







A guide for adults living with type 1 diabetes



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#### This book is dedicated to Rachel Reyna

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JDRF

#### **ABOUT JDRF**

JDRF is the leading supporter of type 1 diabetes (T1D) research in the world. Our vision is simple: a world without T1D. And until researchers find how to prevent and cure the condition, we'll do all we can to help make the lives of people living with T1D happier and healthier.

We drive innovation, demand action and stand with everyone facing life with T1D.

#### RESEARCH

JDRF has been part of every breakthrough in T1D care in the last 50 years. As the world's largest funder of T1D research, we collaborate, connect and coordinate the world's greatest minds to deliver tangible improvements for the T1D community. Learn more at jdrf.org.au/research

#### COMMUNITY

The T1D community is at the heart of all we do. We offer resources and support across every age and stage of T1D, including free books, a peer support program, private Facebook groups, and free online webinars and sessions for community members.

Learn more at jdrf.org.au/community

#### **ADVOCACY**

Along with our team of passionate T1D advocates around Australia, we've changed how governments view T1D. In the past decade, this has helped us deliver over \$500m in new investments in T1D research. Learn more at jdrf.org.au/advocacy

# MORE INFO AND RESOURCES

Visit JDRF's website for lots more information on T1D. It's a treasure trove of handy tips and resources for you and your loved ones (and it's all free!)



# Go to jdrf.org.au/for-adults for links to all this and more:

- articles and videos about every aspect of life with T1D
- free books
- a calendar of social events for our community members

- our T1Dictionary, with explanations of common T1D terms
- our T1Directory, with links to handy organisations and resources
- mental health resources to help you and your loved ones
- registrations for free online chats about a range of T1D topics.



#### **HOW TO USE THIS BOOK**

#### A note from Dr Jane Overland, nurse practitioner and diabetes educator



Living with type 1 diabetes (T1D) can sometimes be hard work. Whether you've just been diagnosed or you've been living with it for a while, there are often hurdles that need to be overcome, and many questions that need to be answered.

We created **Straight to the Point** to help you with these challenges. This book is a credible source of practical help, written and fact-checked by diabetes experts.

We've written it to give you a realistic expectation of what life with T1D is really like, and to remind you that you're not alone.

We've included lots of links for you to find more information, as well as some places you can go to connect with other people who are just like you. Don't feel like you have to read this book all in full from front to back. You might prefer to dip into it as you need. Keep it on your shelf (or if you're reading this online, bookmark it!) so you have somewhere to go when you have questions that need to be answered before your next appointment.

Whether you have a little bit or a lot of experience with T1D, we hope this book gives you the information, advice and support you need to live life to the full.



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Diabetes isn't something to be tackled alone. Surround yourself with a team of family, friends and healthcare professionals you feel comfortable with, and you'll be able to achieve whatever your heart desires.

- Dr Jane Overland

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GETTING TO GRIPS
WITH A TYPE 1
DIABETES DIAGNOSIS

When you were told you had type 1 diabetes (T1D) you probably felt as though your world had been turned upside down. You might have felt like screaming or crying, or just wanted to curl up in a ball and ignore it. All of this is perfectly normal.

A T1D diagnosis can definitely be daunting and overwhelming. But over time you'll learn how to fit diabetes into your life.

You may find the first couple of weeks after your diagnosis are the worst. This is when you'll be coming to terms with injecting insulin and pricking your fingers to check your blood glucose levels. There's also a lot you need to learn about how to manage your diabetes, such as counting carbohydrates, understanding the precautions you'll need to take when you exercise, how to recognise and treat a hypo... the list goes on.

At any time, if it's all too much for you, let your endocrinologist or diabetes team know. They're there to help you through it all.

Speaking of your diabetes support team, never be embarrassed to ask your doctor, endocrinologist or educator to slow down if they're talking too fast or giving you too much information at once. Most of us only remember a quarter of what's said in a 10 to 20 minute conversation, and it's even less when we're stressed. When you're in your appointments with them, it can help to write things down and ask lots of questions.

You may also be too busy learning how to manage your diabetes to think about how you're feeling. The realisation that

# IT'S PERFECTLY USUAL TO EXPERIENCE THE FOLLOWING AFTER A T1D DIAGNOSIS:

Shock: "What the &%^#?"

Denial: "No, this isn't real. I want a second opinion!"

Fear: "This is going to destroy my life!"

Grief: "This is so unfair. I feel so unhappy."

Loss: "I wish things were how they used to be."

Hopelessness: "Life is never going to get better for me."

Despair: "Why me?"

Relief: "At least now I know why I've been feeling like this."

diabetes is for life may not hit you for several weeks, or even months. That's often the time people assume you're coping and getting on top of it all – but this could be when you feel the worst.

A lot of people go through a kind of grieving process after they're diagnosed. It may seem strange, but you may be grieving the future you expected to have that didn't involve all these injections and medical appointments. Like most people, you probably expected to have a carefree life without having to worry about your health too much. It takes time to process what lays ahead, and everybody responds to it differently.

If you're ever struggling, don't be afraid to reach out to friends, family and health professionals. They'll be able to help you through the difficult times.

#### **DIAGNOSIS DENIAL**

You may find it hard to accept that you now have T1D. Most people go through some kind of denial when they're diagnosed. This is a natural reaction. In fact, it's so common that it's accepted as part of the process of dealing with the diagnosis.

This response is a way of coping with bad news. It can keep you from getting depressed and overwhelmed and lets you accept information slowly. And the feelings of denial will usually be gradually replaced by acceptance.

Denial may stay around for weeks, months, or, for some people, even years. It may also come and go, depending on what else is happening in your life.

Sometimes when we have too much on our plate, it can seem easy to let our diabetes care go. We can be in denial that we need to manage our T1D. This usually adds to our stress, as in the back of our minds we know the damage we could be causing to our long-term health.

It's important to know you don't have to 'do' diabetes all by yourself. Family, friends and your diabetes care team are all there to give you support and help you when you need it.

If denial seems to be hanging around and is destructive (for example, if it's leading you to miss insulin injections or medical appointments), it's serious. You'll need some support to get back on track. Ask someone in your diabetes care team for help, or make an appointment with an experienced counsellor or psychologist.



# TELLING PEOPLE ABOUT YOUR DIAGNOSIS

Keeping your diabetes a secret, or choosing not to tell others about your diagnosis, can make it harder to move on and accept it. One thing that can really help is to make sure the people around you know about your diabetes. This will make it a lot harder for denial to take hold in the longer term. (Besides, it won't be long before your family and friends figure out that you have diabetes. Why else would you be injecting insulin?)



Work out who are the most important people to tell, then involve them as much or as little as you'd like. It's okay to tell them you need space to process your thoughts, and that you'll come to them when you're ready. But then they'll at least be there to help you when you're ready to talk about it.

At times, talking to family and friends may not be enough. In that case, you should talk to your doctor or diabetes team about finding a counsellor or psychologist to talk to. Another strategy is to have a support network of people with diabetes you can talk with. See page 42 for tips on where to find other people who understand about life with T1D.

# ADJUSTMENT AND ACCEPTANCE

Most people will eventually travel the road from what they knew towards diabetes being an accepted part of their life. Some find it a short journey; others will take longer to find that acceptance.



Acceptance doesn't always go in a straight line either. Sometimes we go backwards and forwards between being okay with diabetes and not being okay. This is all part of the process – and again, it's completely normal to feel that way!



T1D is a condition that requires you to take charge. Once you know about, understand and feel comfortable with your diabetes, you're more likely to have less stress and be better able to manage your diabetes over the long term.

During this journey there are emotional ups and downs, and some people say it's like being on a rollercoaster. The downtimes can bring feelings of grief, fear, denial and hopelessness. At other times you may start to feel more comfortable with diabetes... then you might go down again. This is okay too! At some point you'll start to have more ups, and the downs you have won't last as long. You'll start to incorporate diabetes into your life. In a way, you'll get back on track – just with a new chapter added to your life.

But be aware that living with T1D 24/7 leads to some ongoing ups and downs. Again, this is normal. After all, we all have bad moments and bad days.

# DIABETES EXPLAINED



#### WHY ME?

If you've just been diagnosed with T1D you're probably wondering, "Why me?". It's important to know it's not your fault that you have diabetes. There's absolutely nothing you could have done to prevent it. It's not associated with a poor diet or an unhealthy lifestyle.

#### WHAT IS T1D?

T1D is an autoimmune disease. Our immune system usually protects us from foreign cells, like viruses and bacteria. But in people with T1D, the immune system mistakenly attacks and destroys the beta cells in the pancreas. This is a problem because beta cells produce insulin, which are needed for life. When the beta cells are destroyed by the immune system, the body can't make insulin.

Without insulin, glucose can't move from your bloodstream into the cells of your body to give them the energy needed to function. When your pancreas can't produce insulin, glucose levels in your bloodstream start to rise, and your body can't function properly. Over time, if left untreated, this high level of glucose in the blood can damage nerves, blood vessels and organs. Left untreated, it can be life threatening.

#### **WHAT CAUSES T1D?**

There's a lot of ongoing research on what causes T1D, but so far there are no clear answers. We do know that:

 pancreas failure is due to damage inflicted by your immune system

#### **DID YOU KNOW?**

Over 130,000 Australians are currently living with T1D, with another 8 people diagnosed every day.

Around 88% of Australians living with T1D are 21 years old or older.

Australia has one of the highest incidence rates of T1D – but we don't know why.

JDRF supports a number of clinical trials into promising new treatments and therapies to find a cure or prevent T1D from developing.

- something triggered your immune system to attack your beta cells
- certain genes put people at a greater risk for developing T1D, but aren't the only factors involved – in fact, around 90% of people diagnosed with the condition have no family history of it
- while there are no proven environmental triggers so far, researchers are looking for possible culprits, such as viral infections and toxins in our food or environment.

# I THOUGHT ONLY KIDS ARE DIAGNOSED WITH T1D?

Being diagnosed with T1D as an adult can be difficult. There's a real lack of understanding about diabetes in the community, and many people don't expect adults to be diagnosed with it.

But while many people associate T1D with children, around half of the people diagnosed with it are adults. So you're really not alone in developing T1D as a grown-up.

# HOW DOES INSULIN HELP MANAGE T1D?

In people who don't live with diabetes, the pancreas produces a low level of insulin across the day. This helps move glucose from the bloodstream into the body's cells to provide them with energy. (It can help to think about insulin working like a key – it opens the door to cells and allows the glucose in.)

When people without diabetes eat or drink something, their blood glucose level rises. The pancreas responds by producing a surge of insulin, and this helps move excess glucose into the muscles and liver to be stored as glycogen. If blood glucose drops, the glycogen is broken down and released back into the bloodstream as glucose. It's then used as energy.

By constantly sensing how much glucose is in the bloodstream, and adjusting how much insulin it's producing, the pancreas should keep blood glucose levels around 4-8 millimoles per litre (mmol/L) at all times.

# In people who live with diabetes, the pancreas doesn't function properly.

It doesn't produce insulin. And because insulin normally works like a key to open the door to the cells to let the glucose in, that doesn't happen as it should; the glucose stays in the bloodstream instead. Blood glucose levels are then higher than normal, which can lead to serious complications.

If your body can't use glucose for fuel, it starts to break down fat to use for energy instead. When fat is broken down, the body produces chemicals called ketones, which are released into the bloodstream.

Small amounts of ketones in the blood (under 0.6mmol/L) can be healthy, but high levels cause the blood to become more acidic. This can lead to a serious condition known as diabetic ketoacidosis (DKA). Symptoms of DKA include nausea, rapid breathing, vomiting and abdominal pain. In severe cases it can be life threatening.

In people who live with diabetes, injecting insulin lets the body use glucose for energy. The insulin opens the door to your body's cells, letting the glucose in so it can be used as energy. This removes the risk of harm from DKA and high blood glucose levels in the short term.

The amount of insulin you'll need to inject each day will depend on your age, your weight and how long you've been living with diabetes. You'll work this out with your diabetes team or endocrinologist. This amount will vary over the years and at different periods of your life, with the aim of keeping your blood glucose levels around the normal range.



# THE MAIN AIMS OF DIABETES TREATMENT:

- · to live a fulfilling and healthy life
- to keep blood glucose levels as near to normal as possible
- to reduce other factors that can increase the risk of complications (such as maintaining healthy blood pressure and cholesterol levels)
- to detect any health problems related to diabetes as early as possible.



You might think that being diagnosed at an older age means you've been walking around with diabetes for many years. But this may or may not be true.

There are now four recognised stages of T1D. Most people never know they have stage 1 or 2, because there are no signs or symptoms of these early stages. In fact, it can be present for months or even years before any symptoms develop. At this time, the condition can be detected with a blood test that checks for T1D antibodies.

Stage 1 T1D occurs when the autoimmune condition is first triggered. At this time, the beta cells are under attack by the immune system, but enough are surviving to keep blood glucose levels normal.

Stage 2 happens when the autoimmune attack has progressed to the point that beta cells are having trouble keeping up with insulin requirements. As a result, blood glucose levels will be starting to rise, but are still below diagnosis criteria.

People are typically diagnosed with stage 3 T1D. This is because a large majority of the beta cells have now been destroyed, so insulin therapy is needed to manage blood glucose levels. This is when typical symptoms appear, like excessive thirst, weight loss and needing the toilet more.

Stage 4 T1D isn't well defined, but it recognises those with long-standing T1D, where all remaining beta cells have been destroyed. This is when long-term complications of diabetes may occur.

#### **HOW LONG HAVE I HAD T1D?**

#### WHY DO I HAVE T1D WHEN NO ONE ELSE IN MY FAMILY DOES?

While siblings and kids of people with T1D have a slightly increased risk of developing the condition, around 90% of people living with T1D have no family history of it.

There are known genetic links to T1D, but having these genes doesn't mean you'll definitely develop the condition. It's important to note that while genes can play a role in T1D, they're not the whole story.

Researchers believe that your environment - starting all the way back when you were in the womb - can also influence your risk. There are currently a number of research groups around the world who are looking into this. Some of these are funded by JDRF.

#### WHAT'S THE **'HONEYMOON PERIOD'?**

If you've only had diabetes for a few weeks or months, you may find that it seems to go away for a while. This can range from a few weeks to a year or so. In this time, you might find that the amount of insulin you need to inject decreases. You may be able to keep your blood glucose levels in the normal or near normal range by taking little or no insulin. This is called the honeymoon period.

Unfortunately, this doesn't mean your diabetes has gone away. After all, by the time you even developed symptoms of diabetes, most of your insulin-producing beta cells had been destroyed by your immune system.

At diagnosis, you may have enough functioning beta cells left to provide you with insulin for a short period of time. While research is progressing into ways to protect these remaining cells, it's not currently possible to stop the autoimmune processes. You'll eventually lose the cells and your ability to produce your own insulin - which is where insulin injections come in.

# STAGE 2

3

STAGE

#### **TYPE 1 DIABETES**

Once called 'insulin-dependent diabetes' or 'juvenile diabetes', T1D occurs when the immune system doesn't recognise itself properly. The body mistakenly attacks and destroys the beta cells in the pancreas that produce insulin. Insulin injections are then needed to control blood glucose levels. Symptoms typically develop quickly (over days or weeks), but the early stages of the condition may have been developing for a much longer time. The early stages of T1D have no signs or symptoms, but can be detected by testing for antibodies in the blood. T1D represents around 10% of adults with diabetes.

#### **TYPE 2 DIABETES**

Formerly called 'non-insulin-dependent diabetes' or 'adult onset diabetes', type 2 diabetes (T2D) occurs when a person doesn't make enough insulin and/or their bodies don't properly use the insulin that's available, known as insulin resistance. T2D is often referred to as a lifestyle disease, because it's more common in people who are sedentary and overweight. But this isn't the entire explanation, as T2D is more likely to occur in people with a family history of it, women who had gestational diabetes, and people of Native American, Asian, Pacific Islander, African American or Latin American ancestry. It's usually managed by diet, exercise and oral medication at the start, but over time, most people with T2D will need to take tablets and/or inject insulin. Around 85-90% of adults with diabetes have T2D.

#### LATENT AUTOIMMUNE DIABETES OF ADULTS (LADA)

People with LADA (or 'type 1.5 diabetes') have features of both T1D and T2D. Their immune system attacks the cells that produce insulin (as in T1D), but they may also have insulin resistance (as in T2D). The insulin-producing cells are destroyed much slower in LADA than in people living with T1D. It can be difficult to tell the difference between LADA and T2D, and a blood test is needed to check for antibodies against insulin producing cells. Up to 1 out of every 3 people who were initially diagnosed as having T2D actually have LADA. Some people with LADA can manage the condition with diet, exercise and medication in the months following diagnosis, but most will need end up needing insulin therapy in the first year.

#### **GESTATIONAL DIABETES**

Gestational diabetes is detected in pregnancy. Pregnant women produce large amounts of hormones such as oestrogen and progesterone, which can cause the body to become resistant to the effects of insulin. By the time a woman reaches the end of her third trimester, her insulin requirements have tripled. If the pancreas can't match the increased demand, her blood glucose levels start to rise. Gestational diabetes can sometimes be managed by diet and exercise, but some women will need insulin treatment. In general, blood glucose goes back to normal after pregnancy. Women with this type of diabetes are at a significantly higher risk of developing T2D later in life.

# MANAGING BLOOD GLUCOSE LEVELS



# WHY WE AIM FOR 'NORMAL' BLOOD GLUCOSE LEVELS

To keep your blood glucose levels in your target range, you now need to do the job of your pancreas. This means injecting insulin several times a day (either manually or with an insulin pump), regularly monitoring your blood glucose levels, and deciding how much insulin to inject to keep your blood glucose as close to your target range as possible.

One of the reasons to do this is to help you feel your best and give you more energy. You can also get very sick very quickly if you don't manage your levels.

#### COMMON BLOOD GLUCOSE TARGETS

When you wake up	5-7mmol/L
Before meals	5-7mmol/L
2 hours after meals	7-9mmol/L
Before exercise	More than 5mmol/L but less than 15mmol/L
Before you go to bed	7-9mmol/L

Another reason you'd want to stay in your target range? Your long-term health.

Aiming for 'normal' blood glucose levels will help prevent or delay the development of diabetes complications. Constantly high blood glucose levels are toxic to the body, and cells in your brain, nerves, eyes, kidneys and blood vessels will then readily absorb glucose without insulin being present. These organs are particularly vulnerable to complications.

# A QUICK NOTE: BE REALISTIC ABOUT YOUR BLOOD GLUCOSE LEVELS

Before we go into more details on testing, we wanted to share some advice: please take it easy on yourself.

Living with diabetes can be incredibly frustrating. Over the course of a couple of days you can eat the same food, take the same amount of insulin and do the same amount of exercise, but your blood glucose levels can be completely different every day. While food and exercise are important factors in how much insulin your body needs each day, there are other things that play an important role. Not all these factors are completely understood or within your control.

For example, on some days injected insulin is less well absorbed. This means insulin will be less effective. Some women also report that their blood glucose levels are higher several days before their period, and then drop once their period starts. This can be caused by high premenstrual oestrogen levels, which make the body more resistant to insulin.

You may also find that your blood glucose levels run high for many hours after an episode of hypoglycaemia (also known as a 'hypo', or low blood glucose levels). This could be the result of overeating to correct the low blood glucose level.

However, if your blood glucose has been low for some time, your body will make and release stress hormones to try to protect you from having dangerously low blood glucose levels. These hormones can trigger a release of the stored glucose from your liver and interfere with the action of insulin. Stress hormones are also produced when you're stressed or unwell, so this can also impact your levels.

Diabetes treatments are much better than in years gone by, but they're still not perfect. So until there's a cure for diabetes, there will be times when your blood glucose level is too high, and other times it will be too low. It's just the way it is!

If your blood glucose is outside the normal range, try not to think of it as being 'bad'. Have a look to see if there's a pattern, and talk to your diabetes team about developing strategies to improve your blood glucose levels.

# TRACKING YOUR BLOOD GLUCOSE LEVELS

Keeping a record of your blood glucose level is an important part of taking care of your diabetes. This helps you track and identify patterns of high or low levels. The information will also help you and your doctor or diabetes team to balance food, exercise and insulin doses.

Ideally you should aim to do at least four blood glucose checks a day. To get the most out of monitoring, your diabetes team may advise you to check your blood glucose levels before and then 2 to 3 hours after eating. It's also a good idea to monitor before and after exercise.



