1 diabetes and explain what the devices are. Show the person the letter from your doctor. The Federal Aviation Authority trains all security staff in what people with diabetes must be allowed to carry. There is no need to 'declare' your supplies on domestic or international flights as they are entirely permitted.

Take a spare prescription. Always take prescriptions for all medications you need and are carrying with you. This will both assist you to get more supplies if needed and reassure security officers that the medications are your own.

Get travel insurance!

It may seem like just another wad of dollars that your travel agent is trying to extract but if only for you and your family's peace of mind, it could be the best investment you ever make. There will most likely be an excess for your 'pre-existing condition' – \$100 extra is common. While you're at it, register your travel plans with www.smarttraveller.gov.au.

[I have done] heaps of travelling with type 1 both in Australia and overseas. Since having type 1, I have been on several 7-10 day treks in Australia and overseas, cycled 900 km around China and competed as a powerlifter. Having diabetes spurs me on to do these things – I want to prove to myself that I can do the same things as anyone else. [The] main things that work for me are: moving my watch/pump to the new time zone as soon as I'm on the plane; taking heaps of supplies – strips, spare meter, hypo stuff, pump consumables, batteries; be prepared; make sure people I'm travelling with know about my diabetes; be careful, but still adventurous with what I eat to avoid food poisoning.

Susan, Age 37, Diagnosed Age 16

Work and study considerations

4.4

Carry all the diabetes supplies you will need in your hand luggage. It can be difficult, though not impossible, to obtain all your diabetes supplies away from home if they are lost. Best to keep them close to hand so you don't have to waste precious time traipsing around an unknown city. It never hurts to have spares in your checked in luggage in case of mishaps.

It is possible to replace lost supplies. If you do find yourself in this predicament, start with a major hospital's emergency room. They should be able to supply enough to get you through. Alternatively, phone the diabetes organisation where you are and ask someone to explain how you obtain diabetes supplies in their state/country. If heading overseas, you can find contact details for the local organisation in advance by visiting the International Diabetes Federation's website www.idf.org.

Wear ID. Make sure you have some form of identification that says you have diabetes, such as a MedicAlert bracelet, especially if travelling alone.

Watch out for hypos. Always carry hypo supplies, especially on long flights, and don't be afraid to ask the flight attendant for a lemonade or extra food if you need it to manage a hypo. There are hundreds more tips and tricks that you can learn from others with diabetes who have travelled extensively. The T1DN website (www.t1dn.org.au) contains some stories of people's travels or you can visit the Reality Check forum to ask more specific questions relating to your travel plans.

I have travelled extensively [as a type 1 diabetic] and highly recommend it to everyone! For your diabetes, it's just about being prepared and always taking 3 times more food/hypo treatments than you think you'll need as well as insulin/spare pump/spare everything and carrying a letter from your doctor explaining about the nature of your medical condition.

Sally, Age 47, Diagnosed Age 12

Work

As long as you keep your diabetes reasonably well managed you can do most jobs without too much hassle – although some are restricted including commercial pilots or army positions in deployment. Some jobs may require medical evidence to prove that you can do the job safely, such as commercial truck driving. However, like all aspects of diabetes, work can mess with your routines, so it's important to let your employer know you have diabetes. It's not compulsory, but it is generally a good idea.

Letting your supervisor and a few colleagues know that you have diabetes means that they should be more understanding if you need to take a few extra breaks, and you can let them know what to do in an emergency. Having to explain why you need them to run and get that can of soft drink as you're going off into hypo-land is never fun.

If you feel your employer discriminates against you or treats you unfairly because of diabetes, the Australian Human Rights Commission can investigate and resolve complaints of discrimination.

Always keep a stash of food and supplies in your drawer or work fridge (clearly labelled – again talk to your supervisor about this) and something in your bag to make sure you are prepared.

Be prepared. I store extra insulin and a hypo-kit in the fridge at work along with a few stashes of lollies. I have been caught out and it's the worst having to try and explain what's happening when you are low.

Jackie, Age 41, Diagnosed Age 35

Study

The same thing goes for study as for work – it is generally better to let your teacher/lecturer know so that they can be supportive.

If you are studying at uni or TAFE, consider registering with the disability services office. You can possibly arrange for extra consideration for exams to allow more frequent breaks, extra time if you have a hypo and not require a medical certificate if you need an extra day for your assignments due to issues with your diabetes. Stress affects diabetes – your medical team will tell you that – so it's important to know you can get the support you need without feeling like you're using diabetes as a crutch.

I like to use the weeks leading up to exams to make sure my control is as tight as can be on the day.

Kait, Age 23, Diagnosed Age 8

Sick days

A common cold or more serious bug can play havoc with blood sugar levels. The most important thing to remember when unwell is to always take your insulin. While sick, you may need to change your insulin doses. Contact your diabetes healthcare team for help with this. In this age of technology, these wonderful people quite often stay in regular contact via phone or text to make sure you're doing okay. This can be very reassuring and let you focus on getting better.

It may also be useful to tell your employer about your diabetes and that when you are sick, you may need to take time off work, because your blood glucose levels can be knocked around a fair bit.