# KEEPING A RECORD OF YOUR BLOOD GLUCOSE LEVELS

Someone very wise once said, "Sometimes you can't see the forest for the trees." And when it comes to managing T1D, this saying is very true. Over time, your blood glucose levels may change in ways you won't notice by just looking at a day or 2 of results. By keeping a record over a longer period, you can often see trends that will help you make changes to improve your blood glucose levels, reduce hypoglycaemia and manage your diabetes better.

There are a few ways you can keep track of how your blood glucose levels are going.

#### **COMPUTER SOFTWARE**

Most blood glucose meters and insulin pumps have the ability to download their data onto a computer so you can view your blood glucose and/or insulin history. The software is available from the pump or meter manufacturer (search online for the manufacturer's website to see what they have available). This generally gives you the ability to see graphs and statistics, which can help you spot trends and make adjustments to your management plan with your diabetes team.

#### DIABETES RECORD BOOKS

You can go old-school and write down your blood glucose levels, food, insulin and activity or exercise levels in a small record book. Your diabetes educator or doctor may have a supply, or you can buy your own online.

#### **PHONE APPS**

You can download apps to your phone that can record and track your blood glucose levels, as well as your activity, food intake and any illnesses. Many of the apps are free to download, while others may cost a few dollars. Give a few a try to see which is the best for you.

# YOUR BLOOD GLUCOSE METER

One benefit of a blood glucose meter is that it automatically stores your results. The downside is that scrolling through the historic data on the screen can make it difficult to see recurring patterns throughout the day, week or month.

#### **DID YOU KNOW?**

Blood glucose levels are measured in units called millimoles per litre (written as mmol/L) everywhere in the world... except for the US, which uses milligrams per deciliter (mg/dl) instead. That's why you'll sometimes see blood glucose readings like 140mg/dl or 220mg/dl in books or on the internet. To convert mg/dl to mmol/L, divide the US figure by 18.

# FINGER-PRICKS: TIPS TO HELP

There's no avoiding the fact that pricking your finger to test your glucose levels can be painful. Today we have ways of checking glucose levels using sensors inserted just under the skin (using continuous glucose monitoring, or CGMs), but you'll still need to prick your finger every now and then to calibrate or check the accuracy of your CGM. Here are some tips to help make it a little easier and less painful.

- There are various finger-pricking devices on the market, and you might find one more comfortable than another. Some lancets are thicker than others, so look for a shorter and finer variety. Ask your educator if they have any free samples you could try.
- Try different blood glucose monitors (some need less blood than others).
- Most devices allow you to adjust the depth of the needle, so if you're not getting a large enough drop of blood, play around to get the right depth. But remember that the deeper the needle goes, the more tissue you'll damage.
- The tips of your fingers can be more sensitive than other parts, so try pricking your finger off to one side.
- Use a fresh lancet every time, as it hurts more when they're blunt.
- Spread your sites and don't just use one finger.
- Instead of using alcohol wipes, just wash your hands beforehand.
- Some people prefer to gently 'milk' their finger before using the lancet, drawing more blood to that area.

- Once you've pricked your finger, let your hand hang down so gravity does the work for you.
- Be careful how vigorously you pump your finger for blood once your it's pricked. It can squeeze blood into the surrounding tissue, causing bruising and discomfort.
- It might be encouraging to know that monitoring your blood glucose becomes less painful over time.

#### YOUR BLOOD GLUCOSE LEVELS: THINGS TO KEEP IN MIND

- Keep a good record of your blood glucose levels. Review them regularly to look for patterns of highs and lows.
- Work with your doctor or diabetes educator to make adjustments to your insulin intake, diet and exercise.
- Learn what causes highs and lows for you. The more you recognise what triggers them, the better you'll be able to adjust your insulin, exercise levels or carbohydrate intake to avoid problems.
- Don't expect perfection!
   Just aim to get more of
   your readings within target.
- Ask for advice from your doctor or diabetes educator when you need it. They're there to help!



#### **TESTING FOR KETONES**

Ketones are the breakdown product of fat. They accumulate in the blood when you don't have enough insulin (often due to illness) or your kilojoule intake is too low. When too many ketones have built up, you can go into diabetic ketoacidosis (DKA), a very dangerous condition.

If your blood glucose level is high you should also monitor for ketones. You can do this by checking your blood using a blood glucose meter that also measures for ketones, or by using special strips that check your urine.

Ketones in your blood or urine can also be a sign that your insulin levels are too low. In that case, you'll need more insulin urgently, so your body can use glucose for energy instead of fat.

#### ABOUT HAEMOGLOBIN A1C (HBA1C)

As well as monitoring your blood glucose levels at home, your doctor or diabetes team will arrange for you to have a special blood test a few times a year. This checks your levels of glycated haemoglobin (also known as HbA1c).

When you check your blood glucose level you're measuring how many molecules (mmol) of glucose are in your blood at the specific time of monitoring. But your HbA1c result looks at your blood glucose for the last 1 to 3 months.

Glucose in your bloodstream will attach itself to the haemoglobin part of your red blood cells. If there's a lot of glucose in your blood, you'll have a higher number of haemoglobin with glucose attached.

The haemoglobin with attached glucose is called glycated haemoglobin, or HbA1c. As your blood cells (and your haemoglobin) live for around 120 days, the HbA1c test gives you an idea of how your blood glucose levels have been tracking over that time period.

# HBA1C MEASUREMENTS AND TARGETS

HbA1c measurements can be reported as percentages (HbA1c as a percentage of total haemoglobin) or the scientific unit of mmol/mol (which is HbA1c millimoles per mole of total haemoglobin).

Ideally you should aim to keep your HbA1c as close to 53mmol/mol (or 7%) as possible – as long as you can do this without significant episodes of hypoglycaemia. Research shows that keeping your HbA1c near this level can significantly reduce your risk of long-term complications.

Over time your targets may need to change, so talk to your diabetes team about what yours should be.

# HBA1C CONVERSION CHART FROM HBA1C % TO SI (SYSTEM INTERNATIONAL) UNITS

HbA1c (%)	HbA1c (mmol/mol)	HbA1c (%)	HbA1c (mmol/mol)
5.0	31	8.0	64
5.5	37	8.5	69
6.0	42	9.0	75
6.5	48	10.0	86
7.0	53	11.0	97
7.5	58	12.0	108

Source: mja.com.au/journal/2011/195/1/change-hba1c-reporting-new-si-units



# TIME IN RANGE (AND WHY IT'S IMPORTANT)

When using CGMs, your time in range (TIR) can be being used as another tool to check your glucose management over a longer period of time. CGMs can track the amount of time your levels have been in your target range, and the times you've been high or low. This is all recorded as your TIR.

#### **TIME IN RANGE VERSUS HBA1C**

While HbA1c is an important test to have done several times a year, it doesn't show how often your blood glucose levels have been too high or too low.

You can have an HbA1c of 7% (53mmol/mol) with your glucose levels ranging from

4-10mmol/L; you can also have an HbA1c of 7% with your glucose levels ranging from 2-22mmol/L. Your glucose levels in the last month will also contribute more to the HbA1c results than your glucose levels 2 to 3 months ago, which can cause a higher HbA1c. Conditions like pregnancy and anaemia can also impact your result.

#### YOUR TARGET TIME IN RANGE

Most diabetes experts agree that the ideal target range is 3.9-10.0mmol/L. There may be times when you'd want to have more of your glucose levels in this range, such as during pregnancy. There may also be times when it's safer to have higher glucose levels – for example, if you're having trouble recognising low blood glucose levels.



Overall, it's generally recommended that most people aim for:

- 70% of their glucose levels to be in range (3.9-10.0mmol/L)
- less than 4% of their levels to be lower than 3.9mmol/L
- less than 1% of their levels to be below 3mmol/L.

As a rule of thumb, a TIR of 70% usually matches with an HbA1c of 7% (53mmol/mol).

#### OTHER HEALTH CHECKS

You may be surprised that your doctor or endocrinologist focuses on factors other than just your blood glucose. The best diabetes management also looks at blood pressure and cholesterol levels.

This is because your risk of diabetes-related complications is lower when your blood glucose levels, blood pressure and blood fats are kept as close to normal as possible.

As well as blood glucose targets, you need to have your blood pressure checked regularly (at every visit to the doctor), and treated if necessary. For someone with diabetes, the target blood pressure reading is 130/80 mmHg or lower.

You'll also need to have your cholesterol checked every year. The target for total cholesterol is 4mmol/L, with different targets for 'good' and 'bad' cholesterols.

#### **GOALS FOR DIABETES MANAGEMENT**

HbA1c	••••	•••••	Less than or equal to 53mmol/mol
LDL cholesterol	••••	•••••	Less than 2mmol/L
Total cholesterol	••••	•••••	Less than 4mmol/L
HDL cholesterol	••••	••••	More than 1mmol/L
Triglycerides		••••	Less than 1.8mmol/L
Blood pressure	••••		Less than or equal to 130/80 mmHg
Body mass index (BMI)	••••	••••	Less than 25kg/m² (where practicable)
Urinary albumin excretion			Timed overnight collection: less than 20g/min Spot collection: less than 20mg/L Women albumin creatinine ratio: less than 3.5mg/mmol
Cigarettes or vapes	••••	•••••	Zero
Physical activity			At least 30 minutes walking (or equivalent) 5 or more days a week (equal to or more than 150 minutes a week)

Source: Diabetes Australia. Diabetes Management in General Practice 2009/10, 15th Edition



To live successfully with T1D you'll need to be fully in control of your diabetes management. This means having a daily management plan, setting goals, solving problems and taking responsibility. But that doesn't mean you're on your own. Clear, ongoing communication between you and your diabetes team is essential.

#### YOUR SUPPORT TEAM

There are lots of healthcare professionals who can help you achieve your goals. Here are a few you might want to check out in the months and years ahead.

# COUNSELLORS OR PSYCHOLOGISTS

Learning how to manage T1D can be hard – and it can be daunting, too. A mental health professional can give you (and your partner or family) support at any time.

#### **DIABETES EDUCATORS**

Credentialled diabetes educators are a goldmine of information on diabetes and how to manage it. They can help you learn about taking insulin, blood glucose monitoring, physical activity, shift work adjustments and lots more tips.

# DIABETES NURSE PRACTITIONERS

Diabetes nurse practitioners fall somewhere between endocrinologists and diabetes educators. As well as helping you learn about managing your diabetes, they can order or help arrange the routine investigations you need. They can also help you adjust your treatment when needed.

#### **DIETITIANS**

A specialist diabetes dietitian can give you helpful information on food choices, portion sizes, the glycaemic index (GI) and menu planning, all taking your own preferences into account. Dietitians are particularly useful if you also live with other conditions related to T1D, such as coeliac disease.

#### **ENDOCRINOLOGISTS**

An endocrinologist is a doctor who specialises in the endocrine system, which includes the pancreas and diabetes. You should see an endocrinologist at regular intervals every 3 months at first, then less often when you get into more of a routine with it all. You'll have been treated by an endocrinologist if you were admitted to hospital when you were diagnosed, and you can choose to see them again or find a different specialist. This will be a long-term relationship, so it's a good idea to find an endocrinologist you like and respect, who is conveniently located, and who you can contact for help when you're sick.

#### **EXERCISE PHYSIOLOGISTS**

An exercise physiologist is a university-trained professional who can help you develop an exercise plan that takes your T1D and personal circumstances into consideration.

#### **GENERAL PRACTITIONERS (GP)**

Your GP will focus on your overall health. They can also provide you with referrals to other specialists and order tests.

# OPHTHALMOLOGISTS OR OPTOMETRISTS

Eye damage from diabetes is very manageable with early intervention. To help keep eye damage at bay, make sure you have an annual check-up with an optometrist or ophthalmologist (these are medical doctors with additional specialist eye training).

#### **PHARMACISTS**

Make friends with your local pharmacist! They'll keep a record of the medications you take and can inform you of any side effects or interactions. To keep your healthcare bills to a minimum, it can also be a good idea to check out local discount pharmacies, too.

#### **PODIATRISTS**

As diabetes can affect circulation and sensation, feet are particularly vulnerable to damage and need careful attention. A podiatrist can help.

# CHECKLIST OF COMMON EXAMINATIONS AND TESTS

TIME INTERVAL	EXAMINATION/TEST	WHO TO SEE
Immediately	<ul> <li>Blood pressure</li> <li>Cholesterol</li> <li>Coeliac disease</li> <li>HbA1c</li> <li>Thyroid function</li> </ul>	Your GP or endocrinologist
Every 3 months	• Blood pressure • HbA1c • Weight	Your GP or endocrinologist
Every 6 months	• Dental exam	Dentist
Every year	<ul><li>Cholesterol</li><li>Coeliac disease</li><li>Flu vaccination</li><li>Thyroid function</li></ul>	Your GP (for vaccinations); GP or endocrinologist for the remaining tests

#### AFTER HAVING T1D FOR MORE THAN 3 YEARS, ADD ON...

Every year	Dilated eye examination     Foot examination	Optometrist/ophthalmologist     Podiatrist
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#### AFTER HAVING T1D FOR MORE THAN 5 YEARS, ADD ON...

Every year	<ul><li>Microalbumin urine test (spot urine test)</li><li>Serum creatinine</li></ul>	Your GP or endocrinologist
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#### FINDING THE RIGHT HEALTH PROFESSIONALS FOR YOU

In all areas of your life you'll come across people you click with and others you don't. The same is likely to happen with diabetes healthcare professionals.

You should now be under the ongoing care of a diabetes specialist or team, so it's important to find medical experts you feel comfortable with. You need to find people you can talk honestly with about your diabetes and any concerns you have. You need to like and trust them.

If you find yourself not liking the person or team you're seeing, or just don't feel comfortable with them, you have the right to get care elsewhere. Be proactive about it or you're likely to stop going to your appointments. That could affect your long-term health.

It might take some time and a few false starts before you find the best health professionals for you, but it's definitely worth persisting. To find experts in your area, you can:

- search the website directories of Australian Diabetes Educators Association (adea.com.au) or Dietitian Association of Australia (daa.asn.au)
- talk to your GP for recommendations
- ask friends in T1D Facebook groups who they see (JDRF's private Facebook group for adults living with T1D is a good place to start – see page 151 for details).

Your next step will be to ring around to ask about what type of services people provide, possible waiting lists and how much appointments cost.

The final step is to try them out!



#### **YOUR T1D MUST-HAVES**

- Blood glucose monitor (also called a glucometer or meter) and strips
- Blood glucose monitor batteries
- Book or app to record your blood glucose levels, food, activity and insulin doses
- GlucaGen HypoKit
- Hypo food
- Insulin
- Insulin pen or insulin pump (also pump batteries)
- Ketone strips (blood or urine)
- Lancing device and lancets
- Pen needles, syringe or infusion sets
- Sharps container
- T1D identification



#### **YOUR T1D SUPPLIES**



# WHAT YOU NEED WHEN HEADING OUT

There are some items you shouldn't be without. You'll need to replace these when supplies run low. They give you the flexibility to do what you like – if you're out and decide to stay at a friend's place, you'll be glad you took your overnight

insulin with you. And by carrying your blood glucose monitor, you can eat unfamiliar foods then check your blood glucose level later.

It's good to have a bag that has enough pockets so you can quickly find what you need, and that protects items from being damaged. It helps if it looks good so you won't mind carrying it around, too! Just search for 'diabetes bag' on the internet to find one you like the look of.



# YOUR INSULIN (AND YOUR PEN/SYRINGE/PUMP)

You should always carry insulin with you, as well as what you need to deliver it, even when you don't expect to eat. You never know when you might be out longer than you expect!

Be careful to regularly check the amount of insulin left in your vial, penfill or pump, as you don't want to run out of insulin.

Insulin pump users should also carry a spare infusion set and inserter as a back-up. Pumpers should carry some rapid-acting insulin and an alternate way of giving it, such as a syringe or pen, too.

If you use intermediate or long-acting insulin, you should take it with you when you go out at night. That way, if you end up sleeping over at someone's place you won't miss your evening or morning injection.

It's also a good idea to keep a spare pen and extra insulin in the fridge at work, in case you accidentally leave your insulin at home.

#### BLOOD GLUCOSE METER, STRIPS AND LANCING DEVICE

It might be tempting to leave your meter at home, but knowing what your blood glucose levels are doing will help you avoid hypos and reduce your risk of high blood glucose levels. If you feel that your meter is taking up too much space in your kit, have a look at the different meters available, as some are quite small. Others store the strips inside the meter so you don't have to carry them separately.

Other monitoring systems, like CGMs, let you check your glucose levels using your phone, but it's a good idea to still carry a meter as back up.

Many meters have software that lets you download your blood glucose results onto your computer, so you can see graphs of your levels to help you identify trends. If this is something you'd like, chat with your diabetes educator or your local pharmacist.

And of course you can't check your blood glucose levels without a lancing device and strips, so make sure you pack those too. There are a few types of lancing devices: some let you choose how deep the lancet will go, and others use a fresh lancet each time. Look at your options and find the one you like most.

#### **HYPO FOOD**

Be sure to carry at least one hypo fix with you at all times. If your blood glucose level is low you'll need to consume food or drink that contains around 15g of carbohydrate to help bring your blood glucose level back into the normal range; 6 to 8 large jelly babies or jelly beans should do.

Your hypo fix will often be in your bag or pocket, and it will need to be kept safe from opening or getting squashed. Some people like to keep it in a small airtight plastic container.

It's also a good idea to carry an extra hypo fix so you can treat yourself if you go low again or need more glucose.

# FINGER WIPES (OPTIONAL BUT HELPFUL)

It's important to have clean fingers when you check your blood glucose levels, as the accuracy can be impacted by any bits of food on your fingers. Usually you'll be able to wash your hands, but you might want to carry wipes with you for those times you can't.

#### **LOG BOOK OR APP**

Managing T1D involves balancing your insulin, blood glucose levels, food and activity, so having some way to track it all can be very helpful. Recording your readings will make it easier for you to see what may have caused a particular low or high, and can help you and your health professionals make long-term improvements in the way you manage your diabetes.

Companies that make insulin or blood glucose meters often provide free blood glucose record books. Your diabetes educator or doctor might have some, or you can buy them online. Books come in different formats for people using a pump or insulin pens.

There are also a lot of apps available. Many are free, so you can try out a few before deciding which app you like best.

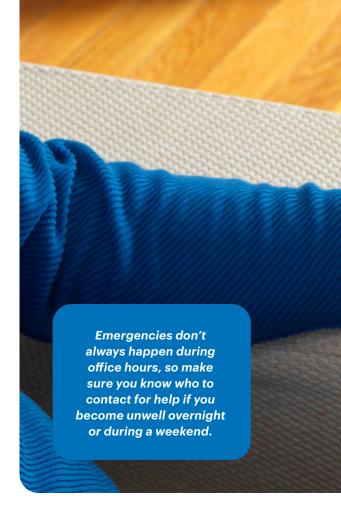
#### **T1D IDENTIFICATION**

It's a good idea for you to carry something that:

- identifies you as a person with T1D
- provides your doctor's contact details
- includes a brief description of the medication you're taking, and its dosage.

In the (hopefully unlikely) event you have a severe hypo, this identification will help health professionals give you the care you need. Organisations like MedicAlert Foundation provide a wallet card as part of its membership, or you can purchase one from Emergency ID Australia (when you do an online search for the company you'll see alternative options, too).

Most phones and smart watches now have a section where you can input your medical details, too. This lets people check for any conditions without needing your password to get into your phone.



You can add your details in the emergency SOS menu in your phone settings.

#### WHAT YOU NEED AT HOME

As well as having a bag of supplies ready for when you leave the house, there are a few things you'll need to keep at home as well.

#### **SHARPS CONTAINER**

Used sharps can't be put out with household rubbish, so a medical sharps container is essential for the safe storage and disposal of used pen needles, syringes and lancets. Sharps containers are available from pharmacies or online diabetes suppliers, and the sizes can vary (you can even get very small ones for travelling).



Check with your local pharmacy or council about the rules for sharps disposal, as these can vary.

#### **KETONE STRIPS**

You should always have some urine or blood ketone strips on hand so you can check your ketone levels. Ketones often build up when you're sick – which is exactly when you don't want to be trying to track down some strips!

#### **GLUCAGEN HYPOKIT**

Glucagon is a hormone produced by the pancreas that helps raise blood glucose levels. It does this by releasing alpha cells, which then trigger the liver to break down glycogen and release it into the bloodstream as glucose. The GlucaGen HypoKit contains a glucagon injection that's used to quickly raise blood glucose levels. It's used when someone has lost consciousness due to a severe hypo, or for those who can't take glucose by mouth.

The kit comes in a small case, which holds a syringe with sterile water and a container of glucagon. The instructions in the kit describe how to mix and draw up the solution, which is then injected into fat or muscle. It's a good idea to teach someone you live with how to use it (you can practice with an expired kit, or ask your diabetes team to help).

You need a prescription for a GlucaGen HypoKit. Make sure you check the expiry date regularly; it can also help to put a reminder to replace it in your calendar ahead of time.

### THE FINANCIAL IMPACT OF T1D

There's no doubt that living with diabetes will impact your budget, but there are a few ways you can minimise the costs. For more tips, visit **jdrf.org.au/finance**.

### PROFESSIONAL HEALTHCARE

When you have T1D, it's important to see a variety of health professionals regularly to keep yourself on track. The cost of seeing those health professionals will depend on who you see and where they work.

Most major public hospitals provide free diabetes services. While services vary, you'll generally have access to a range of diabetes healthcare professionals, including endocrinologists, diabetes educators and dietitians.

You might prefer to get care through the private health system. In this case, you may find that different diabetes professionals charge varying levels of fees, depending on their location and specialty. You should be partially reimbursed through Medicare. If you have private health insurance that may help cover your appointments too.

Australians with a chronic condition like T1D are able to use Medicare to access allied health services like podiatry, psychology and optometry. You can get a maximum of 5 rebated services each calendar year. Ask your GP for more details.

### PRIVATE HEALTH INSURANCE

Some private health insurance policies help cover the cost of an insulin pump. These are the main things to keep in mind when looking for cover:

- all gold tier policies cover insulin pumps, but you can also find silver and bronze level policies that cover them
- you only need hospital cover for an insulin pump (but you can also choose to get extras if you'd like them as well).

Search the Australian Government's private health insurance comparison site (privatehealth.gov.au) to find cover for insulin pumps. Just select 'insulin pumps' from the list of hospital services.

When looking at private health insurance cover for insulin pumps, check when the company will replace the pump once it's out of warranty. The pumps usually have a 4-year warranty, but some health funds make you wait an extra year for a replacement.

### OTHER FINANCIAL ASSISTANCE

You can use **bulk billing** for the blood tests and other pathology tests you need throughout the year – just ask your doctor to request bulk billing. This will mean they're free for you.

The **Closing the Gap** program helps support Aboriginal and Torres Strait Islander people who have a chronic condition. Sign up through your doctor or usual healthcare provider.

The Essential Medical Equipment
Payment is a yearly payment to help
with energy costs associated with
running essential medical equipment
or heating or cooling for medical needs.

The **Low Income Health Card** lets people on a low income get cheaper healthcare and some discounts. Income tests and residency rules apply.

The **Medicare Safety Net** provides financial assistance if you have high costs for out-of-hospital medical services that attract a Medicare benefit. Once you reach the Medicare Safety Net threshold, visits to your doctor and pathology tests will cost less for the rest of the year.

### MEDICATION AND CONSUMABLES

#### **BLOOD GLUCOSE MONITORS**

Blood glucose monitors vary in price but are usually less than \$100. There are lot of types available. There's no right or wrong meter, so just choose one you like.

#### **CONTINUOUS GLUCOSE MONITORS**

There are a number of continuous glucose monitors (CGMs) available in Australia. The Federal Government provides access to subsidised CGMs for eligible people through the National Diabetes Services Scheme (NDSS). All Australians with T1D can apply. Some people can access fully subsidised CGMs (so they're not out of pocket at all), while others make a co-payment. Speak to your diabetes team or contact the NDSS for more details.

Without the subsidy, the annual cost of using a CGM varies. You can expect to pay between \$2500 and \$5000 a year.

#### **GLUCAGEN HYPOKIT**

A GlucaGen HypoKit is used to treat severe hypoglycaemia if you can't eat or drink anything. You need a prescription to buy it from a pharmacy. The cost is partially covered by the Federal Government, so it will cost a little over \$30, or around \$7 with a concession card.





#### **INSULIN**

Insulin is available on the Pharmaceutical Benefits Scheme (PBS). This means if your doctor provides you with a prescription, and you're eligible for Medicare, the cost of the insulin will be subsidised by the Federal Government.

If you use syringes or an insulin pump your prescription will cover 5 x 10ml vials of insulin; if you use an insulin pen, it will cover 5 boxes of 5 x 3ml pen fills. This amount should last you between 3 and 6 months. Your doctor can also include a repeat prescription. Remember that prescriptions are only valid for 12 months.

#### **LANCING DEVICES**

Lancing devices are usually provided with blood glucose meters. Replacement packets of lancets are available through

online diabetes stores or your local pharmacy; prices vary, starting under \$10.

#### **OTHER MEDICATIONS**

Your doctor may prescribe you additional medications – for example, to reduce your cholesterol levels, or to lower your blood pressure. These are sometimes taken as a precaution to reduce the risk of future diabetes complications. You may need to factor these other medications into your budget.

#### **SHARPS CONTAINERS**

Used syringes or pen needles shouldn't be put in your household bin, so you'll need to buy an approved sharps container. These can be bought through your local pharmacy or online diabetes stores, starting at a few dollars for a small bin.



Blood glucose and urine ketone strips, insulin syringes, insulin pen needles and pump consumables are subsidised by the National Diabetes Services Scheme (NDSS), which is administered by Diabetes Australia. You have to be eligible for Medicare to qualify. There's no cost to register, and you don't need to be a member of Diabetes Australia to be eligible.

To register, you'll need to complete a form, have it signed by your GP, endocrinologist or diabetes educator, and return it to Diabetes Australia. You'll then get an NDSS card, which you'll need when ordering diabetes products (keep it in your wallet and/or save it in your phone!).

NDSS products can be bought through NDSS-registered pharmacies. These pharmacies have an NDSS sign in the window or at the counter (or you can ask the staff).

You can also buy diabetes supplies at non-NDSS pharmacies, but the cost won't be subsidised by the Federal Government. This means they'll probably be a lot more expensive.

For more information, visit ndss.com.au



# CONNECTING WITH OTHER PEOPLE WHO 'GET IT'

We can't overstate the value of talking to other people with T1D. There's real comfort in knowing that you're not the only one living with the condition. Of course everyone is different and your diabetes is unique to you, but hearing the experiences of other people and learning what's worked (and not worked) for them can help you develop your own management strategies, too.

### There are lots of ways to get in contact with other people with T1D. You can:

- talk to your diabetes educator about upcoming meetings or education sessions where you could meet local people with T1D
- talk to your doctor and other members of your diabetes team
- contact organisations such as JDRF or Diabetes Australia to find support groups in your area.

Once you tell people about your own T1D, you may be surprised how many people have connections to others with the condition, too.

#### FINDING SUPPORT ONLINE

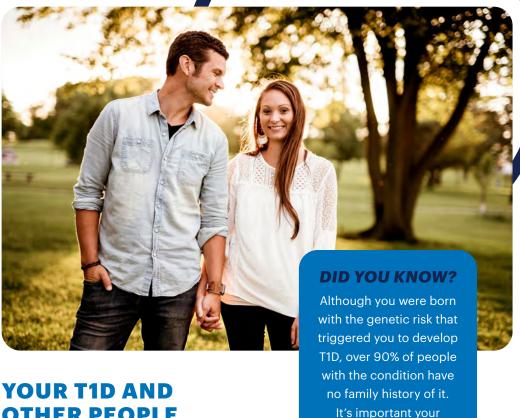
There are lots of websites and support groups online, as well as groups on social media. Search for 'type 1 diabetes' with your suburb or region on social media or in a search engine and you may find a local group.

JDRF also offers private Facebook groups. Depending on your age, you can join our group for young people aged up to 24, or our group for people 25 and over. Just be sure to answer the questions when you request to join!

### Check out all JDRF's private groups at jdrf.org.au/facebook

You may also like to become more involved with the type 1 community through JDRF. Follow us on Facebook, Instagram, YouTube and LinkedIn to learn about our community events. You can also get JDRF's monthly newsletter to stay in the loop – sign up at jdrf.org.au/newsletter.





**OTHER PEOPLE** 



It's not easy being diagnosed with T1D. It can also not be easy to tell your partner, family or friends the news. Here's some advice to keep in mind.

#### **TELLING YOUR** PARTNER OR FAMILY

Just a heads-up: family members, particularly parents, may be distressed by your news, and blame themselves for your diagnosis. And it's perfectly normal for you to not want to have to deal with their emotions on top of your own!

But it's often easier telling them sooner rather than later. It's okay to tell them you need space to process your thoughts. The people who love you should be there to help you when you're ready to talk.

You might find that people show concern for you in ways you find annoying. They could constantly check how you're feeling, or ask whether you need to eat, check your blood glucose or take your insulin. They're doing this because they care for you, but it can put pressure on your relationship. It can help to explain how they're making you feel. Find a good time to talk about it calmly and openly.

parents know that your diabetes isn't their fault (or yours either!).

Misunderstandings about T1D and how it's managed can also cause friction. You might want to take your partner or family members with you when you next see your endocrinologist or diabetes team. This can help clear up any confusion on their part.









JDRF LIVES.
CURING
TYPE 1
DIABETES.

Type 1 diabetes: a guide for friends and loved ones



### TELLING FRIENDS AND COLLEAGUES

Friends who know about your diabetes can be a source of support. Having friends who are willing to listen to how you're feeling, even if they don't have diabetes themselves, may help you better adjust to living with diabetes.

Chances are you didn't know a great deal about T1D before your diagnosis – and your friends, family and colleagues are probably the same. Be open with them about your experience, as it will make it easier for them to understand what T1D is all about. Let them know they may be able to offer practical help – for example, they'll be able to assist you if you have a low blood glucose level and don't have any food on you to treat it.

When making new friends or meeting new workmates, it's normal to not want to tell them about your diabetes straightaway.

But telling them sooner, rather than later, can help. For example, if they don't know you have T1D and you have hypoglycaemia, they may think you're drunk or just rude. Depending on how you feel, you might want to simply explain that you have T1D and that you need to inject insulin. You might consider letting them know about hypos and what to do if you have one.

### TELLING POTENTIAL EMPLOYERS

When applying for a job, one of the big questions is whether you should tell potential employers that you have diabetes. It's understandable if you don't want to tell anyone until you're in the role. Your decision about whether or not to disclose your condition is personal, and will depend on your unique circumstances and what you're comfortable with. This is covered in detail from page 88, in the section about T1D and work.

# COPING WITH THE IGNORANT THINGS PEOPLE SAY

A lot of people have very little knowledge about T1D, which can lead to them saying some ignorant (and downright rude!) things. It's best to be prepared, so here are some common things people say, and what you might want to reply with.

### "DO YOU HAVE TO INJECT IN PUBLIC?"

#### What you wish you could say

"I'm sorry you're so offended seeing what I have to do each day to stay alive. Why don't I just take my sterile insulin pen into the toilet and have my injection there for *your* convenience."

#### What you could say

"This is the most practical and hygienic place for me to do this. I can let you know in advance when I'm going to do it so you can look away for a moment."

#### "MY AUNT HAD T1D BUT SHE CURED HERSELF. WHY DON'T YOU TRY WHAT SHE DID?"

#### What you wish you could say

"She's the first person ever to be cured of T1D – I missed the news when that big announcement was made! And it's kind of weird that I've never heard of the company that must surely be bringing her miracle cure to market."

#### What you could say

"T1D is an autoimmune disease, and there's no cure yet. It sounds like your aunt had type 2 diabetes. That's a different type of diabetes that can often be controlled by changes to diet and lifestyle."

### "SHOULD YOU BE EATING THAT TIM TAM?"

#### What you wish you could say

"Eating this is nowhere near as dangerous to me as being the food police is to you."

#### What you could say

"People with T1D can eat whatever they like – the only difference is that we add our insulin manually. When I eat a Tim Tam I just need to take a bit of extra insulin to cover the carbs. All things in moderation!"

#### "I GUESS YOU HAD A LOT OF SUGAR WHEN YOU WERE LITTLE"

#### What you wish you could say

"You must have swallowed a lot of unreliable information when you were little."

#### What you could say

"You're thinking of type 2 diabetes – it's sometimes caused by diet or lifestyle. But I have T1D. It's an autoimmune condition. It's nothing to do with diet or lifestyle, and wasn't caused by anything I did or didn't do."

#### "AREN'T YOU A LITTLE OLD TO BE DIAGNOSED WITH THAT?"

#### What you wish you could say

"It's funny you should say that, because all this happened a day after I started using one of those face creams that promises to make you look years younger."

#### What you could say

"Not at all. Around 8 Australians are diagnosed with T1D every day, and about half of them are adults. You can be diagnosed at any age."





### DIABETES IN THE MEDIA



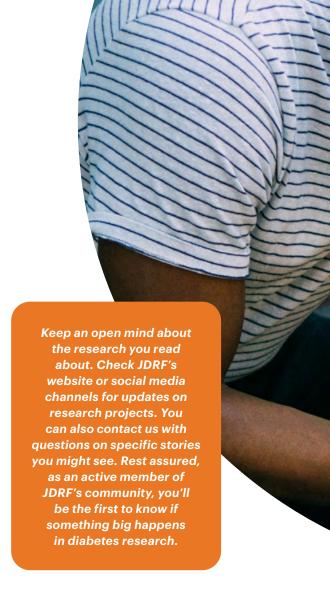
Once you have a connection to diabetes, you'll probably notice more stories about it in the news and on social media. Even if you don't see the stories yourself, a well-meaning person will probably send them to you! Here are a few points to keep in mind.

# THE CURE YOU HAVE WHEN YOU'RE NOT HAVING A CURE

You click onto a news site or social media, and there's yet another story about a diabetes breakthrough. Is it a real cure this time, or just another bit of interesting science? The truth is probably somewhere between the two.

Researchers face the constant challenge of publicly explaining very complicated research results in the simplest way possible. They're under pressure to emphasise the importance of their breakthrough, but to also explain their findings in a 30 second soundbite that makes sense to people outside the research community.

In reality, it can take years for a research project to proceed from the laboratory bench into the form of a readily available treatment for those who need it. That's not to say that a cure won't be found (it's what JDRF is working towards every day!). But it's important to recognise that most research reported in the media is more likely to be an important step towards finding a cure, preventing the condition, or treating people who currently live with it.



### MEDIA AND PUBLIC (MIS)UNDERSTANDING

As a whole, diabetes is a condition that is often in the media. There are a few factors behind this, including dramatic increases in the number or people with type 2 diabetes, a government focus on preventative health, and a spotlight on obesity. While diabetes is often in the news, it's not always portrayed accurately. Unfortunately this can have a big effect on how the public understands different types of diabetes.



The most common misunderstandings are caused by confusion between type 1 and type 2 diabetes. Journalists will often generically refer to 'the risk of diabetes' when talking about obesity, or include images of overweight children when talking about T1D. These kinds of inaccuracies can result in feelings of frustration, anger or victimisation by members of the T1D community.

JDRF places a strong focus on correcting these misconceptions, but there are things you can do to help, too.

If you see an incorrect or misleading news story, you can write a letter or email to the journalist, outlining the mistake they made. You can also contact the editor. If the story has been shared in a social media post, you might also like to make a comment sharing the facts.

Otherwise, you could tell your story to the media during special awareness times, such as National Diabetes Week. You could also become a JDRF advocate to help change the way politicians view T1D. Learn more at jdrf.org.au/advocacy.



**SECTION 2** 

# LEARNING TO LIVE WITH TYPE 1 DIABETES

#### A GUIDE TO INSULIN



Before you developed diabetes your pancreas would release insulin across the day, and also produce surges of insulin in response to food. Now that you have type 1 diabetes (T1D), you need to do the job of your pancreas yourself. This means injecting the right type and amount of insulin at the right times, and managing your lifestyle to try and maintain a hold on fluctuating blood glucose levels.

#### **INSULIN TYPES**

There are 6 main types of insulin used in Australia. Most people need to use 2 or more kinds to mimic the role of the pancreas as closely as possible. Each insulin differs in how quickly it acts and how long its effect lasts. They are:

- co-formulations
- · intermediate-acting insulin
- · long-acting insulin analogues
- pre-mixed insulin
- rapid-acting insulin analogues
- short-acting insulin.

It's common to use a longer-acting insulin preparation once or twice a day. This is **basal insulin** (it's also called background insulin). Basal insulin helps keep your blood glucose levels steady between meals and overnight.

Rapid or short-acting insulin is usually used in addition to basal insulin. This is used to pack away excess glucose that enters your bloodstream when you eat, or corrects high blood glucose levels. This is **bolus insulin**.

#### A FEW IMPORTANT TIPS TO REMEMBER

- Always check the expiry date before opening a new bottle or penfill of insulin.
- Make sure you have at least 1 spare bottle or penfill of each type of insulin you use, in case of accidental breakage.
- Pharmacies won't necessarily stock the type of insulin you use

   they might need to order it in.

   Don't wait until you're out of spares before ordering more.
- Extreme heat and cold will affect your insulin, so keep any spare bottles or pens in the fridge.

### BUYING AND STORING INSULIN

Insulin preparations are available on the Pharmaceutical Benefits Scheme (PBS). This means the cost of insulin is subsidised by the Federal Government through the National Diabetes Services Scheme (NDSS).

The insulin you're prescribed will depend on whether you're using syringes, pens or a pump. For each prescription you'll get one of the following:

- 5 x 10ml bottles of insulin
- 5 boxes of 5 (25 in total) x 3ml penfills
- 5 boxes of pre-filled pens.

This amount of insulin should last you 3-6 months. Your doctor can also include a repeat on the prescription – but remember that repeats are only valid for 12 months after they're written.

Spare bottles or pens of insulin are best stored in the fridge between 2-8°C. This will give it a longer storage life. Be careful not to freeze it, as it will then lose its effectiveness and need to be thrown away. Heat will also affect insulin; don't leave it in your car or where it may get too hot. If you're travelling, you can buy special packs that will keep your insulin cool even on hot days or long flights.

You can keep the insulin bottle or penfill you're using at room temperature. Once opened, you can use an insulin bottle for a month. Any left after that time needs to be thrown out, as it may not be as effective.

#### **INSULIN DEVICES**

#### **INSULIN PENS**

Many people with diabetes use an insulin pen. Different brands and models are available, and which one you use will depend on the brand and insulin you use.

Insulin pens can be disposable or reusable. A disposable pen contains a penfill, and once it's empty you throw away the entire pen. A reusable pen uses a replaceable penfill; once the cartridge is empty, you remove it and replace it.

#### **SMART PENS**

Smart insulin pens can record the amount and timing of each insulin dose. They then transmit the information to a phone app via Bluetooth. The app makes dosing recommendations, with suggested doses adjusted for insulin on board (the insulin still active from a previous insulin dose). The apps can integrate with your CGM and provide helpful reminders, alerts and reports. Smart insulin pens are reusable.

#### **INSULIN PUMPS**

Insulin pumps are small computerised devices that deliver a slow continuous level of rapid-acting insulin throughout

the day and night, providing basal insulin. The insulin is delivered through a cannula (a tiny plastic tube) under the skin, which is changed every 3 days.

Pumps only use rapid-acting insulin. As a result, small doses of insulin are delivered every 5 minutes to provide basal insulin coverage. Pumps can be programmed to vary the rate of insulin delivery based on the time of the day, tailored to your own needs (such as getting more insulin in the morning and less overnight). Your pump can be set to temporarily adjust your insulin delivery rate when your insulin needs are higher or lower, such as when you're stressed or more active.

Insulin pumps are also programmed with information that's used to calculate bolus insulin doses. These are needed to cover the glucose entering your bloodstream after a meal, or to correct a high glucose level. Pumps use lots of information to calculate a bolus insulin dose, including:

- your insulin to carbohydrate ratios (the grams of carbohydrate that 1 unit of insulin will cover)
- your insulin sensitivity or correction factors (the mmol/L change in blood glucose per 1 unit of insulin over 2 to 4 hours)
- your target glucose ranges.

Pumps can be programmed with an active insulin time (how long it takes for bolus insulin to do its job). This helps reduce the risk of insulin stacking, or overcorrecting. Insulin stacking is what happens when doses of rapid-acting insulin are taken close together, and can lead to low blood glucose levels (hypoglycaemia).

Most pumps also have extra features, like extended bolus delivery. This can help better match a delay in glucose entering the bloodstream when eating a meal with carbohydrate and high fat and/or protein.



Pumps can be used with continuous glucose monitoring (CGM) systems. These automate insulin delivery to varying levels. In some systems, basal insulin delivery is suspended when a low glucose level is reached or is predicted to be reached in the next 20 to 30 minutes, helping reduce the risk of hypoglycaemia. Other systems increase and decrease insulin delivery in response to your sensor glucose readings, and give correction boluses to minimise hyperglycaemia. But even if you're using automated systems, you'll still need to count carbohydrates and give yourself insulin before meals.