Karen Hirth, senior pharmacist at The Alfred Hospital in Melbourne, provides the following advice for dealing with colds and flu:

- **Give in.** If you need extra insulin for the term of your bug invasion, it's not the end of the world, despite the fact you may be eating very little. Do lots of blood checks, and work with your diabetes team to increase insulin doses to keep your blood sugars managed.
- **Drink up!** Keep your body hydrated by drinking enough water to manage your thirst.
- **Eat.** I don't mean to sound like your mother, but if you want to get better faster, eat soups with lots of vegies, as well as fruits and custards, and throw in some protein too.
- **Try to avoid bombarding your body with massive doses of vitamin C.** If you're not used to it, massive doses can cause really bad diarrhoea. Lovely!
- **Pills and potions.** If it makes you feel better go for it, but remember almost all currently available agents treat the symptoms not the cause, i.e. you will not get better faster. Some medicines can add to high blood glucose levels. Ask your pharmacist to recommend a suitable cold and flu medication.
- **Check ketones.** Ketones are chemicals in the blood produced when an alternative source of energy to glucose is required because there is not enough insulin to use the glucose properly and fat is broken down. Combined with high blood glucose levels, this can be dangerous and lead to diabetic ketoacidosis. If you are ill and have blood sugars regularly above 15 for a period of time, check ketones either with urine test strips or a blood ketone meter. If ketones are present, you may need to call your doctor or diabetes educator.

[When sick] I'll often set timers or alarms to remind me to test when I'm too sleepy. I find hydralyte sachets make me feel better if I have mild ketones too.

Kait, Age 23, Diagnosed Age 8

Ketones

When you are ill, have an infection or your sugars have been high for a long period for any reason, you need to look out for a very dangerous condition: diabetic ketoacidosis (DKA). So what is it?

As described previously, ketones are produced when your body burns fat to get energy. This happens naturally, of course, if you exercise to lose weight. However, if it happens too much too fast, it is not natural and it's important to understand that 'normally' produced ketones are very different from ketones that develop due to insulin deficiency. Moderate or large amounts of ketones in your body are very dangerous. They upset the chemical balance of the blood and lead to a condition called diabetic ketoacidosis or DKA.

The symptoms of ketoacidosis include nausea, vomiting and abdominal pain. Some people also experience fast and heavy breathing and exaggerated beating of their heart. It is scary! If you experience DKA, you need to go to hospital to be rehydrated and monitored while the ketones in your body reduce to a safe level. Many people with type 1 diabetes have never had an episode of ketoacidosis, but you may have already experienced DKA during diagnosis. Unfortunately, DKA is life threatening, so you need to understand what it is and what to look out for.

[When sick] I often don't mind too much if I ride it a 'little high'. I would rather that than be on a low and feeling ill, not wanting to move, so I allow myself to be a bit high during these times until I am comfortable to get back in the proper range.

Fiona, Age 27, Diagnosed Age 14

What causes diabetes-related ketones and DKA?

DKA can be caused by:

- **Not getting enough insulin.** Maybe you forgot, made a mistake with your insulin doses, or your body is fighting an infection, flu or another illness, so needs more insulin than usual. If there is not enough insulin available, your body cannot access sugars in your blood, so it begins to break down fat for the energy it needs.
- **Not enough food.** When people are sick, they often don't feel like eating. Again your body needs energy and because there is no food for it to break down, it starts breaking down body fat. The same may happen if a person who is not ill simply does not eat, for example, they skip meals or have an eating disorder.
- **Changes during pregnancy.** Pregnant women with type 1 diabetes are at high risk of producing ketones. The rapid changes during pregnancy and changing insulin needs can mean that the body does not get enough insulin or food. As explained above, both of these scenarios can lead to ketones.

Ketones are not an infection, although an infection can give you ketones. Antibiotics do not fix ketones.

Ketones and DKA are not related to kidney function. The presence or absence of ketones in your urine or blood does not indicate anything about your kidney function. The two things are entirely different.

Do I have DKA?

DKA can be measured on a scale based on the level of ketones in your blood – low levels mean you will be relatively symptom free; however, moderate to high ketone levels upset the chemical balance of your blood and you will know about it! If you do have moderate or high ketones and you feel at all unwell, you may need to seek help (health team or hospital) immediately.



I have ketones. What do I do now?

Blood test: less than 0.6 mmol/L

Urine test: low or trace

This is the target, low level. No action is required.

Blood test: 0.6–1.5 mmol/L

Urine test: moderate

This indicates the beginning of a problem.

Your endocrinologist or diabetes educator will have provided you with instructions to follow if you are showing ketones – follow these now.

Their instructions may have included regular (half-hourly) monitoring of blood glucose, increasing or adding insulin doses carefully until your blood sugar levels drop. Also drink plenty of water to stay hydrated.

Blood test: more than 1.5 mmol/L

Urine test: high

You may be at risk of DKA.

Call your diabetes healthcare team immediately for advice.

If you cannot contact your diabetes healthcare team, call your nearest big public hospital and ask to speak to the endocrinologist, diabetes nurse or registrar on call.

If this fails, you need to go to the emergency unit of your nearest hospital.

More detailed guidelines can be found in the 'National evidence-based clinical care guidelines for type 1 diabetes in children, adolescents and adults' page 127, table 17.1. You can find the clinical care guidelines on the NHMRC website: www.nhmrc.gov.au/guidelines/publications/ext004.

Catch it early. Stay out of hospital.

You can test for ketones at home with a simple blood or urine test. Urine testing strips are available from your pharmacist or NDSS outlet, the same way as blood glucose monitoring strips. You pee on the strip, wait as indicated, and check the colour against a chart on the container. This is cheap and easy, and only shows the ketones that were in your body two to four hours earlier. The shelf-life of blood ketone strips is less than urine strips, and pharmacists are still more likely to have urine strips on hand than blood strips (but may not have either because of cost and the fact that usage is insufficiently high for them to carry stock).

The Abbott FreeStyle Optium glucose meter can also monitor ketones in the blood and is the only meter currently available in Australia with this functionality. You need different strips to your blood glucose monitoring ones, but otherwise, it is quite simple to use.