#### **TUBELESS INSULIN PUMPS**

Most pumps use thin plastic tubing to deliver insulin from the pump to the body, but tubeless insulin pumps are also available. These are sometimes called patch or pod pumps. Instead of tubing, the patch pump is attached to the skin, and a cannula is inserted underneath it. The patch needs to be replaced every

#### WHEN USING A PUMP, KEEP IN MIND ...

If your glucose level rises and you can't explain why, there's a chance the cannula under your skin is kinked, or has dislodged. This can make your blood glucose level rise, and ketones can then develop. If in doubt, change your infusion set or patch pump.

It's also a good idea to keep a back-up supply of long-acting insulin, just in case your pump fails. Long-acting insulin should be taken as soon as possible after a pump fails, and the dose should be repeated every 24 hours until a replacement pump is available. If you don't have long-acting insulin, short-acting insulin can be given by injection every 2-3 hours. If you're using an insulin pump, it's important to ask your diabetes team for a pump emergency plan.

3 days. These pumps need to be used with a personal delivery manager (PDM), which sends information to the pump for insulin delivery. PDMs are about the size of a mobile phone. At the moment, there's no phone app to program patch pumps. These pumps aren't integrated with CGMs, so they can't automatically adjust insulin delivery if glucose levels are rising or falling.

#### **DIY LOOPING**

Some people have developed their own 'closed loop' system, using a DIY model that lets insulin pumps and CGMs 'talk to' each other. These devices haven't gone through Australia's strict regulatory processes, so safety should be your top priority if you're looking at this option. If you'd like to learn more, search Facebook for Australian DIY looping groups.

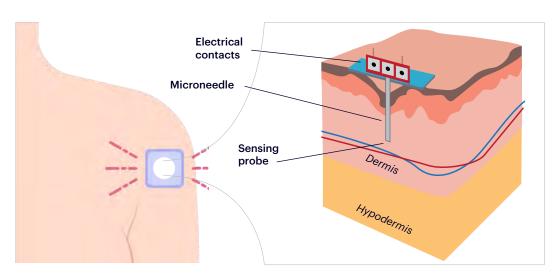


### CONTINUOUS GLUCOSE MONITORS (CGMS)

Traditionally, people with diabetes needed to prick their fingers throughout the day to check their glucose levels. Thankfully it's now possible to measure glucose levels 'continuously' (but there are still times when you might need to do

a finger-prick, such as if you need to confirm your sensor reading).

There are a number of different CGM systems now available in Australia. The system you use will depend on a few factors, including whether you're using injections or an insulin pump to manage your diabetes.



An example of a continuous glucose monitor (CGM) system.



#### WHEN USING A CGM, KEEP IN MIND...

Glucose levels measured by a CGM sensor can lag behind levels in the blood, especially when they're changing quickly. This means your CGM can still show that your glucose level is low for up to 30 minutes after you've had food to treat a hypo. To help reduce the risk of rebound highs, it's best to check your levels with a finger-prick before having another hypo treatment.

You can get inaccurate results (typically false lows) if the sensor moves, so it's important to put it somewhere it won't be knocked. Lying on your CGM can also give a false low reading.

You can get false high readings if you've taken paracetamol or a high dose of vitamin C. Always do a finger-prick if your CGM reading doesn't feel right.

#### **HOW CGMS WORK**

All CGM systems use a sensor or a tiny electrode that's self-inserted under the skin. This sensor is replaced every 7 to 14 days, depending on the system. The sensor is attached to a transmitter or small disc.



The sensor measures the level of glucose in the fluid in your tissue every 1 to 5 minutes.



The transmitter sends the reading to a device, such as a phone app or insulin pump.



The CGM system uses this reading to estimate how much glucose is in your blood.

Alarms can be set to alert you when your glucose level is too high or too low. As measurements are taken every 1 to 5 minutes, you can also see which direction the glucose level is trending. Some systems can alert you up to 20 to 30 minutes before the sensor glucose is expected to be too high or too low, letting you take action early.

Some systems now let you view your CGM data on some smartwatches. The smartwatch doesn't actually monitor glucose levels; it just gets data from the CGM sensor and transmitter via an app.

#### KEEPING YOUR CGM SENSOR ATTACHED

Some people have a hard time keeping sensors attached, particularly if they spend a lot of time in the water or if they sweat a lot while exercising or working. Sensors can also get displaced while playing sport. Unfortunately, sensors can't be reused once they come off. To help prevent this it's best to place the sensor where it's less likely to be knocked – for example, at the back of the arm.

Using over-tape can also help keep your sensor on. You can get transparent hypoallergenic films or kinesiology tape-like products. These come in a variety of pre-cut sizes and shapes, as well as rolls for custom cutting.

Spraying on antiperspirant (unscented) can also help with skin that often gets sweaty. Using wipes such as skin glue or Skin Tac can help keep them sticky, too.

### DEALING WITH COMMON CGM SKIN ISSUES

Some people occasionally develop hypersensitivity to CGM sensors, their over-tapes or pump infusion sets. Cleaning the area with antibacterial soap and rotating through multiple sites can help.

Applying nasal steroid spray to the skin before inserting a sensor or pump infusion set can also help, while liquid barriers like Cavilon offer protection from adhesive glues.

Careful removal techniques can help reduce skin irritation, so try to remove your sensor or pump adhesive tapes slowly. Removal aids such as Niltac and adhesive removal wipes help loosen the adhesive glue from the skin. You can also try household oils, like baby oil or olive oil.

#### **HOW TO INJECT INSULIN**

Insulin needs to be injected into the layer under your skin, so it's best to pinch up the skin to get to the right depth.

Rapid or short-acting insulin is best injected into your abdomen, as it's absorbed quicker from here. Your outer thigh and upper buttocks can be used as alternate sites for longer-acting insulin.



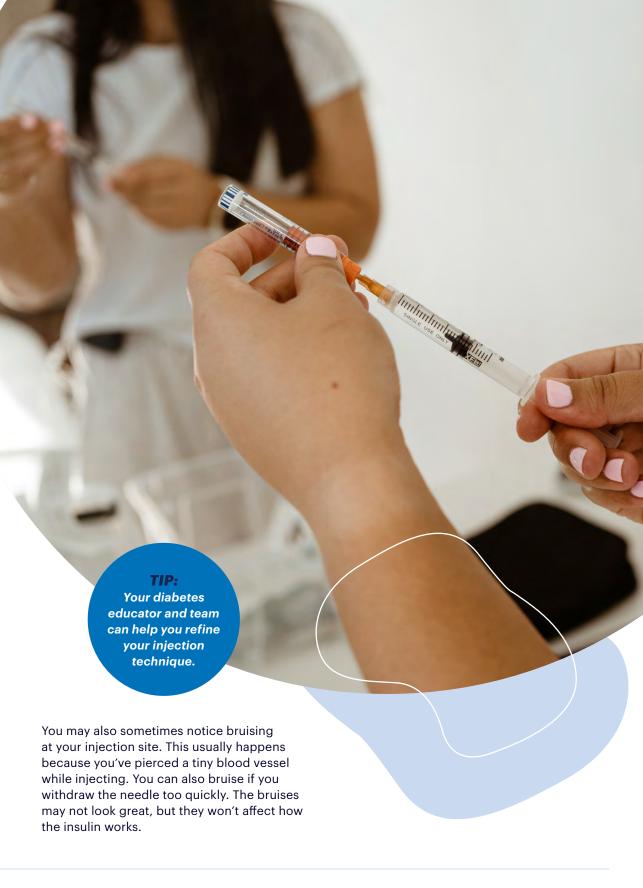
Lipohypertrophy is an abnormal build-up of hard tissue under the skin. It can happen in areas of repeat injection, and these lumps are thought to affect insulin absorption. You can avoid it by rotating your injection sites for example, inject into a different part of your stomach each time throughout the day.

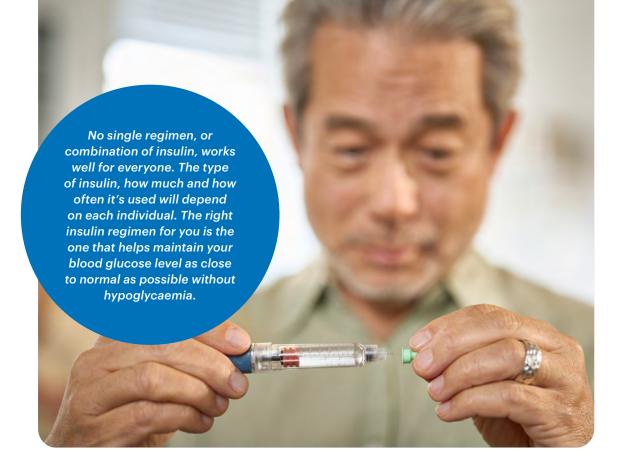
#### **GETTING USED TO INJECTIONS**

Giving your first injection can be a daunting experience. However, over time, you'll probably become much more relaxed about injecting yourself.

If the injections hurt a lot, you may be injecting the insulin just under the skin, where you have a lot of nerve endings. The needles are best given at a 90° angle using a 4-6mm needle, but your diabetes team may personalise this for you.

Using different insulin preparations or injecting insulin straight from the fridge can also help make the experience less painful or uncomfortable.





### CALCULATING HOW MUCH INSULIN YOU NEED

Your endocrinologist or diabetes team will help work out how much insulin you need. You'll probably need a couple of different insulin preparations to best manage your diabetes. Your team will also help you decide on what combination of insulin is right for you.

# WORKING OUT HOW MUCH INSULIN TO TAKE WITH FOOD

To try to mimic the mealtime release of insulin, you may be asked to count how many carbohydrates you eat, and take a dose of rapid or short-acting insulin to cover the total number of carbohydrates in each meal or snack. Your diabetes team or endocrinologist will help you decide how much insulin to give for each

carbohydrate. They may refer to this as your 'insulin-to-carb ratio'.

An initial insulin-to-carb ratio is usually calculated using the '450 rule'. This rule states that you can estimate your insulin-to-carb ratio by dividing 450 by your total daily insulin dose. For example, if you need around 45 units of insulin a day, your initial insulin-to-carb ratio would be 1 unit of insulin per 10g of carbohydrate (450÷ 45 = 10).

A carbohydrate exchange is a serve of food that contains 15g of carbohydrate. A third of a cup of cooked rice or a sandwich slice of bread are both examples of a 15g carbohydrate exchange. Using the 450 rule, if you're counting in exchanges of carbohydrate instead of grams, your insulin-to-carb ratio would be 1.5 units per 15g carbohydrate exchange.

For example, if you have a ham and cheese sandwich and a large apple for lunch (containing around 60g of carbohydrate, or 4 exchanges), injecting yourself with 6 units of rapid-acting insulin should result in your blood glucose level returning to 1 to 2mmol/L of your pre-meal blood glucose within 2 to 3 hours.

It probably sounds daunting to be making these decisions yourself, but learning how to count carbohydrates and understand your insulin-to-carb ratio will give you more freedom to decide how much you want to eat at each meal.

Get more details in the 'All about food' section of this book from page 67.

#### MANAGING HIGH OR LOW BLOOD GLUCOSE LEVELS BEFORE A MEAL

If your blood glucose level is high before you eat, and you only take enough insulin to cover the carbohydrate in your food, your blood glucose level will still be high after the meal. Taking some 'extra' insulin with your meal will help get your levels back close to the normal range in about 3 to 5 hours, depending on the type of insulin you're using. Most people call this a 'correction'.

Just as your diabetes team will help you work out your insulin-to-carb ratio, they'll also help you calculate your 'insulin sensitivity' or 'correction factor'. The goal of the sensitivity factor is to give you a personal estimate of how much a single unit of insulin will lower your blood glucose level, and how much extra insulin you'll need to return your blood glucose levels to normal if they're high.

It's important to remember that your sensitivity factor is just an estimate, so there'll be times when 1 unit of insulin will lower your blood glucose level by more than this, while other times it will lower your levels less. Monitoring your blood glucose levels will help you see if this sensitivity factor is right for you (most of the time) or if it needs modifying.

Your insulin sensitivity factor can also be used if your blood glucose level is too low before a meal. In this case you would subtract an amount of insulin from your mealtime or bolus injection.





### INSULIN LEVELS RIGHT

The amount of insulin you need to inject each day is influenced by your age, your weight and how long you've been living with diabetes.

As an adult, once all your beta cells have been destroyed, you'll probably need to inject around 0.5 to 0.7 units of insulin per kilogram of body weight each day to keep your blood glucose levels in near target range. Around half of that will be given as basal (background) insulin.

In this case, if your blood glucose

level was 12mmol/L before a meal

and your goal blood glucose was

7mmol/L, taking an extra 2 units of

insulin with the meal would help bring your blood glucose level down by

5mmol/L, to the target level, within

3 to 5 hours. And if your blood

glucose level was 4.5mmol/L before

a meal, you would subtract 1 unit of

insulin from your mealtime bolus.

Intermediate or long-acting insulin is often given once or twice a day to mimic the basal insulin profile of people without diabetes.

Monitoring your blood glucose levels before meals will help you and your diabetes team work out whether your basal insulin levels are right. Ideally, your blood glucose level should be around 5-7mmol/L when you wake up and before meals. Blood glucose levels consistently above these targets would usually mean that your basal insulin dose needs to be increased, while blood glucose levels consistently below your targets would mean that your basal insulin dose needs to be decreased.

In general, basal insulin is adjusted by 2 to 4 units per day every few days until your blood glucose levels are in the target range. If you're injecting basal insulin twice a day, the morning injection should be adjusted if your blood glucose levels before lunch or dinner aren't within target. The evening dose should be adjusted if you're concerned about your levels overnight or on waking. As always, you should talk to your diabetes team to work out safe dose adjustments for you.

### WHAT TO DO IF YOU MAKE A DOSING MISTAKE

Like everything in life, taking your insulin regularly will become a habit. But if you're not concentrating, or you're in a hurry, you may make a dosing mistake. It happens - don't beat yourself up about it! But it's good to know what to do next.

If you take too much rapid-acting or short-acting insulin, you'll need to watch your blood glucose for the next 3-6 hours. You'll also have to balance the extra insulin by eating carbohydrates every hour or so, if needed, to stop your blood glucose level from dropping too low.

If you haven't taken enough insulin with your meal, or you've forgotten to take it, and you've realised within half an hour of eating, you can compensate by taking extra rapid-acting or short-acting insulin (a correction dose). The extra insulin dose should be based on how many extra grams or exchanges of carbohydrate you had in your meal.

Taking extra insulin more than half an hour after food can increase your risk of hypoglycaemia before the next meal. It may be safer to leave your high blood glucose level untreated, unless you haven't taken any mealtime insulin at all. In this case, you should check your blood glucose and use your sensitivity or correction factor to decide how much insulin to take.

If you take intermediate or long-acting insulin more than once a day, and you confuse your morning and evening doses, you'll need to check your blood glucose level every few hours and balance your blood glucose with extra food. Taking a larger dose of intermediate or long-acting insulin will put you at risk of hypoglycaemia for many hours. Generally, 1 to 2 exchanges of carbohydrate every 2 to 3 hours should be enough to prevent hypoglycaemia at these times. You should also set your alarm to wake you up so you can check your blood glucose levels every 2 to 3 hours if you've accidentally taken extra insulin at night.

Talk to your diabetes team if you often have trouble remembering if you've taken your insulin dose. There are insulin pens that let you check your last dose, including how much and when you took it. These pens are easy to use and can help you from under- or double-dosing.



# TROUBLESHOOTING UNEXPLAINED HIGH OR LOW GLUCOSE LEVELS

If you have ongoing unexplained high blood glucose levels, you should make sure your insulin is still okay to use. Check the expiration date. You should also check that it looks as it should. To do this, turn your insulin vial or penfill upside down – if you see any tiny particles, it's probably gone bad and needs to be replaced.

If your high blood glucose levels coincide with a new batch of insulin, the insulin may have been damaged due to issues with storage. Try a new batch.

If you're using a pump, check your line isn't kinked and that your infusion set is properly attached. If everything is okay there's a high chance the cannula is kinked. You should give yourself a correction dose of insulin using a syringe or insulin pen and re-site your cannula.

IMPORTANT NOTE: Some CGM systems can give false high readings after you take paracetamol. Don't dose insulin based on your CGM if you've taken Panadol or other medications containing paracetamol in the last 4 to 6 hours. In that case, you'll need to rely on finger-prick checks instead.

#### POTENTIAL CAUSES OF HIGH BLOOD GLUCOSE READINGS

- Being less active than usual
- Eating too much carbohydrate
- Emotional or physical stress
- Illness
- Infection
- Menstruation
- Other medications
- Outdated or bad insulin
- Pregnancy
- Taking insulin after your meal
- Too little insulin

# POTENTIAL CAUSES OF LOW BLOOD GLUCOSE READINGS

- Being more active than usual
- Drinking alcohol without eating sufficient carbohydrate
- Illness
- Not eating enough carbohydrate
- Too much insulin

### WHAT YOU NEED TO KNOW ABOUT HYPOS

When you have diabetes and inject insulin, there'll be times when you have too much insulin in circulation. This may be because you accidentally injected more than you needed, or you were more active than you thought you'd be, or your meal was delayed, or your meal ended up having less carbohydrate than you'd guessed. It could also just be because the insulin preparations we use aren't perfect and don't work exactly the same each day!

No matter the cause, there'll be times when you have too much insulin and your blood glucose level drops below 4mmol/L. This is known as hypoglycaemia, or a 'hypo'.

Having a hypo can be a scary experience. The symptoms can vary for different people, but they may include:

- blurred vision
- · changes in behaviour
- difficulty concentrating
- dizziness
- feeling anxious
- hunger
- shaking
- · sweating.

If you feel like this, you should check your blood glucose level. If it's low, you'll need to eat or drink something that contains carbohydrate to bring your blood glucose back up into the normal range.

How much carbohydrate you need will depend on how low your blood glucose has dropped. In general, 1 exchange (or 15g) of carbohydrate will raise your blood glucose level by about 2-3mmol/L.

The amount of carbohydrate you need will also depend on the timing and cause of your hypo. For example, if it's due to increased exercise or taking too much insulin, you might also need to eat a snack to prevent a further hypo. You're also likely to need less carbohydrate to treat a hypo if you're using an insulin pump that reduces insulin delivery in response to your sensor glucose readings.

### Examples of a quick hypo fix (or 15g of carbohydrate) include:

- 150ml of normal (not diet) soft drink
- 3 Glucodin tablets
- 6 to 8 large jelly beans.

You need to carry a hypo fix with you at all times. You might keep them:

- beside your bed
- in your back pocket
- in your car glovebox
- in your desk drawer
- · your handbag or backpack.

Sugary fluids, like juice or soft drink, and sugary lollies, such as jelly beans, are digested quickly. These are likely to raise your blood glucose level faster than other hypo treatments.

Carbohydrate foods that also contain fat or protein, like chocolate, muesli bars or biscuits, take time to digest so aren't good hypo fixes. But as they provide glucose over time, they can be used to stop your blood glucose dropping low again if you still have some regular mealtime insulin working, or you're going to be more active.

You should always check your blood glucose 10 to 15 minutes after treating a hypo. If your blood glucose level is still low, you should eat another 15g of carbohydrate, then recheck your blood glucose after another 10 to 15 minutes.

Don't rely on your CGM to check if you need to eat more carbohydrate after a hypo. Your CGM can still register that your glucose level is low for up to 20 to 30 minutes after food is taken to treat a hypo, even when your blood glucose level has actually started to rise. To help reduce your risk of rebound highs, check your levels with a finger-prick before having another hypo treatment.

You may find that your blood glucose levels run high for many hours after

a hypo. This can be related to overeating to try to correct the low blood glucose level. Some of it may also be related to the hormones your body will make and release if your blood glucose has been low for some time. These hormones, often referred to as stress or counter-regulatory hormones, try to help raise your blood glucose level to protect you from having a more serious hypo. They can also interfere with the action of insulin.

Remember that to stop the highs, you have to stop the lows. Checking your blood glucose levels across the day will help you and your diabetes team or endocrinologist work out when you need less insulin and when you might need more. It may seem counterintuitive, but it's possible to lower your HbA1c with less insulin in a day, rather than more.



If you (or your family members) can't resist sneaking some of your hypo fix, you can buy glucose tablets from the pharmacy to keep in your pocket, car or bag instead. These taste pretty ordinary so no one will love snacking on them! They also don't melt or get sticky in hot weather.

Hypo symptoms are possible at different blood glucose levels, and can change depending on recent fluctuations. If your blood glucose levels have been high, you may get symptoms of a hypo when your level is 4 to 5mmol/L (or higher); if you've been having a lot of lows, you may lose your warning signs altogether. It's important to treat your hypo if your blood glucose level falls below 4mmol/L, even if you don't have symptoms.

### GETTING HELP IN AN EMERGENCY

If you're not able to recognise the signs of low blood glucose levels, or you ignore them, there's a risk that your level will drop so low that you won't be able to treat the hypo yourself. For this reason it's a good idea to teach your family, friends and colleagues how to recognise and treat a hypo if you can't. Wearing an ID bracelet that identifies you as having

It's important to let your diabetes team know if you've had an episode of hypoglycaemia that needed an ambulance or a GlucaGen injection. You'll likely need your insulin reduced. Having a recent severe hypo means you're at risk of further episodes, especially in the weeks following the hypo. If you have a hypo while driving you could cause an accident, so you shouldn't drive for 6 weeks following severe hypoglycaemia.

T1D will also help strangers or people you don't know very well to realise what's wrong if you become seriously unwell and need treatment.

The person helping you should only give you something to eat or drink if you can respond to them. If you can't, they need to call 000 for an ambulance. They can also give you an injection of glucagon. Glucagon is a hormone that triggers a release of stored glucose from your liver. This injection (called GlucaGen) is available on the PBS through a prescription from your doctor. Talk to your endocrinologist or diabetes team about this injection and whether you should keep a kit handy just in case.

# PREVENTING AND IMPROVING HYPOGLYCAEMIA UNAWARENESS

If you start having low blood glucose levels too often, you'll find it harder to recognise hypo signs. The obvious signs of shaking and sweating can seem to go, and a feeling of vagueness or a change in your behaviour may be your only symptom. This is often referred to as hypoglycaemia unawareness. To try to avoid this, it's important to let your doctor or diabetes team know if your blood glucose level is dropping below 4mmol/L regularly (more than 3 to 4 lows in a week, or less if you're newly diagnosed).

Being unable to recognise hypoglycaemia can be a serious complication. The major hormone that makes the liver release glucose to raise the blood glucose level is glucagon, and glucagon secretion is reduced in most people within the first 2-10 years after a T1D diagnosis. This means that your blood glucose levels will drop faster, giving you less time to recognise and treat hypoglycaemia.



When responding to a low glucose level your body will also release other hormones, like adrenalin. Adrenalin is responsible for the early warning signs of a hypo, like shaking and sweating. Like glucagon, the adrenalin response to hypoglycaemia reduces over time. It's further reduced if you have repeat episodes of hypoglycaemia. These factors can all make hypo symptoms milder and harder to recognise.

This can all be made worse by alcohol. When drinking, you become less capable of acknowledging the situation, and your liver is blocked from releasing the glucose needed to raise your blood glucose level.

These tips can help reverse hypoglycaemia unawareness:

- avoid any blood glucose level less than 5-6mmol/L
- · avoid excessive alcohol
- check your blood glucose levels closely, and treat them before they go too low
- reduce the frequency of low blood glucose levels for at least 2 to 3 weeks
- set your blood glucose targets higher
- talk to your doctor or diabetes team.

#### **ALL ABOUT FOOD**



For many years, people with diabetes were told that they must eat 3 meals and 3 snacks a day, with fixed carbohydrate amounts, to keep their blood glucose steady. Thankfully, with modern insulin options that allow for more flexible dosing, most people with T1D no longer need such a strict diet. Having said that, maintaining some routine can help you manage your insulin dosing and blood glucose levels.

### WHAT IS CARBOHYDRATE?

Carbohydrate is the body's main and preferred energy source. When you eat any type of carbohydrate it's broken down into glucose and absorbed into your bloodstream, where it can be used for energy.

The major carbohydrate groups are:



grains, such as bread, cereal, rice and pasta



dairy, such as milk and yoghurt



starchy vegetables and legumes, such as potatoes, corn and kidney beans



fruit and fruit juice



discretionary foods, such as sugar, cakes, biscuits and lollies.

It's important to have a good understanding of how much and what type of carbohydrate is in the foods you eat. This will help you work out how much insulin you need with meals.

Healthy eating is important for everyone in the world, no matter their diabetes status. The food we eat provides us with fuel for energy and nutrients for overall health.

Your diabetes team can help you tailor your insulin treatment around your lifestyle. To make sure you're getting the right amount of insulin, you'll need to consider what you eat and how much of it you have, so you can match it with your insulin doses.

### HOW MUCH CARBOHYDRATE DO YOU NEED?

The amount of carbs you need depends on your energy and nutritional needs, as well as your preferences.

The general recommendation is for carbohydrates to make up about 40-50% of your total energy intake. This is so you can fit in all your serves of the different nutritious carbohydrate foods, like grains, dairy and fruit.

A dietitian can help create a healthy eating plan that suits your preferences and meets your needs. Making any big changes to your diet will influence your diabetes management, so make sure you also let your diabetes team know.

#### **COUNTING CARBOHYDRATE**

Knowing how to count the carbohydrates you eat (known as carb counting) can help you better understand how your meals and snacks impact your blood glucose levels. This is because research has shown that the total amount of carbohydrate matters most to your blood glucose control.

In other words, you might choose to eat a bowl of pasta or a sandwich for lunch and it won't affect your insulin needs if the 2 meals are fairly equal in total carbohydrate.



If your insulin therapy includes set doses of rapid-acting insulin with your meals, you'll need to be able to count carbs to ensure you eat the same amount of carbs at the same times each day. This will make sure you 'match' the insulin and keep your blood glucose levels in your target range.

If you'd like more freedom, your team might suggest you use an insulin-to-carb ratio. This tells you how many units of insulin to take for each carbohydrate exchange or gram you eat. Using an individualised ratio means you can vary the amount of carbs you eat and still calculate the right dose of rapid-acting insulin to cover the expected rise in your blood glucose level.

Adding up how many carbohydrate exchanges you eat will help you decide how much insulin to take with each meal. For example, if your insulin-to-carb ratio is 2 units of insulin for each carbohydrate exchange, and you have a sandwich and a glass of milk containing around 3 exchanges, you'd need 6 units of rapid-acting insulin with your meal.

Monitoring and recording your blood glucose levels before and after each meal will tell you and your diabetes team if your carb counting, insulin-to-carb ratio and insulin sensitivity are correct. If all is well, your blood glucose level should be down to within 1-2mmol/L of your pre-meal blood glucose within 2-3 hours of eating.

To work out how much carbohydrate you eat, it's a good idea to weigh and measure your food for a while, until you can visualise the amount of carbs it contains. You don't need to weigh food forever, but it can help to repeat this from time to time. For example, if you think you usually eat a cup of rice, which is around 3 carbohydrate exchanges, use a cup measure when you serve it to confirm your estimate every now and then.

All this probably sounds daunting, but measuring your food and learning to count carbs will help give you freedom to decide how much you want to eat at each meal. Being confident with portion sizes will also make it easier to estimate when eating out.



Consider using similar plates and bowls to help you visualise your portion sizes. As you get more comfortable, try measuring the amount of food found in different sized plates, bowls or takeaway containers to make it easier to estimate the carb amount when you're not at home. For example, measure how much rice is normally included in your lunch takeaway to help you keep on track at work.

#### **FAT AND PROTEIN**

Fat and protein are vital parts of a healthy diet. Protein is important for growth and repair of cells. It also plays a role in producing antibodies that help fight infection, and helps create hormones to keep your body working well.

The best sources of protein are:

- dairy products
- eggs
- legumes, including lentils, chickpeas and dried/canned beans
- · meat, including poultry and fish
- nuts and seeds
- · soy products.

Fat is a rich source of energy and is important for carrying fat soluble vitamins A, D, E and K, as well as antioxidants. Certain types of fat, such as those found in fish, nuts, seeds and some oils, like olive and canola oils, supply the essential fatty acids that play a role in regulating many body functions.

While carbohydrate foods have the largest and most direct effect on blood glucose levels, proteins and fats can influence blood glucose levels too.

Protein and fat don't directly raise blood glucose levels in the immediate way that carbs do, but they do raise levels later. The more fat and protein in your meal, and the more sensitive you are to these nutrients, the more noticeable the effect.

Eating fat and protein with carbohydrate can mean that in the first few hours after a meal, your blood glucose levels rise slower, compared to what happens when eating carbs alone. This is because these nutrients delay how quickly the stomach empties, which slows down the absorption of glucose from digestion.

From about 3 hours after the meal, fat and protein can make your blood glucose levels rise. There are a couple of main reasons for this: partly because fat and protein tell your liver to release extra glucose, and partly because they make your body temporarily more resistant to insulin. This makes it harder for your insulin to work well, making your blood glucose level higher than expected after your meal. This effect on your blood glucose levels can last for several hours after eating.

Not everyone will notice the effects of fat and protein on their blood glucose levels, and carbohydrate will still have a bigger impact than these nutrients. But if you find your levels harder to manage after some high fat and/or protein meals, talk to your diabetes team to find an insulin dosing solution that works for you.

#### **FIBRE**

Fibre is a plant material that's not absorbed by your body. It's found in vegetables, fruit, legumes, nuts, seeds and wholegrains. It helps keep your digestive system healthy, and can improve control of both blood glucose and cholesterol levels. Following a high fibre diet can also be helpful for healthy gut bacteria and weight management, as high fibre foods help fill you up without providing you with excess energy.

#### **SUGAR**

It's a common myth that people with diabetes need to avoid all sugar. This just isn't true!

As part of general healthy eating and to avoid large increases in blood glucose levels, it's recommended to limit foods containing a lot of added sugar (such as table sugar, lollies and regular soft drinks). These have little nutritional value and won't satisfy your appetite. But that doesn't mean they're banned – small amounts of sugar as part of a healthy diet are fine, such as a teaspoon in hot drinks or added to your morning porridge. And of course, sugary foods that are fast sources of glucose are important to have on hand in case of low blood glucose.

Fruit and milk products contain naturally occurring sugars, but unlike sucrose (table sugar), these foods offer a lot of nutritional value, and play an important role in a healthy diet.

#### VITAMINS AND MINERALS

Micronutrients are essential, but aren't used for energy the way other nutrients are. Micronutrients are used all over the body; for example, calcium and vitamin D are used for building strong bones, B vitamins are used for brain function, and iron and zinc are used in your muscles.

Ensuring you eat a diet that includes a wide variety of foods is the easiest way to make sure you meet your vitamin and mineral needs. A dietitian will be able to discuss your individual requirements and the types and amounts of foods to eat.

#### **GLYCAEMIC INDEX**

Different types of carbohydrate foods are digested at varying rates, and can have different effects on your blood glucose level. This impact is measured using the glycaemic index (GI), which tells us whether foods will raise blood glucose levels quickly or slowly.

High GI carbohydrate foods, such as jasmine rice, are digested quickly. They can cause a sharp, fast rise in your blood glucose level. Foods that are low GI, like pasta, take longer to digest. As a result, it takes longer for the glucose to enter the bloodstream. Low GI foods cause less of a glucose spike straight after a meal.

Research has shown that this index is a useful tool for managing blood glucose levels. Low GI diets improve blood glucose control while reducing the risk of hypoglycaemia. They've also been found to reduce spikes in blood glucose levels after meals in those on multiple daily injections (MDI) and insulin pumps.

It can help to swap high GI carbs for low GI options to reduce glucose spikes and lower your overall GI. But keep in mind that the amount of carbohydrate you eat is still important. A small serve of a high GI carb won't raise your blood glucose levels by a huge amount. And having a large amount of a low GI carb food will lead to a lot of glucose in your bloodstream; this may have a big impact on your glucose levels, so you'll still need to match it with additional insulin.

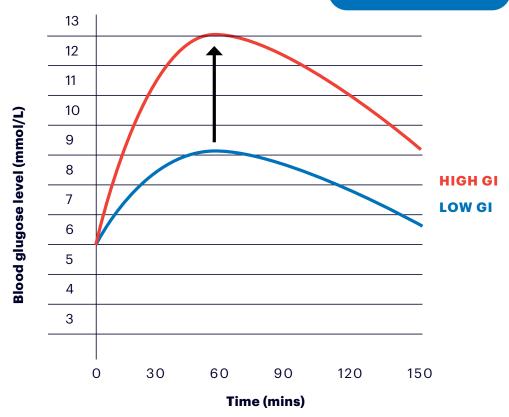
### WORKING OUT WHAT'S IN YOUR FOOD

In Australia, all packaged foods have a nutrition information panel. You can use this to make sure you know what you're eating.

Of course, not all food comes in a packet with a nutrition label. Use resources such as *The Pocket Traffic Light Guide to Food Carbohydrate Counter*, available as a book in your JDRF T1D pack, to help you know the carbohydrate, fat and energy content of a huge variety of foods. It's also available as an app, and there are many other apps that can tell you the nutritional details of different foods. Check out the resources section of this book from page 150 for more helpful websites and apps.



Foods or recipes that display this GI symbol have been assessed to meet certain nutritional criteria around kilojoules, fats, carbohydrates, sodium, protein and fibre. Find out more at glycemicindex.com



Low GI foods have been proven to reduce spikes in blood glucose.

#### **READING FOOD LABELS**

#### **NUTRITIONAL INFORMATION**

SERVINGS PER PACKAGE: 11 SERVING SIZE: 23g (4 biscuits)

		Per serve	Per 100g
Energy	1	385kJ	1650kJ
Proteir	1	2.7g	11.7g
Fat			
	Total	2.4g	10.2g
	Saturated	0.7	3.0g
Carbol	nydrate		
	Total	13.4g	57.8g
	Sugars	0.4g	1.6g
	Dietary fibre	2.7g	11.6g
Sodium		132mg	530mg

#### **SERVING SIZE**

The 'serving size' is determined by the manufacturer and can vary from product to product. The information in the first column tells you about what's in a serve of the food. Your job is to decide if that's how much of the food you're planning to eat. If you're going to have more or less, you may need to work out how many carbs and other nutrients you'll have.

#### **PER 100G**

Use the 'per 100g' column to compare similar products (for example, which product is lower in fat or salt per 100mg).

#### **FAT**

Generally try to aim for less than 10g of total fat per 100g. Check the saturated fat – that's the kind that's unhealthy for your heart. When comparing products, choose the option with the lower amount of saturated fat.

For dairy products or other items (such as frozen meals) where you'll have more than 100g, look for products with less than 3g of total fat per 100g.

### CARBOHYDRATE TOTAL

The carbohydrate total includes both sugars and starches. After eating, your blood glucose level will depend on the total amount of carbs you eat.

Check the total carbs per serve, but be sure to take into account how much of the food you're actually going to eat. In the example on this page, if you were only going to eat 2 biscuits, you would need to divide the total carb amount per serve by 2.

#### **SUGARS**

This section tells you how much of the total carbohydrate is sugar. It includes added sugar as well as naturally occurring sugars like lactose (milk sugar) and fructose (fruit sugar). This isn't as important as the total amount of carbs.

#### **DIETARY FIBRE**

When looking at different products, look at the fibre 'per serve' column and pick the option with the most fibre. More than 3g per serve is a good goal. Try to have at least 30g of fibre a day.

#### **SODIUM (SALT)**

Choose, where possible, products with reduced or no added salt. Low salt foods contain less than 120mg of sodium per 100g. In general, look for foods that contain less than 450mg of sodium per 100g. Higher salt foods should be eaten in small quantities and/or less often. Compare different products by looking at the 'per 100g' column.

## SUGAR-FREE AND FAT-FREE OPTIONS

Compare the total carbohydrate content of a sugar-free food with the label on a standard product. If there's a big difference in carbohydrate content, you may want to choose the sugar-free option, as it will have a lower impact on your blood glucose levels (for example, regular versus diet soft drink). But if there's little difference in the total grams of carbohydrate between the 2, choose whichever option you'd prefer!

Watch out though – some sugar-free foods, such as sugar-free lollies, are sweetened with sugar alcohols, which can have a laxative effect if you eat a lot of them. Make sure to read the label carefully to make the best choice.

And be aware that foods labelled as 'no added sugar' may contain naturally occurring sugars. For example, some fruit yoghurts may not have sugar added as they're made; instead, they're naturally sweet due to the sugars from lactose in the yoghurt and fructose in the fruit. These foods may still be high in total carbohydrate, so you'll have to check the nutrition label.

Fat-free foods can be higher in carbohydrate and contain almost the same kilojoules as the 'full-fat' versions they're trying to replace. Fat-free options aren't always a better choice than the standard product, so read your labels carefully.

#### **GLUTEN-FREE DIETS**

People with T1D have a higher risk of developing coeliac disease, an autoimmune condition where the body reacts abnormally to gluten. Coeliac disease can result in gastrointestinal symptoms, fatigue and malnutrition.

A strict and lifelong gluten-free diet is currently the only recognised medical treatment for coeliac disease.

Gluten is in many foods that are rich in carbohydrate, so it's important to choose the right foods to maintain both your blood glucose levels and a healthy diet.

Gluten can also be used as an additive in meats (such as sausages) and dairy foods (such as flavoured milks). It's important to check the nutrition information and ingredient panels of all food and drinks. A dietitian can show you how to do this.

Gluten-free sources of carbohydrate include:

- grains, such as rice, polenta (cornmeal), buckwheat, millet and quinoa
- starchy vegetables, such as new potatoes, sweet potatoes, yams, cassava (tapioca) and plantains.

Most supermarkets stock a range of gluten-free breads, pasta, cereals and crackers. Eating out might be a bit more challenging, but a lot of restaurants now provide gluten-free alternatives.

Your blood glucose may change after you start a gluten-free diet, so closely monitor your levels and keep in contact with your diabetes team. You should also talk to an accredited dietitian to make sure your diet is nutritionally balanced.

Coeliac Australia can help you find restaurants that have been accredited as gluten-free.
Visit coeliac.org.au



#### **LOW CARB DIETS**

Some people with T1D say they find it easier to manage their blood glucose levels while following a low carb diet.

While research into adults with type 2 diabetes has shown that it may help in the short term, there's been very limited research looking at the risks and benefits for people with T1D.

If you're considering a low carb diet, keep the following advice in mind.

- As with any diet, it's important to plan meals and snacks carefully to make sure you meet your nutrition needs.
- Low carb diets often mean increased fat intake, so make sure to consider your overall kilojoule intake. To help your heart health, it's best to choose foods that are rich in healthy fats, including nuts, avocado, eggs and seafood.

- Reducing carbs and increasing your protein and fat intake will influence your insulin requirements.
   It's important to regularly check your blood glucose levels and change your dosage accordingly with your health team.
- Low carb diets aren't for children, pregnant or breastfeeding women, people with kidney failure, or those with a history of disordered eating.
   If you decide to try a lower carb diet with any of these conditions, you'll need to keep in very close contact with your team.
- Athletes following a low carb diet should get specialised advice from a dietitian. This will make sure your capacity for high intensity exercise isn't compromised.
- An accredited practicing dietitian can provide you with essential advice and support. Find someone local to you on the Dietitians Australia website.

## FOOD, DRINKS AND YOUR LIFESTYLE



#### **EATING OUT**

Lots of people choose to eat out at restaurants, buy takeaway or get food delivered. The good news is that this doesn't have to change now you have T1D – you'll just need to think a bit more about what you eat and how to dose your insulin.

Most chain fast food restaurants have nutritional information about their menu items on their website. You can look up your favourite items and record how many carbohydrate exchanges (and other nutrients) they have. If it's a popular chain, the nutrition information can often also be found on nutrition websites and apps.

Nutrition information can be harder to come by when eating at a friend's house or at a restaurant. In this case you need to make your best estimate, taking into account the size of the serving and the amount of carbohydrate you think is in the food. Checking your blood glucose before you eat and then several hours later will help 'test' whether your estimate was right. If your glucose level has risen by more than 2-3mmol/L, you've probably underestimated the amount of carbohydrate in your meal. Next time you'll know you need more insulin.

When you eat out, your meal may be served later than usual. To avoid a hypo, it's a good idea to wait to have your insulin when the meal actually arrives.

#### **ALCOHOL**

In Australia, it's recommended that men and women drink no more than 10 standard drinks in a week, and no more than 4 standard drinks in a day. Having more than this can increase your risk of being diagnosed with a number of different cancers, heart disease, high blood pressure, strokes and dementia.

A standard drink is 10g of alcohol (ethanol). That means:



a middy (285ml) of regular strength beer or cider



a schooner (425ml) of light beer



a nip or shot glass (30ml) of spirits



a small glass (100ml) of wine or sparkling wine

For people with T1D, excess alcohol increases your risk of hypoglycaemia. When you drink alcohol (which your body considers a toxin), the liver prioritises breaking down the alcohol and removing it. While your liver does this it can't do all the other jobs it normally would, such as releasing stored glucose if your blood glucose level starts to fall. This effect can last for many hours after you've been drinking. It can increase the risk of hypos overnight and even into the next day.