You could choose to test for ketones when ill, under stress or when your blood glucose levels are consistently high, i.e. above 15 mmol/L.

The basics

Okay, so we're pretty sure that you already know how to use the internet to find information. We're also pretty sure that jumping on the net for instant answers is one of the first things you'll do after diagnosis. The internet and social media is changing how we interact with one another. Social media has brought the diabetes online community – a group of people who participate in conversations about diabetes on the internet – together. Check out forums, Facebook pages, Twitter conversations, blogs and even YouTube vids to see people right around the world talking about their experience with type 1 diabetes.

There are a few things you should keep in mind when looking for more information on diabetes. A Google search for 'diabetes' returns close to 300,000,000 hits* and given the internet is a public forum where anybody can publish whatever claims or assertions they like, not every site you find in relation to diabetes will house accurate information. Without a doubt, a lot of sites in that search are full of incorrect information. The last thing you want to do when you're trying to get your head around your new condition is rush in and find yourself caught up in a tangled mess of misinformation, advertising and leads to false dieting or cure scams.

When you start researching everything related to diabetes and type 1, it's a good idea to remember the following points in the boxes to the right.

Social media is a brilliant way to feel supported and empowered with diabetes. There are many blogs around, tweetchats (#OzDOC Tuesday nights 8.30–9.30 pm and others around the world), Facebook pages... Encourage your healthcare team to participate too, so they have a greater understanding of what you live with 24/7.

Sally, Age 47, Diagnosed Age 12



Finding good information takes time

Wherever you look, make sure your source is reliable

Find out who owns or has written the information – sites produced by governments and health institutions or reviewed by editorial boards may be more reliable than those written by individuals. You can also look for sites that comply with the HONcode (www.hon.ch) for honest and trustworthy health information.

Look at a range of sources

Don't just look at one site or use one search engine. Check out a range of options to help identify what information is reliable and what is not – if the same thing is mentioned or backed by a variety of different, reliable sites, chances are it's genuinely valid.

Make sure the information you're looking at is up-to-date

Reliable sources should have a year of publication for any articles or information they post. Often the date is in small print at the bottom of the page or under the article heading – check this for each page to prevent getting sucked into outdated theories or advice.

Beware of bias/sneaky advertising

Some sites are hosted or sponsored by individuals or companies with specific agendas (e.g. pushing a particular product or program). Reliable information should be balanced and offer clear consideration of both pros and cons. Advertising should be clearly identified as such, and commercial sponsorships disclosed upfront. Government-sponsored websites are a good way to avoid bias and commercial advertising.

Watch out for scams

Be very wary of sites offering online consultations, prescriptions, programs or cures. Unfortunately, if a site is proposing a fantastic plan or product and it all sounds too good to be true, it probably is.

stay connected

READ UP

find others

KEEP
TALKING

Join in

Connecting with others

Since T1DN commenced developing this Starter Kit (version 1 was published in 2004), there have been significant changes in the way people communicate about their lives with diabetes due to social media, increased capabilities of mobile phones and increased use of the internet as a primary communication tool. This is generally referred to as the Diabetes Online Community or DOC and, in a way, we feel that we were quite early adopters in this space due to our two internet forums: Reality Check (www.realitycheck.org.au) and Munted Pancreas (muntedpancreas.com).

However, we recognise the internet is a big place, and we'd encourage you to search the length and breadth for information that will assist you in managing your diabetes. This could include the following:

- **Blogs:** the diabetes blogosphere has grown massively over recent years, and there are now many Australian diabetes bloggers in this space. Check these out for real-life stories of how people live with diabetes, and you will quickly find that you are not alone in your daily frustrations!
- **Facebook:** there are plenty of diabetes Facebook pages and groups out there, designed to both provide information and create discussion. Our page can be found at www.facebook.com/type1diabetesnetwork.
- **Twitter:** don't be scared of Twitter! It's a great opportunity to connect with and learn from people with type 1 diabetes right across the globe and a range of regular diabetes chats are held globally. Twitter is also where you can find the newest stories about diabetes or newest product news. Our Twitter account can be found at www.twitter.com/T1DN. Check out the #DBlog, #OzDOC and #DOC hashtags.
- **Webinars:** webinars provide a way for people to watch a presentation about diabetes from the comfort of their own homes. T1DN has recently started running webinars, with a range of interesting guests including dietitians and athletes. Keep an eye on our forums, Facebook or Twitter for details of upcoming events.

Basically, there are many options out there for getting information and networking around diabetes. Diabetes used to be primarily about the information you received from your health professionals and information brochures from medical companies. Now, there are forums, blogs, Twitter chats, Facebook pages, consumer-led websites and even consumer-led awareness campaigns all managed via the power of the internet and social media. It's worth exploring these options to see what is useful for you!

Being able to be in contact with other T1s through social media has saved my sanity (and probably my health!). Honestly, that connection with other people who actually REALLY KNOW about what you're going through 24/7 makes such a difference – and makes living with diabetes much less lonely!

Cassie, Age 27, Diagnosed at 10

Section 5

eating and drinking



Food: the carb connection

5.1

With all the hype about low carbohydrate diets over the past few years, you could easily mistakenly think that carbs are the enemy and something to be avoided at all costs. But if you have type 1 diabetes, carbs are really important – actually the most important part of your diet. You don't actually need to eat more or less carbs than normal, but you do need to balance your intake of carbs with the amount of insulin you take and the exercise you do.

Food is made up of protein, fat and carbohydrate along with vitamins, minerals, dietary fibre and water. All of these are important parts of a healthy diet, but it is carbs that impact most on blood glucose levels.