To avoid hypoglycaemia, it's best to avoid drinking large amounts of alcohol in a session, and to make sure you always eat some carbs before and while you drink. It's also recommended you don't include the carb content of alcoholic beverages in your carb counting calculations.

If you've been drinking, you should test your blood glucose level before you go to bed, and eat a snack if your level is normal to low.

CGMs can be very helpful overnight in these situations. Make sure you use the alert function. You can also use temporary targets or activity modes on automated pumps. Ask your diabetes team about this.

You may sometimes find that your glucose level rises too high after a drink that contains carbohydrate, like spirits mixed with regular soft drink, or large amounts of beer. You might also find that you eat more when you drink alcohol. Where possible, choose diet soft drink as a mixer and keep an eye on your food intake.

#### LOW CARB VERSUS LOW ALCOHOL

Different alcoholic drinks have different amounts of carbohydrate. For example, spirits and wine don't have carbs, but beer does. In general, it's the amount of alcohol in a drink, rather than the amount of carbohydrate, that's most important.

#### **WEIGHT GAIN AND LOSS**

Before you were diagnosed with T1D, you probably lost a fair bit of weight in a very short time. Some of this was due to fat and muscle loss because your body was burning fat for energy, instead of burning glucose. And around half the weight loss would have been caused by dehydration; as your blood glucose levels rose, your kidneys were working overtime to filter the 'excess' glucose.

It's normal to regain several kilograms when you start using insulin. This is when your body rehydrates, when the excess glucose is taken up by your body's cells, and your kidney function returns to normal. In the longer term, your body will also replace the fat and muscle stores that were lost before your diagnosis.



If you'd like to lose weight, talk to your endocrinologist or diabetes team for personalised advice.

## BUILDING A HEALTHY RELATIONSHIP WITH FOOD

Our relationship with food is about so much more than eating to satisfy our hunger or to nourish our bodies. Food is a social part of our lives: we share meals to connect with loved ones, catch up with friends over coffee or beer, relax with comfort foods after a long day, and celebrate big events with special foods and drinks. Diabetes adds a layer of complexity to your relationship with food, as what you eat has such an immediate and real impact on your glucose levels and insulin dosing decisions.



It can be easy to start thinking of foods as 'good' or 'bad', depending on how they affect your glucose levels or how much insulin you'll need for them. But there are no 'bad' foods. There are certainly foods that, ideally, make up a bigger portion of our meals, such as fruits and vegetables. And of course there are foods that are best saved for 'sometimes' as part of an overall healthy eating plan. There are also foods you'll find trickier to dose insulin for, and you might need to work with your diabetes team to dose for those.

To build and maintain a healthy relationship with food in social situations, try to follow these tips.

 Don't let your diet be something you judge yourself for, and don't let food dictate how involved you can be at social events. how you're relating to food.
Turn to page 105 to read more
about this, including the signs
that you're at risk of developing
disordered eating habits.

- Find a sustainable healthy eating plan that's easy to follow and fits with your lifestyle, preferences and your body's natural cues.
- Make sure your eating plan is flexible enough for you to be able to adapt to changes in your day, or to join celebrations for special occasions.
- Try to avoid being too restrictive or rigid – don't ban yourself from certain foods, and don't hold yourself back from joining in at events.
- Have a good time and enjoy the moment!

#### **EXERCISE AND T1D**



There's no doubt that exercise is good for you. It can help reduce stress, is great for your mental state, helps with weight management, increases your insulin sensitivity, and is good for your overall health. Everyone should try to be active for at least 45 minutes per day 3-4 times per week.

As a person living with T1D, being more active may affect your blood glucose levels. To manage this, you'll need to understand a bit about how different activities affect your glucose levels, how to adjust insulin, and when and how much to eat. Remember these guidelines are all just a starting point – as always, talk to your diabetes team for individual advice.

What happens to your blood glucose levels during and after exercise will depend on the balance between:

- the amount of insulin you have on board
- the timing of exercise (when you do it, and how long for)
- the type of exercise (aerobic or anaerobic)
- your blood glucose level before doing the activity
- your food and fluid intake.

## TYPES OF EXERCISE AND THEIR IMPACT

Different types of activity have different effects on blood glucose levels. Here's a general guide to some common kinds of activities.

**AEROBIC EXERCISE** includes activities like swimming, jogging, cycling and walking. These usually lower blood glucose levels during and after the activity.

**MIXED EXERCISE** includes team sports such as soccer, basketball, netball and hockey. These activities may result in no change to glucose levels, or they might increase or decrease during the activity, then lower afterwards.

anaerobic exercise includes activities like sprinting, weight lifting, strength and power sports. These usually push glucose levels up initially, but can still lower them afterwards. This happens because your body releases high levels of adrenalin that trigger your liver to break down stored glucose and release it into your bloodstream.

CGMs are a great tool to help you identify how exercise affects your glucose level patterns. They also give you information about what happens during and after exercise, including overnight.

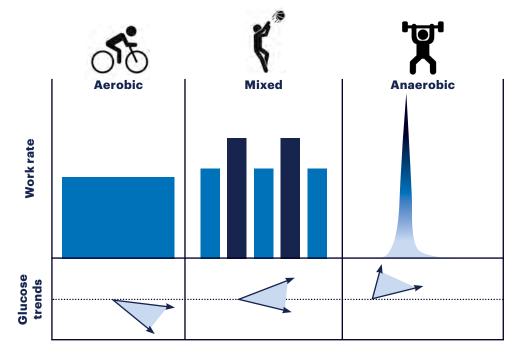
To help you learn your body's response to exercise, it's best to check your blood glucose levels before, during (every 30 minutes or so, if possible) and after exercise – including tracking it every couple of hours afterwards.

Being aware of your glucose levels around exercise will make it easier to see trends, and will guide you and your diabetes team when developing your management plan.

#### **EXERCISE AND INSULIN**

There are a few key things to think about when you're getting ready to exercise:

- · the action and timing of your insulin
- the duration of the activity
- the type of activity you plan to do
- your carbohydrate needs.



Adapted from Riddell MC et al., 'Exercise management in type 1 diabetes: a consensus statement'.

Lancet Diabetes Endocrinol. 2017 May;5(5):377-390.

The goal is to start exercising with just the right amount of active circulating insulin on board. Having too much active insulin reduces the amount of glucose the liver can add to blood, increasing your risk of a hypo.

On the other hand, exercising with too little insulin stimulates glucose production from the liver, which can cause hyperglycaemia.

If you have a hypo in the hours before you exercise, you're more likely to have a low blood glucose level while you're working out. You'll need to monitor your levels closely during exercise.

## INSULIN ADJUSTMENTS BEFORE EXERCISE

Before an activity, aim for your blood glucose level to be around 5-10mmol/L. If it's below 5mmol/L and you're doing an

aerobic or mixed activity, have a 10-20g carbohydrate snack before you start exercising.

If your blood glucose level is above 15mmol/L, check for ketones. If your ketones are high, a corrective insulin dose should be given and you're best to delay exercising.

To reduce the risk of hypoglycaemia and the need for insulin adjustments, you may like to try exercising when you're at the tail-end of your long-acting insulin dose, or after the peak of your rapid-acting insulin (for example, before breakfast, lunch or dinner).

If your exercise is planned within 1 or 2 hours after a meal with insulin, reduce the mealtime insulin dose by about 50% to prevent low glucose levels during the activity. Of course, this is all just a starting point and should be based on your own responses and personalised advice from your diabetes team.

If you're using a pump, reducing basal insulin delivery by 50-80% or using the pump's exercise, ease off or temporary target setting can help prevent hypoglycaemia. Ideally this should be started up to 60 to 90 minutes before exercise. Suspending your pump when you start exercising hasn't been shown to be helpful in preventing hypos.

### INSULIN ADJUSTMENTS AFTER EXERCISE

Insulin adjustments can help avoid the risk of early and delayed hypoglycaemia that can happen up to 12 hours after exercise. To prevent hypos following a workout, it's recommended you halve your bolus insulin with your meal after exercising.

Exercising in the late afternoon or night may increase your risk of having a hypo overnight, often around 2-3am. This risk can be lowered by reducing your evening insulin by 20% and eating a meal containing low GI carbohydrate and protein after exercising.

If you use an insulin pump, reducing the basal rate by 20% or using the exercise, ease off or temporary target setting for up to 6 hours after exercise can help prevent an overnight hypo.

If you're doing very strenuous activity or competition sports, your blood glucose levels may climb during exercise, then stay high for some time afterwards. A 15-minute cool down can help bring your glucose levels back into your target range.

To manage high blood glucose levels after exercise:

- do a 15-minute cool down
- give a correction bolus start with 50% of your normal correction.

As you get more experienced you'll be able to fine-tune insulin adjustments to your individual responses. Adjusting your insulin dose for exercise is just like any other component of diabetes management – to get it right, you need practice and more blood glucose monitoring.

## EXERCISE AND YOUR CARBOHYDRATE NEEDS

There are a few factors to think about when planning your pre-exercise carbohydrate intake, like the timing of the activity in relation to your insulin delivery, the type of activity you'll be doing, and whether you're using injections or an insulin pump.

For athletes, a pre-activity meal containing both protein (20-30g) and carbohydrate (around 1g per kilogram of ideal body weight) is recommended to maximise muscle and liver glycogen stores. If possible, have the meal 2-3 hours before exercising so you won't have too much bolus insulin onboard.

### CARBOHYDRATE INTAKE BEFORE EXERCISE

You may need to eat extra carbs right before exercising, even if the activity is timed well with your insulin action. This will depend on your blood glucose level, how long you'll exercise for, and if you'll be doing aerobic or anaerobic activity.

If your blood glucose level is less than 5mmol/L and/or you're planning to do aerobic activity for more than 30 minutes, have 10-20g of carbohydrate as glucose or as a low-fat carbohydrate drink or snack 10-15 minutes before starting exercise. Checking your blood glucose before, during and after exercise will then help you develop your own plan. Just be careful not to have too much carbohydrate, as this will make your blood glucose levels high.



## CARBOHYDRATE INTAKE DURING EXERCISE

You might need additional carbs to stop low blood glucose levels during your workout. How much you'll need will depend on the timing of the exercise in relation to the action of your insulin.

If you're exercising without prior insulin reductions, a general guide is that you include 15-30g of carbohydrate per hour of exercise. Exercise snacks need to be easy to eat and low in fat so you don't get too many extra calories – for example, you might like to try a banana or a low-fat cereal bar.

Remember to drink and stay hydrated during exercise, too. Water is the best choice for activity that will last less than an hour. For exercise longer than an hour, you might want to grab a sports drink. These offer carbohydrates while also rehydrating you.

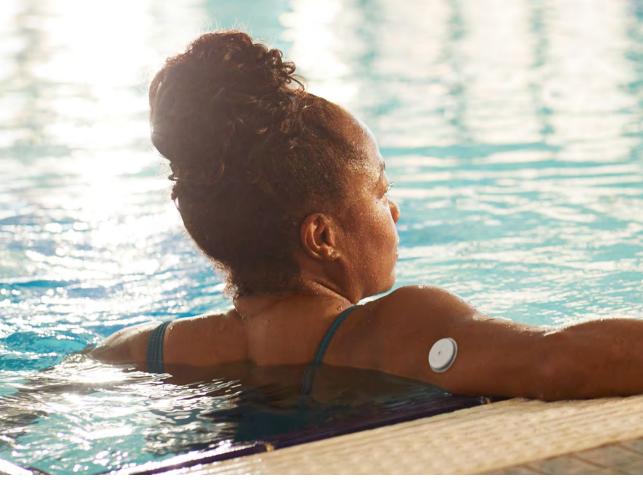
#### **TIPS FOR SAFE EXERCISE**

- Always wear/carry diabetes ID.
- Always have a blood glucose meter and hypo treatment with you.
- Check your blood glucose levels often, or wear a CGM.
- If your blood glucose is below 5mmol/L, have 10-20g of carbs.
- Drink plenty of fluids. If the activity lasts longer than 60 minutes, consider a sports drink for carbs and fluids.
- Always eat something containing both carbohydrate and protein after exercise (this may be at your next meal).
- Always check your blood glucose levels overnight after exercise, or wear a CGM with alerts.
- Don't drink alcohol after exercise, as it increases your risk of delayed hypoglycaemia.

## CARBOHYDRATE INTAKE AFTER EXERCISE

After exercise it's important that you eat enough carbohydrate and protein to replace the fuel used by your muscles. Eating well will help prevent post-workout low blood glucose levels.

Try and eat within 1-2 hours of activity. Food eaten up to 4-6 hours after any type of exercise usually needs 25-50% less insulin than usual.



## T1D DEVICES AND WATER-BASED EXERCISE

Going to the pool or beach for a swim? As with all physical activity, it's going to be a process of learning how your body reacts to this particular kind of exercise.

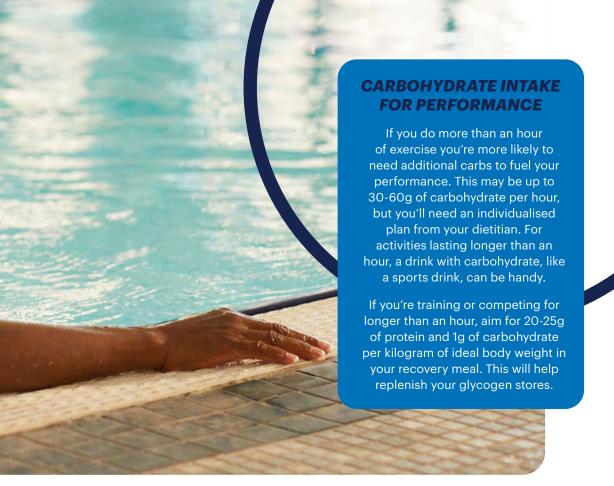
For some people, swimming lowers blood glucose levels. For others, it can cause

CGM sensors and transmitters are water resistant and can be used while swimming, but it's not recommended you immerse the transmitter in very hot water, like a hot tub. Some pumps are also water resistant, but you should check the manufacturer's advice. It's also important to check there are no cracks in the pump before jumping into the water.

a rise. For a long and intense session (lasting over an hour) you may need to eat something containing carbohydrate to stop your glucose level dropping too low.

Here are some tips to keep in mind when swimming and wearing a pump or CGM.

- In general, water-resistant CGMs and pumps can be worn to a depth of 2.4m for up to 30 minutes.
- The adhesives that stick on sensors and pump infusion sets can become loose after spending a lot of time in the water. You might want to consider using over-tapes or a product like skin glue or Skin Tac to help them stick.
- Make sure all tubing is safely secured so the tubing and pump don't get caught up or pulled off while you're swimming.



- Take your blood glucose meter with you. It's important to make sure you have an alternative way of checking your glucose levels if your CGM falls off.
- Also pack a spare infusion set or patch pump, as well as your hypo food.

Pumps can be disconnected for a short amount of time without a big impact on blood glucose levels. After 30-60 minutes, however, blood glucose levels will start to rise when the effect of the short-acting insulin from the pump will begin to wear off. After 2 hours there's a risk of ketones developing, so the pump should be re-attached at least every 2 hours, with a correction bolus given if your blood glucose level is high.

## EXERCISING FOR WEIGHT LOSS

Being active is an essential part of losing weight, along with a healthy diet. If you're trying to lose weight it's important to minimise any additional carbohydrate intake to prevent hypos during or after your workouts.

You'll need reductions in both your basal insulin and mealtime insulin dose as you lose weight. And as exercising and weight loss will make your body more sensitive to insulin, your correction doses may also need to be decreased. Talk to your diabetes team about all this.

A diet higher in protein and lower in carbs, with a focus on low GI carbohydrates, may help you feel full while still meeting your activity needs.

## MANAGING SICK DAYS

Being stressed or unwell can affect your blood glucose levels. During times of mental or physical stress, especially if you have the flu or a serious bacterial infection, your body will make and release stress hormones. These hormones can trigger a release of stored glucose from your liver and interfere with your insulin's action. On these days your body will need a lot more insulin. Before you had diabetes, your pancreas did this automatically for you. But now if you get sick you may not be taking the amount of insulin your body needs.

With too little insulin, your body will start to burn fat as an alternative energy source. This produces ketones, which can build up and make you even more unwell. In fact, this situation can be life-threatening. This is the worst-case scenario.

How your stress hormones are impacted can depend on what kind of illness you have. You're less likely to produce stress hormones if you have a gastro-type bug; in this case, your blood glucose levels are more likely to be low because you're not eating, or because you can't absorb the food properly. There are other illnesses, like chicken pox, that seem to have little or no effect on blood glucose.

## WHAT TO DO IF YOU'RE UNWELL

If you have a relatively minor viral illness, like a cold, there's not much you can do, apart from taking something to help you manage the symptoms, like paracetamol. Keep an eye on your blood glucose level, but it probably won't be impacted much. Remember you may not be able to rely on your CGM if you've taken paracetamol.

If you get a high sensor glucose reading, make sure you do a finger-prick check before taking more insulin.

If you've got a serious viral or bacterial infection you'll need to keep up your fluids. This is especially important if your blood glucose levels are high or you have a fever, as you'll be more likely to get dehydrated.

If you've got a tummy bug, it's important to keep drinking fluids. You should aim to drink about 1 to 2 glasses of fluid every hour or so. Whether you need to drink low calorie or sugar-based drinks depends on what your blood glucose level is doing, so you'll need to keep an eye on your levels every few hours. If your blood glucose is normal to low, you should drink regular soft drink or another drink with kilojoules. You may also need to take less insulin. But if your blood glucose is high, all you need is the fluid, so water or a diet drink will be a far better choice.

Your insulin requirements can be greatly increased with gastro illnesses, so you'll need to monitor your blood glucose levels closely. How often you need to check your blood glucose will depend on how unwell you feel and whether you're wearing a CGM or doing finger-prick checks. If you're using a CGM, consider turning on a high glucose alert. Alert on high (13.9mmol/L) would be a good place to start. You should also check that your CGM is set to alert on a low reading, such as 3.9-4.4mmol/L.

If your glucose is high, especially if you feel like you're going to throw up or you actually vomit, you should monitor either your blood or your urine for ketones. If you have ketones, you'll need to take extra insulin so your body can use the glucose in your blood for energy, rather than burning fat. Develop a plan with your diabetes team that covers how much insulin you should take when you're not well.

If you're seriously unwell and it's after hours or your doctor isn't available, go to the emergency room. If you can't get to the hospital you may need to call an ambulance. It's also a good idea to keep an up-to-date list of all the medications you take, and a schedule of when you take them, so your healthcare providers can quickly review your medication history.



#### **TIPS FOR MANAGING SICK DAYS**

- Monitor your blood sugar levels more frequently. How often you'll need to do it depends on the seriousness of the illness, but a general target is around every 4 hours.
- Don't stop taking insulin. Never completely stop taking insulin, even if you're not eating anything. Insulin is critical for normal metabolism without it, your body starts to burn fat, which can cause diabetic ketoacidosis (DKA). To work out the dose, use your blood glucose level to guide you, or call your diabetes team for help.
- Check your urine for ketones. The presence of ketones in urine, no matter what your blood glucose level is, shows that your body needs insulin. If a test shows that you have ketones, take additional insulin and lots of fluids.

- Drink plenty of fluids and try to eat.
   Having small amounts of food every
   3-4 hours can help keep your blood glucose levels as normal as possible.
- Be careful with over-the-counter medicines. Remedies for colds, allergies and upset stomachs may contain ingredients that raise or lower blood glucose levels, or that imitate the symptoms of high or low blood sugar. Read the labels before you take any over-the-counter medication, and call a pharmacist for advice if you're unsure.
- Have a 'game plan' and don't hesitate to ask for help. Ideally, you and your doctor should develop a strategy for managing sick days before you get sick. Put it in writing and then make adjustments as you get more experience with sick days.

#### Get medical advice if:

- you can't keep any food or liquid down
- you have ketones in your blood or urine and they don't go away within a few hours
- you have vomiting or diarrhoea that lasts more than 8 hours
- your blood glucose is over 15mmol/L and you can't bring it down
- your illness lasts longer than 2 days.

#### **GOING INTO HOSPITAL**

Having to go to hospital, whether it's for a planned procedure or an emergency visit, can be stressful and uncomfortable for anyone. But it shouldn't be more difficult when you have T1D, provided you're properly prepared. The key is to be informed, plan ahead, and take an active role in managing your diabetes while you're there.

If you know you'll be heading to hospital, the following tips can help. If it's an emergency and you have no time to prepare, just do as many as you can.

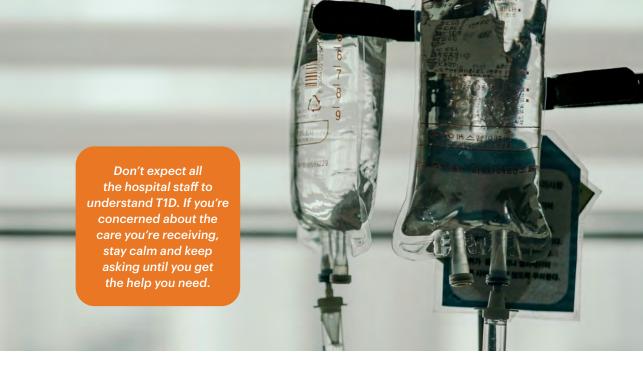
#### **BEFORE YOUR HOSPITAL STAY**

- Consult with your doctors before you go into hospital. Make sure everyone involved in your care has accurate information about you.
- When you make your surgery appointment, request that your procedure is scheduled first on the morning list so your routine is disrupted as little as possible.
- If you use an insulin pump, check that hospital staff are familiar with how it works.

- Talk with your diabetes team about the procedure and what to expect. Discuss any concerns you have about how you'll manage your T1D throughout your stay.
- Each hospital has a protocol for managing patients with diabetes, but it's still a good idea to make sure the surgical team is aware of your individual management plan.
- Ask a family member or friend to be your advocate while you're in hospital. They can speak on your behalf if necessary, and support you throughout the process. Talk to this person about how you manage your diabetes and any concerns you have going into hospital. Give the hospital staff their name and contact number when you're admitted.
- Take all your medications, as well as your blood glucose monitoring equipment (including strips), spare lancets, hypo kit and your medical ID bracelet.
- Basal insulin delivery should continue when you're fasting before surgery, and then during the procedure. To reduce the risk of hypoglycaemia, a lower basal rate can be used but the stress of surgery can lead to hyperglycaemia, so it can help to continue the normal basal rate during short procedures. Talk to your diabetes team for guidance.

#### **DURING YOUR HOSPITAL STAY**

- Check your blood glucose levels often (at least 6-8 times per day) if you're not using a CGM.
- Take a piece of paper with all your important medical information on it, such as your medical history, previous procedures, allergies, and names and doses of all the medications you take.



- If it applies to you, make sure you tell the hospital staff of any dietary requirements you have, such as needing gluten-free meals.
- Check when meals will be served so you can time your insulin injections.
- Be prepared for the possibility of having a hypo in hospital. Check with your diabetes educator about what precautions you can take and what treatments can be used.
- Keep in mind that when you're in hospital your blood glucose levels may be higher than usual. The stress of your illness, lack of activity, different medical procedures and even infections can cause your blood glucose levels to rise. While this can be frustrating, it's quite common.

#### WHEN IT'S ALL OVER

 When you're discharged, make sure you've written down instructions about any changes to your insulin dosing or medication, and any instructions about meal plans and activity levels during your recovery.  You'll also need information on who and when to call for medication adjustments or other medical problems.

## T1D DEVICES, MEDICAL TESTS AND SURGERY

Manufacturers of insulin pumps and CGMs recommend that these devices are removed for x-rays and CT and PET scans.

In most cases, you can keep using your pump and/or CGM during surgery. They may need to be removed if imaging will be taken during the procedure, or if high-frequency electrical heat (diathermy) will be needed.

Insulin pump infusion sets are changed every 2 to 3 days. It's recommended that you change your infusion set the morning or afternoon of the day before surgery, giving you enough time to check that it's working properly. A plastic infusion set is preferred because of the risks of metal cannulas with diathermy. Your infusion site also needs to be away from the surgery site. The pump should also be readily accessible to the anaesthetist.

#### WORKING AND STUDYING

Whether you're thinking about your current job or are looking at finding a new role, you probably have a lot of questions about how to manage your T1D at work, or how to talk to other people about it.

## TELLING OTHERS ABOUT YOUR T1D

Your medical information is confidential, so your employer doesn't need to be told about your diabetes. The only exception is if you work in a position where your diabetes may have safety implications for your colleagues or the general public, such as if you drive a public transport vehicle or are a police officer.

On the other hand, you might want to tell your employer about your T1D. You might need the company to make some changes to help you manage your diabetes, such as ensuring you get regular meal breaks.

Your decision about whether or not you want to tell your colleagues is personal. It will depend on your circumstances and what you're comfortable with. If you tell them, be ready for them to ask questions – most of them probably don't know much about T1D or what living with it really means for you. Talking about how it's treated can help.

Some people living with T1D might feel embarrassed to share their diagnosis with workmates. But there are benefits to telling them – for example, if they don't know you have diabetes, they could misinterpret signs of hypoglycaemia and think you're drunk or just being rude. You could also let them know about hypos and what they can do to help.

## TIPS TO HELP YOU MANAGE YOUR DIABETES AT WORK

- You may need to adjust your insulin dose depending on the type of work you do (for example, if you're more or less active at work).
- Keep a well-stocked hypo kit handy at all times.
- Don't skip meal breaks. Stop when you need to eat.
- If you're unable to eat regularly, or you're going into a long meeting, keep a drink containing carbohydrate on hand, like orange juice, milk or a latte. Sip it slowly to reduce your risk of hypoglycaemia.
- Don't ignore a hypo. Treat it immediately and re-treat if necessary.
- Check your blood glucose level before you give presentations or go into important meetings. Adrenalin and nerves can make it hard to know if you're having a hypo or are just nervous.
- Despite all the advances in managing diabetes, there are certain jobs that may no longer suit you. If you have foot problems, for instance, wearing steel-toed boots on a concrete floor all day may not be for you. Speak with your doctor or diabetes educator if you're worried about possible health risks associated with your job.

#### **JOB INTERVIEWS**

There are drawbacks and merits to both disclosing and not disclosing your diabetes status during job interviews. While people with diabetes successfully do a huge range of jobs, some employers may be reluctant to hire someone with T1D because of misconceptions – for example, they may wrongly assume that people with diabetes can't do a job that involves regular driving. If you choose to tell your

JDRF has a free booklet you can share with colleagues that explains the basics of T1D. It answers many questions and lets them know the truth about common diabetes myths. You can pass it around, leave it in the breakroom or on a staff noticeboard, or send the link to your team for them to download their own copies. It can be downloaded from jdrf.org.au/family-friends



potential employer about your T1D, you need to be ready to dispel these myths.

It's possible to turn your diabetes into a positive. People with T1D have to be aware of the time, keep to a routine, follow a healthy lifestyle and attend regular diabetes reviews. These qualities demonstrate responsibility, self-discipline and organisational skills – these are important traits! Emphasising this at an interview can be to your advantage. Being open about your T1D can also help prevent misunderstandings or issues once you're employed.

#### **SAFETY SENSITIVE JOBS**

Being diagnosed with T1D doesn't impact employment in most industries, but some roles may be restricted. These are called 'safety sensitive' roles, as people or property could be put in danger if you have a hypo at work. These roles vary in their limitations. It could mean a bit more extra preparation before you get the job, while a few others will be completely ruled out. The rules and laws do occasionally change, so check on the current status of the role in your state or territory.

- Airline cabin crew and pilots.
   You'll need to supply reports from your endocrinologist. Your case will then be assessed by the airline doctor.
- Ambulance, fire and police services. This depends on the requirements in your state or territory. For example, in NSW, the ambulance and police services assess potential candidates on a case-by-case basis.
- Australian Armed Forces. People who take insulin can't serve in the Armed Forces.
- Passenger transport. This depends on the service provider, and includes buses, trains and trams. You'll need to pass the driving medical check.
- Prison service and community corrections. You'll need to be cleared by a doctor for some roles.
- Transporting hazardous materials and large cargos.
- Working at heights, or working offshore. This includes working on construction sites, with ladders, or working on oil rigs.

## DEALING WITH DISCRIMINATION

Discrimination can come in many forms. It might be someone refusing to hire you after an employment medical, or your employer could limit your responsibilities or even fire you. They may also be unwilling to accommodate your need for regular meal or snack breaks, or to provide a private location where you can check your blood glucose or inject your insulin.

Workplace laws require employers to take reasonable steps to accommodate your needs. For instance, if you need to take a short break to have a snack or check your blood glucose level, your employer would be legally obliged, in the majority of cases, to allow such a break.

Contact the Fair Work Ombudsman if you believe you're being discriminated against. Visit fairwork.gov.au

## REASONABLE ADJUSTMENTS AT WORK

People living with T1D can request modifications to help them work safely. Unless these workplace modifications would result in 'unjustifiable hardship' (that is, a steep cost), employers have to agree to make reasonable changes.

Have a think about what might help you. Some of the things you might want to request include:

- regular snack breaks (on top of the minimum award break times)
- a private, clean place to check your blood glucose levels and give yourself insulin
- hypo prevention and treatment packs in easy to reach places (like your work station and the staff first aid kit)
- a sharps container kept on the premises.

To make these changes, employers can apply for a grant under the Employment Assistance Fund, run by the Australian Federal Government. (You have to work at least 8 hours a week for your employer to be eligible).

#### **MANAGING SHIFT WORK**

Shift work can put a strain on anyone's health, even those who don't have diabetes. While there's no evidence to say you shouldn't perform shift work, you should be aware that managing your T1D may be more difficult, especially if your shift roster and patterns change quickly.

Shift work can increase your risk of high or low blood glucose levels. This is due to changes in your body's circadian rhythms, which regulate daily processes like hunger and fatigue. When you start eating and sleeping at different times, your body's internal clock is disrupted, which can affect your blood glucose levels.

Different insulin regimens, such as taking long-acting insulin analogues at the same time once or twice a day, supplemented by rapid-acting or short-acting insulin when you eat, can help. Regularly monitoring your blood glucose levels during and after shifts can also help.

#### **HEALTHY EATING FOR SHIFT WORK**

Mealtimes often occur at irregular times during shift work. This can be a challenge for people with T1D. But with some careful planning, you can still eat healthily – no matter what hours you work.

 Keep a supply of carbohydrate foods handy. Shops and cafeterias may not be open when you're at work, so make sure you have a supply of long-lasting (non-perishable) carbohydrate foods. It can be a good idea to keep things like dried fruit, cereal bars, baked beans or canned spaghetti in your locker or desk.



- Include regular meals and regular carbohydrate intake in your routine.
   No matter what working hours you have, try to eat 2 or 3 meals with some carbohydrate foods, and spread your meals across the day (or night).
- Many people don't drink enough water, but it's important to keep up your fluids. Even slight dehydration can lead to tiredness and headaches. Try to have at least 6-8 glasses of water a day.

#### STUDYING AND EXAMS

When living with T1D, your ability to concentrate can be affected by high or low blood glucose levels, so it's a good idea to monitor your levels closely when studying. It's also helpful to keep a close eye on your blood glucose levels while you're doing exams. Most schools and universities will let you take your blood glucose meter and strips with you when sitting for exams, as well as small amounts of carbohydrate food or drink (such as juice or dried fruit).

If you're using a CGM and your phone is your receiver, you'll need a letter from your diabetes team stating that you need your phone for exams. It should explain that your phone must be within 6m of you during your exam, and say that your phone has been set to alarm if your blood glucose level is too high or too low.

You're often given extra time to complete an exam if you had to treat a hypo or if you had to have a break because of high blood glucose levels. Speak to the student office to find out the rules beforehand. When you arrive for your exam, let the staff know that you might need to stop and eat or go to the toilet during the exam.

For lots more advice on studying and exams while living with T1D, download Testing Times, JDRF's guide for students. Get your free copy at jdrf.org.au/testing-times

## DRIVING AND DIABETES



Many people worry that they won't be allowed to drive once they're diagnosed with diabetes. But the good news is that you can certainly get – or keep – your driver licence if you have T1D. There are just a few rules and restrictions you'll need to stick to.

Licensing authorities are mainly concerned about the possibility of you having a hypo while driving. They're also mindful of diabetes complications like eye problems. All states and territories use a set of national guidelines to assess people with diabetes who want to start or continue driving. These guidelines, called 'Assessing Fitness to Drive', protect your safety and the safety of the community as a whole. They attempt to balance safety and any unfairness against you.

In case of an accident, you should always have something on you that identifies you as having T1D, such as a MedicAlert wristband or bracelet, as well as a card for your wallet or glove compartment. You can also buy seatbelt covers that show your T1D status.

## LICENSING LAWS AND PROCESSES

You need to immediately let the licensing authority in your state or territory know that you've been diagnosed with T1D. If you don't notify them and then have an accident, you could be charged with driving offences. It's best to tell your insurance company, too – you may have problems with insurance claims if you're involved in an accident and haven't let them know.

Once you've notified your licensing authority, they'll forward you a form. Your doctor or diabetes educator then has to do a medical review and sign the form to say you're fit to drive.

To keep your licence, you'll need a medical review at least every 2 years. If you hold a commercial licence, it will be an annual review.

It's important to plan ahead for your medical review. You can have an eye check beforehand, and take along other results, including records of your recent blood glucose results.

## REMEMBER: 'ABOVE 5 TO DRIVE'

Remember the phrase 'above 5 to drive'. Your blood glucose level should be above 5mmol/L every time you get behind the wheel.

You need to check your blood glucose level before driving, as having low blood glucose levels can impair your ability to drive safely. Also make sure you always have a hypo fix and a long-acting carbohydrate snack in your car.

If you're driving long distances, you need to check your blood glucose before driving and then again every 2 hours.

Also make sure you plan to have regular meal breaks.

It's important to know that if you have a hypo while driving and cause an accident, you may be charged with the serious offence of reckless or negligent driving. It's your responsibility to prove beyond a reasonable doubt that you were having a hypo and not legally responsible for your actions. But if it can be shown that you knew you were having a hypo and neglected to treat it, the charges may still stand.

#### WHAT TO DO IF YOU FEEL LOW WHILE DRIVING

If you're ever driving and feel that your blood glucose level is low, it's vital you stop. Don't try to treat a hypo while driving. Even a mild hypo can be dangerous, as it can affect your reaction time and concentration.

- Pull over and stop driving as soon as it's safe. Take the key out of the ignition.
- Check your glucose level. Treat your hypo if needed.
- Wait for 15 minutes. After that time, recheck your blood glucose and eat some long-acting carbohydrate.
- It's important that you don't restart the car until you've treated your hypo, feel absolutely normal and are above 5mmol/L. It's also recommended that you wait at least 30 minutes after your hypo symptoms have completely gone before you drive again.
- Remember: while waiting can be annoying, it's better to arrive late than to potentially cause a serious accident.

#### **UNCONSCIOUS HYPOS** AND DRIVING

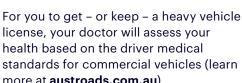
If you have a hypo that leads to you losing consciousness, you'll need to get medical clearance before you drive again. In most cases you'll have your license temporarily suspended, and you'll need a review with your diabetes specialist before your license is restored.

#### **COMMERCIAL DRIVING AND HEAVY VEHICLE LICENCES**

Just like private vehicle drivers, commercial drivers must advise their state or territory licensing authority of any illness or condition that might affect their driving ability. Penalties can be enforced if you don't report your T1D diagnosis.

Unconditional heavy vehicle licenses aren't issued to people with T1D, but a conditional license may be granted. standards for commercial vehicles (learn more at austroads.com.au).

Your state's licensing authority will then consider the doctor's report and other factors, such as your accident history and the type of vehicle you drive, before deciding to grant you a licence.





## STAYING HEALTHY AND ENJOYING LIFE

# YOUR FUTURE HEALTH AND POSSIBLE COMPLICATIONS

Here comes the part none of us likes to think about: the possible complications of life with type 1 diabetes (T1D).

Thinking about long-term health complications can be difficult and upsetting. And it can be hard for anyone to make changes to the way they live now to try to lower the risk of problems later.

But managing your diabetes by taking your insulin, regularly checking your blood glucose level, eating properly and getting enough exercise is the best way to reduce your risk of developing complications. It's also essential that you don't smoke.

## WHY DO COMPLICATIONS HAPPEN?

The long-term health problems related to diabetes are linked to having higher blood glucose levels over a long period of time. In general, the most common complications are:

- damage to the large blood vessels of the heart, brain and legs (macrovascular complications)
- damage to the small blood vessels, causing problems in the eyes, feet, kidneys and nerves (microvascular complications).

Certain cells don't need insulin for glucose to move into them. These kinds of cells are found in the brain, nerves, eyes, kidneys and blood vessels. If your The parts of the body that can be most affected by diabetes complications are:

- eyes
- feet
- gums
- heart and blood vessels
- kidneys
- nerves.

blood glucose levels are high, the cells that don't need insulin will absorb large amounts of glucose. Eventually, this can be toxic to the cells. As a result, the organs will be vulnerable to damage.

While complications are clearly linked to higher blood glucose levels, other factors can also play a role, like your genes.

Once you've lived with diabetes for a couple of years, you're at risk of developing some subtle changes to the organs that have non-insulin requiring cells. But many of the complications won't show up until you've had it for many years – and sometimes even decades.

## CHECKING FOR COMPLICATIONS

Complications usually develop silently and gradually over time, so it's very important to get regular check-ups. If changes to your organs are found early, there are strategies to stop or delay the progression of the complications.

For this reason, it's recommended that you're screened for complications 2 to 5 years after being diagnosed with diabetes, and every year after that.

Here are a few of the common issues that can arise, and how your GP or medical team can test for them.



#### **EYE PROBLEMS**

People with diabetes have a greater risk of developing eye problems. This can include:

- cataracts, a thickening and clouding of the lens of the eye, which blurs vision and can make it hard to see at night
- diabetic retinopathy, which involves changes in the retina due to damage or growth problems in the retina's small blood vessels
- glaucoma, which can happen when pressure builds up inside the eye, decreasing blood flow to the retina and optic nerve. If left untreated, glaucoma can lead to vision loss.

**How it's checked:** Regular visits to your ophthalmologist or optometrist can detect changes in your eyes.

Laser treatment, injections or implants can be used to prevent vision loss if retinopathy is detected. Cataracts and glaucoma are also manageable when caught in the early stages.



#### **GUM (PERIODONTAL) DISEASE**

People with diabetes are more likely than others to develop gum disease because they may have higher blood glucose levels, more plaque, less saliva, loss of collagen in the gum tissue, and poor blood circulation in the gums.

Signs of gum disease include bleeding, sensitive and painful gums, receding gums or discoloured teeth.

**How it's checked:** Make sure you have regular check-ups with your dentist.



#### **HEART AND BLOOD VESSELS**

People with diabetes have a higher risk of developing problems with the heart and large blood vessels. This can lead to:

- foot ulcers and infections, due to blockages of blood vessels supplying blood to the legs and feet. This can lead to the loss of a toe, foot or the lower leg
- heart attacks, due to blockages of the blood vessels that supply blood to the heart
- strokes, due to blockages of the blood vessels that supply blood to the brain.

**How it's checked:** Your blood pressure, cholesterol levels and the pulse in your feet should be regularly monitored by your GP or healthcare team.



#### **KIDNEY DISEASE**

Prolonged high blood glucose can damage the blood vessels in the kidneys and eventually lead to kidney disease (also called nephropathy). Early-stage kidney disease doesn't cause symptoms, but if it isn't addressed it can result in kidney failure. This can eventually lead to needing dialysis.

If kidney disease is picked up early, there are treatments that will stop and possibly reverse the damage.

How it's checked: Your GP or diabetes healthcare team can use a urine sample to test how much protein (or microalbumin) is passed by your kidneys.

You should also have the creatinine levels in your blood checked at least once a year. High levels may mean your kidneys aren't working well.



## NERVE DAMAGE (NEUROPATHY)

Diabetic neuropathy is a type of nerve damage that can affect nerves in many parts of the body. The most common early symptoms you might notice are numbness, tingling or sharp pains in your feet or lower legs. If left untreated, nerve damage can cause a number of problems, such as ulcers. It can lead to problems with your gut, heart rate and blood pressure, and is also a factor that contributes to the development of impotence in men.

**How it's checked:** Your doctor or diabetes team should check your feet at least once a year to see if there are any changes to your nerves.

## TIPS TO HELP LOWER YOUR RISK OF COMPLICATIONS

- Aim to keep your blood glucose levels between 3.9-10mmol/L as much as possible (it's recommended that you aim for 70% of your glucose readings to sit in this range).
- Be physically active, doing at least 30 minutes of moderate physical activity most days of the week.
- Don't smoke.
- Drink alcohol in moderation.
- Eat a healthy, balanced diet.
- Have regular check-ups of your feet, eyes, teeth and gums.
- Keep your blood pressure and cholesterol levels down.