When you eat carbs, they break down into glucose, which is absorbed into your bloodstream. You then need insulin to transport the glucose from your bloodstream into your muscles and cells where it is used for energy. In someone without diabetes, the body always produces just the right amount of insulin to deal with the carbs they eat. But this doesn't happen when you have type 1 diabetes. Instead, you need to calculate the amount of insulin to take to match the amount of carbohydrate you eat. You need to do this to avoid your blood glucose levels going too high or too low.

Having diabetes doesn't really affect what I eat, although it probably stops the hardcore binges. Like, I would never have more than two Tim Tams because it's not worth the headache of highs/lows. It stops me eating obvious sugary foods like Coke, doughnuts, lollies so probably a good thing for overall health :)

Fiona, Age 27, Diagnosed Age 14

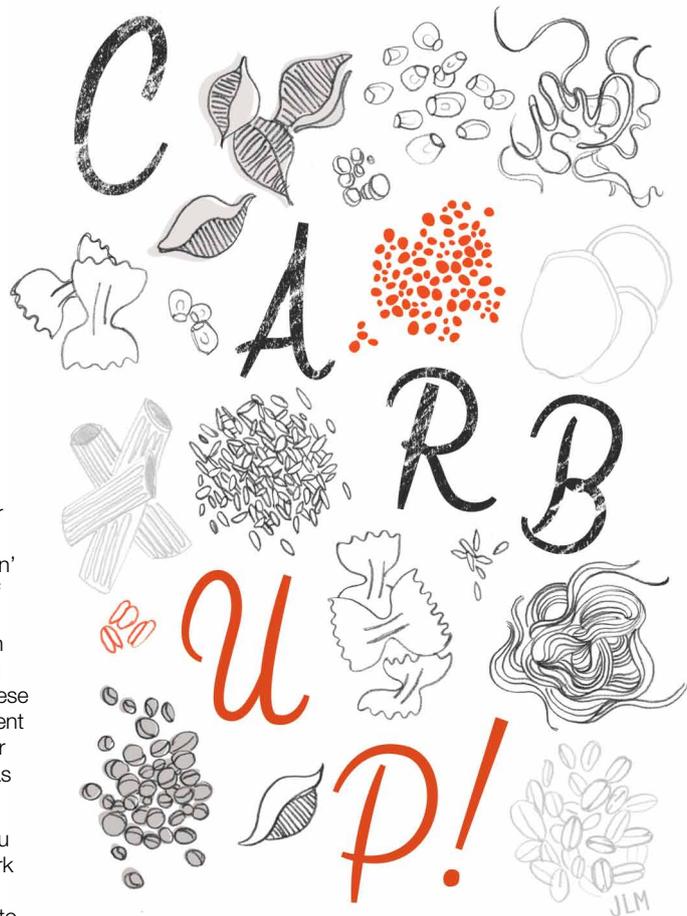
I have found a pump really helps [with managing food]. The main thing was learning how to carb count right from diagnosis. I used to carry a small carb counting book around with me but there are heaps of great apps now that help with this! At home, a pair of digital kitchen scales is essential for accurate carb counting!

Susan, Age 37, Diagnosed Age 16

Other factors, such as exercise and stress, can make this relationship a bit more confusing, but essentially insulin and carbs need to be matched. There are two ways of doing this:

1. eating a set amount of carbohydrate and taking a standard dose of insulin at each meal, or
2. applying the principles of flexible insulin therapy where you learn to adjust your insulin dose to what you eat.

Either way, you need to learn how much carbohydrate is in the food you eat.



Grams, exchanges or portions?

There are a few different ways to quantify the amount of carbohydrate you eat. You can count up the total number of grams of carbs, or count the number of 'portions' or 'exchanges' of carbs in your meals and snacks. A 'portion' or 'exchange' is the amount of food that contains 15 g of carbohydrate. For example, 1 average slice of bread, 1 medium apple and a 300 mL glass of full-fat milk all contain around 15 g of carbs, or 1 carb exchange. This means you should need the same amount of insulin if you ate any of these foods. Some specialists use 10g of carbohydrate to represent a portion or an exchange, rather than 15g. It doesn't matter which you use, as long as you are consistent and as long as your insulin doses are calculated accordingly!

A dietitian can help you work out the amounts of carbs you need to eat from day to day and meal to meal and will work with you and your endo to determine the right amount of insulin to take. They will also help you decide the best way to count your carbs, depending on your type of insulin delivery.

So which foods contain carbs?

Carbs are made up of starches and sugars. Starches include breads, cereals, grains, pasta, noodles, rice, legumes, and starchy vegetables such as potato, sweet potato and corn. Sugars include added sugar as well as the natural sugars in fruit and dairy products. Whether sugar or starch, all carbs break down to glucose and raise your blood glucose level.

Since being diagnosed with diabetes I eat more, but more healthy things. I never used to snack but now I make sure I have some fruit or a yoghurt 3 hours after meals, otherwise I will get a hypo.

Ashleigh, Age 22, Diagnosed Age 22

Find out more

The following websites are a good place to start for more information on eating with diabetes and the carbohydrate content of foods:

- The Traffic Light Guide to Food for Type 1 Diabetes, www.traffilightguide.com.au, includes a carb calculator, and is now also available as an app.
- Calorie King (www.calorieking.com.au) has the nutrition information (including carb content) for most Australian brand foods including restaurant and fast food meals.

Many thanks to Dr Kate Marsh, Advanced Accredited Practising Dietitian and Credentialed Diabetes Educator for preparing this information.

Quality or quantity?

When you have type 1 diabetes, the emphasis when it comes to carbs is on quantity as matching carbohydrate and insulin is the key to keeping blood glucose levels on track. But it is also important to consider the quality of carbs you are eating. To make sure you get all the nutrition your body needs, maintain good health and reduce the risk of other health problems (e.g. heart disease and cancer), choose mostly nutrient-dense unprocessed carbs such as wholegrains, vegetables, legumes and fruit.

Less healthy choices include foods such as biscuits, cakes, pastries, chips, soft drinks, lollies and highly processed grains (e.g. white bread and many puffed and flaked breakfast cereals). These are best kept as special occasion rather than everyday foods – this is the case for everyone, not just when you have diabetes! The other consideration when it comes to choosing carbs is the glycemic index – this is explained further in the next section. Choosing low GI foods can help to optimise blood glucose management.

An accredited practising dietitian (APD) can help you work out an eating plan to suit your needs, food preferences and lifestyle. They can also explain more about carbs and GI, and help you work out how different foods affect your blood glucose levels.

To find an APD who specialises in diabetes, contact your local diabetes centre, Diabetes Australia in your state, or DAA (Dietitians Association of Australia).

Learning to count carbs is fairly difficult. In the beginning, I did question most of my food decisions and whether I really needed the snack. Previously I didn't eat a lot of pasta or bread and to start with [after diagnosis] I overdid it with these thinking I needed carbs.

Maureen, Age 49, Diagnosed Age 48

The glycemic index may seem like another dietary fad (and there are plenty of them!), but a significant body of research now shows the benefits of low GI diets, particularly when it comes to managing diabetes. While it can't be used in isolation, GI is one tool that may help you to manage your blood glucose levels.

What exactly is it?

The glycemic index (or GI for short) is essentially a way of ranking carbohydrate foods according to the speed at which they cause your blood glucose levels to rise and fall. When we eat, carbs are broken down during digestion into glucose and provide the body with energy, but different carbs have different effects on our blood glucose levels. Some are quickly digested and absorbed (high GI), while others break down slowly, gradually releasing glucose into the bloodstream (low GI).

How can a low GI diet help?

While the amount of carbohydrate you eat is important in determining how much insulin you take, the GI of a food can also play a part. Because different carb foods are digested and absorbed at different rates, even if you have the same amount of carbs, the type of carbs you eat determines how quickly and how much your blood glucose level rises and falls after a meal. If you tend to get spikes in your BGLs soon after eating but they fall quickly over the next few hours, then switching to lower GI foods can help prevent these post-meal spikes and between-meal hypos. Studies in people with type 1 diabetes have shown that a low-GI diet can improve overall blood glucose management while reducing the risk of hypos.

Low-GI diets have been shown to have other benefits including helping with weight management and reducing the risk of many chronic conditions. Unlike many other fad diets, a low-GI diet also fits very well with the general healthy eating recommendations including eating more fibre, fruits, vegetables, and wholegrain breads and cereals.

Is it really low GI?

One problem with GI is that it isn't simple to measure – it is tested in real people and can't be determined by the composition of the food. This means that many foods haven't been tested, although the number is increasing all the time. When looking for low-GI foods, your best bet is to look out for the Glycemic Index Foundation's Low GI Certified symbol. As well as certifying that a food is low GI (as tested by approved methods), it must also be an overall healthy choice within its category, having to meet criteria for energy, total and saturated fat, sodium, and, where appropriate, fibre and calcium.

It's not just about GI

While low GI foods have benefits for blood glucose management, the GI shouldn't be used in isolation when making healthy food choices. You may notice that some low-GI foods are high in saturated fat (e.g. chocolates, pizza and potato chips), while some high-GI foods may still be good choices because they are nutritious and relatively low in energy and carbohydrate (e.g. watermelon). So, when using GI, think quality, nutritious carbs first, and then go for the lower GI options.

Where to start

Following a low GI diet isn't difficult; in many cases it just means substituting one food for another.

<i>High GI food</i>	<i>Low GI alternative</i>
Bread – white or wholemeal	Bread containing lots of wholegrains; sourdough and pumpernickel breads
Processed breakfast cereals	Unrefined cereals such as rolled oats or natural muesli or a low-GI processed cereal such as those containing barley or psyllium husks
Plain biscuits or crackers	Biscuits made with dried fruit, oats and wholegrains
Cakes and muffins	Make them with fruit, rolled oats, rolled barley, oat bran, rice bran, barley bran, psyllium husks, nuts and seeds.
Potato	Substitute with Carisma™ or Bellita potatoes or corn; make mashed potato with half cannellini beans.
Rice	Try longer grain varieties such as basmati, Doongara® (Sun Rice® Clever Rice®) or try pearled barley, quinoa, cracked wheat or noodles instead.



Where can I find out more?

If you want to learn more about GI, the following books and websites are a good place to start:

- Sydney University GI website www.glycemicindex.com
- GI Symbol program www.gisymbol.com.au
- Sydney University GI newsletter www.ginews.blogspot.com
- *The Low GI Diet Diabetes Handbook* (2007) by Dr Stephen Colagiuri, Kaye Foster-Powell, Jennie Brand-Miller and Alan Barclay
- *The Low GI Diet Shopper's Guide* (2012) by Kaye Foster-Powell and Jennie Brand-Miller

Many thanks to Dr Kate Marsh, Advanced Accredited Practising Dietitian and Credentialed Diabetes Educator for preparing this information.

Can people with T1 drink alcohol?

By now, you've heard that living with type 1 diabetes can be a bit tricky, but it does not mean that you cannot enjoy life like anyone else (with a bit of extra planning). In regards to alcohol, you just need to be aware of how alcohol affects your body and your diabetes, and how to respond to these effects.

"People with diabetes can include alcohol in their diet in a responsible way."[†] Elizabeth Staum, dietitian and diabetes educator at the Joslin Diabetes Center, a diabetes research organisation affiliated with Harvard University.

What do you need to know about type 1 and alcohol?

It is definitely possible to drink alcohol if you have type 1 diabetes.

Everyone has different reactions to alcohol and there is no hard and fast rule on how to manage drinking. Alcohol may cause blood sugars either to rise or to drop rather unpredictably. You need to know how each drink affects your blood glucose levels.

If you are going to be drinking it is very important to be extra prepared! Why? Alcohol is one of the trickier things you will face when managing your type 1 diabetes because when you drink alcohol, your liver focuses on processing the alcohol, meaning it shuts down the usual process of producing and releasing glucose.

[When I'm drinking alcohol] I just reduce the amount of background insulin at nighttime to stop the dreaded early morning hypo.

Fiona, Age 27, Diagnosed Age 14

Further information

Diabetes Australia has an alcohol and diabetes fact sheet that can be found at: www.diabetesaustralia.com.au/Documents/NDSS/Resources/Diabetes_Information_Sheets/ALCOHOL-2009.pdf.

Diabetes Daily has a useful page discussing alcohol and diabetes at www.diabetesdaily.com.

Effects on blood sugar levels

The main risks with alcohol consumption are that it can lead to hypo unawareness (see page 15), hypos may be more likely and it may be more difficult to recover because the liver is not releasing glucose. In addition, you and the people around you can mistake a hypo for drunkenness. This can be risky as it means hypos might be missed and go unmanaged.

Dancing and other physical activities as well as drinking too much or having an empty stomach can increase your risk of a hypo. The last thing you want is a nasty hypo to ruin a good night! It's a good idea to check your glucose levels and eat a light snack or small meal before you start drinking. Some people recommend snacking while drinking – about one serve of carbs for every 2–3 drinks. This helps keep your blood sugar levels in the optimal range and hopefully prevent you from experiencing hypoglycaemia while you're drinking or afterwards – this is most dangerous while you are asleep, but some people find they tend to hypo the next day as well.

Alcoholic drinks containing moderate or high levels of carbohydrate, such as dessert wines, mixed drinks, ciders, beer and drinks mixed with regular soft drinks or fruit juice, may cause high blood glucose levels – but BGLs may drop soon after due to the alcohol, although this varies from person to person. Drinks like gin, vodka, red wine, some low-carb beers or distilled spirits (without mixers) are lower in carbs, so may not cause an initial spike in blood glucose levels, but will still lower blood sugars later on. Many Reality Check members recommend Calorie King (www.calorieking.com.au) as a useful source of the carbohydrate content of food and alcoholic drinks. Yes, it is an unpredictable balancing act! Over time you will figure out what works for you.

Hypo or drunk?

As described in the hypoglycaemia section (see page 14), having a hypo can make you feel slightly tipsy or drunk. Many of the symptoms, such as confusion, giggling, disorientation, loss of balance and (sometimes!) aggression, can be similar. As a result, it can be confusing when you are drinking to tell whether you are drunk or on the way to having a nasty hypo. Never assume that behaviour change or loss of consciousness is alcohol-related – it is always safer to ensure that either you've checked your blood glucose and it isn't low, or if that is not possible (often), that treatment for a hypo is given. This may require glucagon or a paramedic or other assistance if you lose consciousness or start vomiting. Having a friend with you who knows about your diabetes can be very helpful.

I always make sure I'm nibbling or having a decent meal with/before drinking, and that someone knows I'm diabetic, especially if I seem more 'drunk' than I should logically be, as it could be a low.

Kait, Age 23, Diagnosed Age 8



Tips on alcohol from people with T1D

- Make sure you don't forget your insulin, especially long-acting insulin if you are on multiple daily injections. It can be easy to fall asleep without taking your usual long-acting – set a reminder on your phone or have a friend help you remember.
- Ensure someone around you (preferably a few people) knows you have type 1 diabetes, knows how to recognise when you are having a hypo and knows what to do to help you.
- Staff within a pub or bar may mistake your hypo for drunkenness. Again, having a friend to assist you can make a big difference. Many Reality Check members recommend wearing or carrying some form of identification; if a hypo is mistaken for drunkenness this identification can be a lifesaver! It's helpful to make sure your friends know that acting drunk or passing out could be a result of a hypo rather than alcohol. If they aren't sure, they should get you some medical attention rather than hoping you 'sleep it off'.
- Eat a carb-filled meal before heading out and carry a few extra hypo-fixes in case you need carbs later.
- Bear in mind that drinking alcohol stimulates the palate; keep an eye on whether you need to give some insulin with your snacks!
- Stick to sugar-free drinks/mixers where possible, and avoid dessert wines and juice-mixed cocktails. You will soon find what works for you – for example, one Reality Check contributor avoids rum at all costs due to big highs and crashing lows. Not fun!
- Follow each alcoholic drink with a glass of water. This keeps the body hydrated and lessens the risk of becoming very drunk very quickly.
- Check, check, check, check, check, check (with drinking/dancing/grazing on carbs mixed in). For some people with diabetes, this means checking every hour or every second hour. BGL information is important to indicate potential trends especially until you know how you react to alcohol. Excess alcohol, even small amounts in some situations, can inhibit decision-making, so checking might go out the window if you don't have a plan to follow.
- Before bed, check your BGL and ensure it is at a safe level, drink a HEAP of water to avoid dehydration and sleep with both water and your preferred hypo-fix within easy reach. If you have just been diagnosed and feel nervous, you may wish to organise for someone to check your sugars every four hours or so, or at least rouse you after about eight hours to check sugar and get some carbs and insulin as needed.
- If you can, have someone check on you in the morning, just to be safe.
- Talk to an accredited practising dietitian about the different types of alcohol and how each one might affect your blood sugar levels.

It sounds like a lot of planning, but with a bit of trial and error you'll find out what works for you and you can still go out and have a great night!

Recreational Drugs

5.4

Can people with T1 take recreational drugs?

How recreational drugs affect people with type 1 diabetes is not well understood because there are many different types of drugs that affect the human body in various ways. However, it is safe to say that any recreational drug is likely to impact the management of your type 1 diabetes, because it is likely to impair your mental state. You might forget to eat, get the munchies, forget your insulin, lose motivation or have difficulty making decisions.

Because there is very little information about the interaction of recreational drugs with diabetes, it is hard for us to provide any advice on keeping safe. Knowing what others have experienced might be helpful even though it cannot be seen as factual or inform you on how drug use could affect your diabetes. We are not going to tell you what to do or how to lead your life, but always remember, drugs are a big unknown and therefore a big risk. Until proper medical research has been completed, you need to take responsibility for your decisions.

If you do decide to experiment, try to minimise the risk by having a friend who can look out for you as described for drinking alcohol: make sure you test, help you if you're hypo and get medical attention if it's needed. Yes, we know that in many situations this will not be possible, or not acceptable, but equally there are situations where you may not have thought of this option.

Further information

With regards to alcohol, we focused on harm minimisation and planning with some helpful hints, but with drugs we are effectively saying do it at your own risk, given the illegalities and safety concerns associated with recreational drugs. However, a user's perspective can be found on the T1DN website, www.t1dn.org.au.

I partied hard for about 10–12 years after my diagnosis and didn't let my diabetes stop me from drinking or using various drugs (marijuana, speed, ecstasy, LSD and ice). I was sensible though in that I made sure that I always had a close friend with me when I was drinking or taking drugs and I usually cut back my insulin doses to avoid lows (would much rather be high at these times). Thankfully, I never had any major problems!

Anonymous

real stories

Why Not?

Cassie

Age: 27

Age at diagnosis: 10



When I was first diagnosed, I was 10 years old. After a Saturday full of sports and running around, a random friend-of-family test had come back showing my BSL as 'HI'. I sat in the back of the family station wagon, prepared to go to hospital, almost in tears. I was scared. I'd read the *Baby-Sitter's Club* books; I knew diabetes was dangerous. I knew it meant you weren't supposed to eat cake or lollies. I knew it meant you were sick if you did. I knew it made you different from other kids. I knew it meant needles. Self-pity and a thousand not-quite-finished thoughts were starting to race around in my head.

"What's the matter?" my Dad asked me, turning around from the front seat. "What are you thinking?"

I looked at him and didn't know what to say.

"Why me?" I asked, the tears starting to roll down my face.

"Why did this have to happen to me?" I liked the way my life – my world – was right then, and I didn't want it to change.

"Why not?" Dad answered, stopping my self-pity short.

Why not? Such a harsh question to throw at a 10 year old, but it was the beginning of the best advice I ever received. There are many answers for 'whys' in the world, but there are just as many answers for 'why not's'. In the end, neither of them count more than the other, whatever is – just is. Find a way to make the most of whatever you've got and get on with it.

Over the years, diabetes wise, it became my motto.

"I can't be diabetic."

"You can't have that piece of cake."

"You shouldn't run cross-country."

"We don't want her on school camp."

"Can you even go overseas on school exchange?"

Why not? Why not? Why not?

Whatever the concern, whatever the doubt, for me 'getting on with it' came to mean finding ways around the why nots associated with my diabetes. I decided that, wherever possible, I was not going to let diabetes control my life; things were going to be the other way around.

If I wanted to, I was not going to not have/do something simply because of my diabetes. I am diabetic – but I am more than that. My life became about fitting diabetes in with my life, not restricting life because of diabetes. I could have that piece of cake – after I gave myself a little more insulin. I would run cross-country – carrying my supplies with me the entire way. I could go on school camp, and overseas and on exchange.

I am diabetic. But it's never stopped me. In the last 17 years I have made the most of my life and have done many things despite any initial doubts associated with being diabetic. I have travelled solo overseas since the age of 16 to places like Switzerland, Indonesia and Vanuatu, and have lived in remote villages, out of backpacks, handled crazy highs and lows alone and sourced backup equipment when mine got lost. I have competed in regional/district sports, cross-country and athletics; I've completed university and Honours, received academic awards and been selected for international programs. I have joined the SES (Queensland's State Emergency Service) and participated in several major operations and land searches. I'm a paramedic with the Queensland Ambulance Service – I work shift work. I play sport, I surf, I have a motorbike, I'm married, I am a mum.

I'm pretty normal, despite the diabetes. I've learnt that, with a little bit of work, I can still do anything I want –

And why not!?

My story

Fiona

Age: **25**

Age at diagnosis: **12**



I had a few throat/chest infections in a row at the beginning of 2000. I was given antibiotics, but because I loved school, I continued to go every day. For a few weeks I was thirsty and hungry all the time. I'd always been a bit of a big eater and I'd always been very skinny – my Mum used to joke about where I managed to put all the food I ate. I was very active though and my parents just put it down to that. I ate a very healthy diet and competed for a swimming club and a hockey club several days a week. I started to feel so thirsty, like I could never drink enough water, I'd take two jugs and a glass of water to bed every night and drank constantly through the day but I never seemed to get enough.

It lasted a few weeks and I was called into the doctor's surgery one Saturday morning after receiving another set of antibiotics the day before. They said they wanted to do a finger prick blood test on me; I had no idea what was going on. My blood sugar was in the high 30s I think. It was then that I was told I had type 1 diabetes. I didn't have any idea what diabetes was and neither did my family. We thought it was something older people got as a complication as my Grandad had got type 2 after he had a stroke.

I had seen a boy with type 1 diabetes on Blue Peter [a children's TV program] when I was younger and the only thing I could remember was that he was very rarely allowed ice-cream.

My GP told me I would have to go straight to the children's ward in the hospital and I'd be there for at least two weeks. I was petrified! I hated the thought of being anywhere where someone had died and that was the first link I had with a hospital. It wasn't until I got on the scales and had a look at my ribs in the mirror that anyone realised I'd lost so much weight. When I got to the hospital, I was given a bed and a number of blood tests were run, I felt absolutely starving; I wasn't allowed to eat until almost 3 pm (which was almost 4–5 hours after I arrived at the hospital). I remember the relief after being allowed to eat a hospital canteen sandwich; I ate it so quickly I can't even remember what was on it. I was so scared but the nurse working on the ward was so lovely (and she turned out to be my friend from school's Mum – and my future diabetes nurse).

I don't really remember much except being told that I would have to wait to be set up with medication. I didn't have any fear of injections so I think that helped. When the diabetes doctor and nurses both arrived, I received my first insulin injection (I think it may have been the only one I've not done myself). I felt a lot better and didn't feel as thirsty almost immediately. When I was discharged from the hospital, the first thing we did was go to the supermarket; I think the only thing that me and my Mum remembered was that I couldn't eat anything that had more than half sugar to carbohydrate. We spent almost two hours looking at everything for sugar content. My diabetes nurse came every day for a week and I was made to stay off school for an entire week – I was quite determined that I was going back to school as soon as possible but I agreed to stay off until the following Monday. She [my diabetes nurse] came to my house every morning before breakfast and every evening at about 5 pm to make sure I was coping with the injections.

real stories

Fiona's story

(continued)

I am so glad I got diabetes when I did. If I had been any younger I think I would have struggled to let my Mum give me injections and if I'd have been older I would have been more gutted with the diagnosis.

I decided on day one that I wouldn't let it rule my life. I was told of the complications of bad control and was determined that this wasn't going to happen to me. My dream was to become an astronaut and go to the Moon or Mars. It was a little while after diagnosis that I found out I couldn't do it and I think that helped. I decided if I couldn't go into space, I'd help others do it instead and decided to be a rocket engineer.

My family were amazing; they gave me so much help and support and made sure that I was fine. I remember getting quite upset and angry because so many people asked me if I was OK and I felt that I was but that by them asking I remembered I wasn't normal anymore. I think my friends also made things better. I had arranged to go on holiday with my best friend and her parents to Tenerife in the summer and although I never thought anything of it at the time, her Mum took on so much responsibility with letting me still go on holidays with them. She used to be a nurse and she had type 1 diabetes in her family so that wasn't an issue to her. I didn't learn until many years later that my Mum said she would understand if they didn't want me to come anymore. I am so glad they didn't mind and I'm glad I didn't know it could have been an issue; it definitely helped that I didn't ever feel different to anyone. I think any knock backs would have hit my confidence levels whether they were diabetes related or not. I feel that I would have loved to have someone to talk to that was going through the same thing when I was younger, but I was too old for the young camps and for some reason there were none running the years I wanted to go. I finally went to a camp when I was 21 and it was amazing; it was so great to meet others who had felt the same thing at some point. I volunteered this year at a diabetes family weekend and it is amazing. I am definitely going to try to volunteer for more as soon as possible.

To be honest I now love my diabetes, I know it's such as weird thing to say, but I do. I don't think I'd be the same person today if I didn't have it.

I was always very committed and very hardworking, however, I feel that I have been able to achieve so much more than I ever thought possible. 'No' is not a word in my dictionary when it comes to things I can't do because I have diabetes.

I learned to drive at 17 and I know the risks; I have to make sure my blood sugar is at an acceptable level before I get in the car and sometimes this can take a little longer than I'd hoped, but I can still do it. I have been all over the UK in my car with my boyfriend and friends – none of whom learned to drive until much later than I did. I did as well as I could at school and I was voted highest academic achiever in my senior class and also won Sportswoman of the Year for the city I lived in. When it came to university, I knew I could do better. I chose Mechanical Engineering as my degree program and followed this through to the end achieving a 1st Class Honours degree. This didn't come easy and I really needed to work at it to achieve it but I didn't let my diabetes stand in my way. I changed my mind about my main focus from aerospace engineering to medical-based engineering.

I thought it would be amazing to design my own insulin pump, but when I got given my Honours project in my final year, I loved the design of prosthetics even more. Once I finished I was offered a PhD in Oil and Gas industry work and I decided to go with it. I loved it. I am still writing up my thesis at the moment but I know I will achieve it. Since school, I've had a huge interest in swimming and had always wanted to be a lifeguard. I wouldn't take no as an answer and I had to pass a medical to be allowed to work for my city council as a lifeguard and swimming teacher, but I have had no issues with having diabetes. I do carry food on me all the time when I am lifeguarding, but I didn't let diabetes stand in the way. I do this part-time to subsidise socialising, travelling and my car. I moved away from home for my PhD studies and loved it. I had my boyfriend for support but I was independent enough to manage on my own if I needed to. I have always jumped in feet first into everything I can. I can ski, I climb mountains, I have been abseiling, white-water rafting, gorge walking and paintballing. I also love hanging out with my friends – whether it be the cinema, girly cocktail nights or sleepovers, or romantic nights out with my boyfriend.

You only live once and you may die tomorrow, so I always live for the moment. I am very careful however [with my diabetes] and I have no complications after 13 years. I love adventure and having diabetes isn't something that can stand in my way.

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