## COELIAC AND THYROID DISEASES

T1D is an autoimmune disease, which means your body's immune system has mistaken the beta cells in your pancreas for something foreign, and has worked to destroy these cells. If your immune system has turned on you once, you have a higher chance of it happening again – which is why you're more likely to be diagnosed with another autoimmune condition, such as coeliac or thyroid disease.

While some people develop obvious symptoms of thyroid or coeliac disease, others don't. For this reason, it's recommended that you have a simple blood test to screen for them every 2 to 3 years.

#### **THYROID DISEASE**

The thyroid is a small gland at the front of the neck. It manufactures the hormones that help control metabolism and growth. If the thyroid is overactive, it releases too much thyroid hormone into the bloodstream. This causes a condition called hyperthyroidism. This makes the body use energy more quickly than it should, and chemical activity in the cells (like metabolism) speeds up.

Many people with diabetes find life hard at times, and depression, anxiety and burnout are very common. After all, managing a condition for the rest of your life would be tough on anyone! It can help to get counselling, or to talk to other people who understand.

On the other hand, an underactive thyroid produces too little thyroid hormone. This is called hypothyroidism. This means the body uses energy more slowly, and chemical activity in the cells (such as metabolism) slows down.

Both hyperthyroidism and hypothyroidism can have a negative impact on your blood glucose levels. If your blood glucose levels go out of control for no obvious reason, it can be worth talking to your GP about being tested for thyroid disease.

#### **COELIAC DISEASE**

Coeliac disease is a digestive condition that damages the small intestine and interferes with absorption of nutrients from food. People who have coeliac disease can't tolerate a protein called gluten, which is found in wheat, rye and barley. When people with coeliac disease eat foods with gluten in them, their immune system responds by damaging the small intestine. This affects how they absorb essential nutrients, such as glucose, as well as vitamins and minerals.

The treatment for coeliac disease is a strict gluten-free diet. This can make managing diabetes harder, as many gluten-free foods tend to be higher GI (learn more about GI on page 70). But there are also a lot of gluten-free foods that are lower GI, including legumes, quinoa, buckwheat grain, and many fruits and dairy products.

A dietitian with knowledge of diabetes and coeliac disease will help you with an eating plan to manage both conditions.

#### KEEPING YOUR SPIRITS UP

When living with T1D, your physical health is usually your focus – and it's what your medical team will often emphasise, too. After all, a lot of time and energy goes into managing your diabetes targets and your physical health.

Because of this, the emotional and psychological effects of living with T1D are often overlooked. But managing your mental wellbeing is just as important as the physical side of things. It's vital you look after all aspects of yourself.

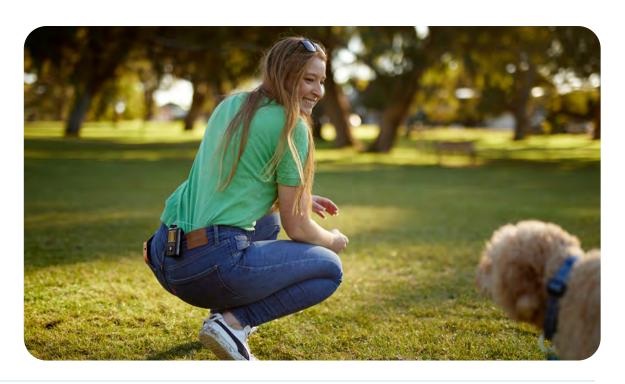
#### OVERWHELMED AND UNMOTIVATED? YOU'RE NOT ALONE

Diabetes is different to other chronic diseases. You need to make a multitude

of decisions every day – in fact, a study found that you can be expected to make an extra 180 decisions every day when compared to the average person living without T1D. No wonder it's so easy to feel overwhelmed!

And T1D is a sensitive creature, too. It brings so many physical targets and tests with it, but it can be affected by stress, activity or exercise, illness, excitement, travel, work and routine changes, hormones, age and stage of life, food and drink choices, your insulin type, dose and site of injection... the list goes on.

Feeling like you lack control can lead to a lot of frustration and anxiety. This can make it harder to hold on to your motivation to keep managing your T1D as well as you can. People also often put themselves down when things go wrong, which can lower motivation. And it's very common to feel guilt when your results aren't as good as you, your family or health professional expect them to be.





It's helpful to have realistic goals and a good understanding of what diabetes is about and how you can personally manage it. Try to keep an eye on the bigger picture and take a problem-solving approach, rather than reacting to individual readings.

Sometimes life just gets in the way and you need to identify if there are other issues going on that are impacting your diabetes. It's important you tell your healthcare team about your needs and priorities. You need to feel that you're listened to and that you're comfortable approaching them with any concerns.

## WHEN OTHER PEOPLE AREN'T HELPING

Sometimes you might feel like your friends or family are blaming you for

your diabetes being out of whack. This can also lower your motivation to get back on track. It's important to work out if their feedback is helpful or unhelpful for you. Do reminders and questions about your diabetes management make you feel better or worse? Talk to your friends or family about how they make you feel.

The words and phrases you and your loved ones use when talking about T1D can also affect how you feel. For example, if someone says you're "testing" your blood glucose levels, it might make you feel like there's a pass or fail outcome. You could suggest they call it "monitoring" your levels instead. This can reduce some of the feeling of failure that can come when your numbers are outside your target range. Likewise, if people talk about your diabetes being "under control", or saying someone has "good (or bad) control", you could suggest they talk about "managing" blood glucose levels or "being in (or out) of target range" instead.

## DIABETES AND YOUR MOOD

Something the textbooks forget to tell you? That your mood and actions can be closely linked to your blood glucose levels.

As you may have already noticed, you might feel short-tempered and out of sorts when your blood glucose is high.

You might also find that your personality changes when your blood glucose level is low. If you're usually loud and outgoing, you may become quiet and withdrawn; if you're naturally a serious person, you might find yourself laughing at silly things. If you're normally even-tempered, you could become argumentative.

These changes may make you feel embarrassed, but it's okay to tell people that you'll be back to your "normal" self soon, after you treat your blood glucose level. You're not using your diabetes as an excuse, you're simply stating a fact!

## DEPRESSION: THE SIGNS AND WHERE TO GET HELP

Unfortunately, people who live with T1D are at a higher risk of experiencing depression than those who don't. We're not saying this to scare you – it's just important that you know the signs so you know if and when you need help.

Symptoms of depression can include extended periods (which last more than 2 weeks) of:

- becoming withdrawn or not going out
- feeling overwhelmed, tearful, guilty or irritable
- feeling sad, down or miserable most of the time

- having physical symptoms, like feeling tired all the time, having a churning gut, disturbed sleep and poor appetite
- losing interest or pleasure in most of your usual activities
- stopping doing things you used to enjoy
- thoughts about being a failure, being worthless, or thinking that life is not worth living.

If you notice any of these signs, please speak to a trusted healthcare professional, family member or friend. If this is difficult, organisations such as Beyond Blue and Black Dog Institute have information, resources and people to chat with. (You can find their details on page 152.)

Getting professional advice from a psychologist or counsellor can help you learn how to reactivate your life, solve problems and manage any negative thinking. This can help you recover quicker, and also teach you some strategies to prevent a relapse. Your doctor may also prescribe antidepressants, if that's something you'd be interested in.



#### **DIABETES BURNOUT**

T1D is like a job – and you have to do it 24 hours a day, 7 days a week, 365 days a year – so it makes sense that many people experience burnout at some point. The effort to manage it can start to feel too hard and frustrating, especially when your results aren't what you'd hoped for.

Studies have shown that most people living with diabetes experience worries, fears and negative feelings around their T1D at some stage. When this happens for a long period of time, it can lead to diabetes burnout. It's specific to diabetes, very common, and difficult to avoid completely.

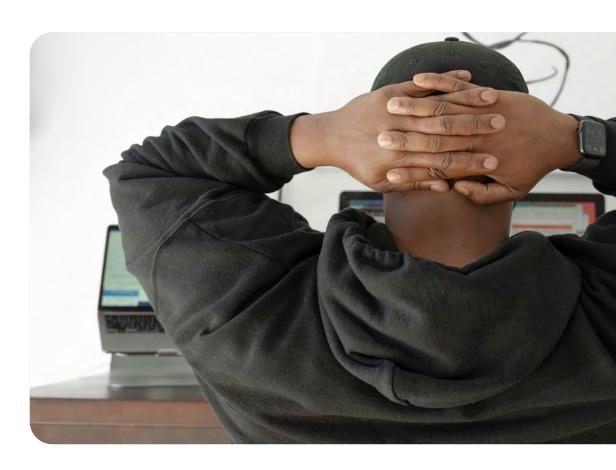
If left untreated, diabetes burnout can lead to prolonged high blood glucose

levels, which can cause serious physical problems. It can also lead to other psychological issues.

So what does diabetes burnout look or feel like? The rest of your life could be ticking along well, but you might not have the energy or the will to do what you need to do to manage your T1D.

Signs of burnout can include:

- ignoring or trying to forget your diabetes most of the time
- not checking your blood glucose levels
- not worrying about your eating habits or exercise
- stopping or reducing your insulin injections.



#### STRATEGIES TO AVOID BURNOUT

You need realistic expectations and practical strategies to manage the emotional side of diabetes.

- One simple trick is to try changing the way you think about your blood glucose levels. After you experience your initial (and perfectly normal!) emotional reaction to a high or low blood glucose reading, don't dwell on it. Instead, try to look at your results as information to help you decide what to do next. There's no point in ever wasting time and energy mentally punishing yourself over a blood glucose reading.
- Use what you know to plan ahead and make positive adjustments. Think of blood glucose monitoring as a tool or guide to help you work out what to do.

- Try to use words like "high" and "low" blood glucose levels instead of "good" and "bad". Remember, our language matters!
- Simplifying your diabetes regime for a short period of time can sometimes help reduce your mental burden. Work out what part of your diabetes care you're finding the most difficult, and come up with a plan to get some support in that area. Talk to your diabetes team for some strategies and advice to help.
- It's also important to care of your overall wellbeing. You can improve your mental health and help reduce diabetes burnout by taking part in regular self-care activities and the essential '4Rs':
  - recreation
  - regular exercise
  - relationships that are nurturing
  - rest (6-8 hours of sleep a night).



If you think you're already experiencing burnout or you're at risk of it happening, it can help to ask yourself these questions:

- What particular area of my diabetes care is causing me problems?
- Is there something happening in my life that might be conflicting with my diabetes care, making it harder?
- What problems outside of diabetes could be addressed?
- What are my expectations for my diabetes management? What do I want?
- Are my goals realistic right now?
   Am I aiming too high?



## GETTING THE SUPPORT YOU NEED

When things aren't going so well with your T1D, it's important to work out why. But it's also really important to be kind to yourself and acknowledge that living with diabetes can be hard.

If your diabetes management is off track, there are problems getting in the way. This doesn't take away your responsibility, but it does open up possibilities for change. The problems might be directly related to your T1D, such as a need for a management change, or they might be separate, like if you're having issues at work. Because at the end of the day, all the things that happen in our lives are connected and contribute to our overall wellbeing.

You need to give yourself a break and tackle problems by getting the support you need to identify and address them. Talking to other people who understand is very important. Chat with a friend, family member, partner or someone in your diabetes team.

Many public health services have specialist psychologists in the diabetes team. Your GP can also refer you to a psychologist or mental health social worker. This is more affordable if your GP fills out a mental health treatment plan, which lets you claim part of the cost through Medicare. If you have private insurance, you may be covered for part of the counselling cost (check with your particular fund).

## DO MORE THAN JUST WORRY ABOUT DIABETES - TAKE ACTIVE STEPS TO CARE FOR IT

- Be an active participant in your own care. Talk to your healthcare team about your needs. Learn everything you can about diabetes and your body.
- Be proactive. Find out your options and do what you can. Get information from a trusted book, website or professional.
- Prepare for visits to health professionals by listing the topics you want to talk about. You may also want to ask your doctor to send you a copy of your blood results, like your HbA1c results, so you can get ready for your appointments ahead of time.
- Visit your doctor, diabetes educator and/or dietitian to get the latest information about diabetes management, or to reset your diabetes management goals at any time.

#### **BUILD A SUPPORT NETWORK**

- Get counselling, peer support and advice from other people with diabetes through organisations like JDRF.
- Talk with others about your fears of diabetes complications. And remember there are no certainties in life – you can only increase or decrease your risk of developing complications.

#### **TAKE IT EASY ON YOURSELF**

- Avoid personalising other people's stories. We're all different, and what happened to someone else won't necessarily happen to you!
- Continue with, or develop, a variety of passions and interests. There's a lot more to your life than diabetes.
- Make realistic goals, and approach them in manageable steps.
- Rely on your sense of humour.
- Remember that you're much more than your diabetes.

#### YOUR BODY IMAGE



Body image is what you think you look like, and isn't related to your actual appearance. Many factors can affect your body image, and living with a chronic condition is one of them. Changes in your weight, and other aspects of life with T1D, can impact how you feel about your body. This applies to men and women equally.

Some people find injecting insulin causes significant weight gain. Others find weight gain difficult, particularly when their blood glucose is elevated. On top of that, bruises or marks from injections, or wearing an insulin pump, can also be a physical reminder of your diabetes. These can all have a negative impact on your body image.

If you struggle to maintain a healthy weight, it can help to concentrate on the healthy habits you'd like to adopt, instead of getting stuck on how much you weigh. You can work with a dietitian or personal trainer to develop a plan, then try to focus on that plan and not your body size.

Are you able to meet your goals for eating and activity? Use this to measure success, not how your body looks or what the scale says.

At times you might need more support to deal with your self-esteem or body image. It can help to have professional counselling. Together, you can work on improving how you feel about yourself, or identify ways to change your thinking and behaviours. Talk to your doctor or healthcare team and ask them to recommend a counsellor.

## GETTING THE BALANCE RIGHT

Living with T1D can be challenging. There's no doubt about that. There's day-to-day attention on the type and amount of food you eat, how many carbohydrates you have for every meal and snack, and how much insulin you need to take. With lots of discussions around food and eating, it's easy to feel overwhelmed. This may lead to you worrying about eating and your weight.

Weight fluctuations can happen around the time of your diagnosis, with weight restoration when you start using insulin. This is a normal part of recovery, as insulin helps your body heal and muscles rebuild. But these weight fluctuations can trigger body image worries.

You might start to feel a desire to control your weight. You may be faced with the dilemma that you want to manage your diabetes well, but don't want to put on weight. This can be very confusing, especially if you don't have supportive people to help you.

Research has shown that there's a difference between healthy diabetes management (where some attention is paid to food and body weight) versus an excessive focus on what you eat and weigh (to the point that it's more important than anything else). It's important to talk to your friends, family and health professionals if you need support to achieve this balance. It isn't easy doing it on your own.

## A NOTE ON DISORDERED EATING

Having diabetes means you might be at a higher risk of developing an eating disorder. There are a few factors that contribute to this – for example, restricting food can be a way of coping with your diagnosis, feeling in control and managing stress levels. These behaviours could also be a way of coping with the challenge of managing your daily tasks, like taking insulin, glucose monitoring and going to medical appointments.

On top of that, having a fear of hypoglycaemia can make it difficult to stay on track with your eating and diabetes management. Some people may also feel like they lose control of their eating when they have hypos.

#### **SIGNS YOU MAY NEED HELP**

You might be at risk of disordered eating if you find yourself:

- avoiding checking your glucose levels
- cutting back on the amount of food you're eating (this might be followed by binge eating)
- feeling anxious about your weight
- missing social events with your friends if they involve food
- starting to be secretive about what you're eating and how much exercise you're doing
- wanting to avoid normal tasks of managing diabetes
- wanting to skip your appointments with health professionals or doctors.

#### WHERE TO GO FOR SUPPORT

If you're finding it hard to manage your feelings around body image, eating and your weight, you might be hoping your problems go away on their own. Or you might think that your worries aren't severe enough to ask for help.

But the most important thing to do is to tell someone you trust that you're struggling. The earlier you reach out and talk to someone, the more likely you are to improve.

> Let family, friends and health professionals know you're having a tough time. It's hard work having diabetes, and the more support you have, the better.

Talking to your GP or healthcare professionals can be a good starting point. They're the experts in diabetes and can provide support in balancing your eating and T1D. It might also be a good idea to talk to a mental health professional, such as a psychologist.

Talking to your health professionals can help you develop confidence with managing your diabetes. It will also build the skills you need to cope with the emotional impact of living with T1D.

## ALCOHOL, SMOKING AND DRUGS



Want to still have a glass of wine with friends, or a couple of beers on a hot day? You can! It just may take a bit more planning. But now is the time to give up smoking – and you have more to think about if you take drugs, too.

#### **DRINKING AND T1D**

As well as asking yourself the usual questions before heading out ("What will I wear? Will I drive or am I going to drink? How will I get home?"), you now have to think about the diabetes supplies you'll need to take with you. Keep the following in mind as you get ready.

- Take your blood glucose meter and strips. No matter what you're planning an afternoon watching the footy, a night on the dance floor, a few cocktails with friends you'll need to keep track of your blood glucose levels. Walking, dancing and other physical activities can lower your blood glucose level, while most drinks and food will raise it. It's important to keep track of what's going on.
- Pack a hypo kit. If you're out and have a hypo, you don't want to be stuck looking for a waiter or queuing at the bar for an emergency lemonade.
- Carry lollies. Try to put them in a container or packaging so they don't get squashed.
- Pack your insulin. You can buy special packs that will keep your insulin cool even on a hot day – perfect if you're going to a festival or camping.

### AVOIDING ALCOHOL-RELATED HYPOS

Alcohol increases your risk of having a hypo, but there are things you can do to lower your chances of it happening.

For example, if you're going out drinking, make sure you eat some carbs at the beginning of the night – a snack with 2 to 3 exchanges of carbohydrate is usually ideal. You should also eat some carbohydrate every few hours while you're drinking, and then again before you go to bed.

If you've had problems with low blood glucose levels overnight in the past, it may be worth reducing your evening dose of insulin by 10-20%. You could also use a setting on your insulin pump that reduces the amount of basal insulin it delivers, such as the exercise setting, easy off or temp target. This reduction may need to be even greater, especially if you're planning a very active night (if you know you're going to be dancing a lot), or if you played sport during the day. Talk with your diabetes team before you try it.

Your liver usually releases small amounts of glucose into the bloodstream, which your basal (background) insulin balances. But your body also uses your liver to get rid of alcohol. While the liver is busy eliminating alcohol from your system, it stops releasing glucose. This puts you at risk of hypoglycaemia overnight. As a general rule, it takes your liver an hour to process a standard alcoholic drink – so having 8 drinks means your liver would be busy for 8 hours.

#### THE MORNING AFTER

The day after a night out can also be a challenge. Delaying or missing your morning insulin can result in your blood glucose levels rising too high. To avoid this, set an alarm so you wake up within an hour or so of your usual waking time.

If you're hungover and don't feel like eating, take your normal or a slightly reduced dose of your intermediate or long-acting insulin and go back to bed.

If you're so hungover that you're throwing up, you should treat it like any other time you're vomiting. Put your usual sick plan into action (read more about that on page 84), and keep a close eye on your blood glucose levels and ketones. You should also set your alarm to wake you again in 2 hours so you can check that your blood glucose level isn't too low.

#### **TIPS FOR DRINKING SAFELY**

The guidelines for drinking alcohol are the same for everyone, no matter their T1D status. Australia's National Health and Medical Research Council (NHMRC) says that to reduce the risk of harm from alcohol-related disease or injury, men and women should drink no more than 10 standard drinks a week, and no more than 4 standard drinks on any day. Overall, the less you drink, the lower your risk of harm from alcohol.

But we're all human, and sometimes you might want to ignore the guidelines! If you're planning on having a couple of drinks, a bit of extra thought can ensure you have a great night.

Check your blood glucose regularly.
 It can be easy to have a hypo when you're out, especially if you've been dancing or more active than usual.
 It can also be easy to end up feeling sick from high blood glucose levels, especially with sugary drinks and

- mixers. (The good news is that it hurts less to check your blood glucose levels after a couple of drinks!)
- Be aware that it can be harder for you to tell if you're having a hypo when you've had a few drinks. You may miss the symptoms or be very deep into the hypo before you notice it. And other people may not be able to tell you're having a hypo because they'll just think you're drunk or they might be drinking and less observant than usual themselves.
- Make sure that someone you're with

   or a few people know that you
   have T1D, and let them know how
   to treat a hypo. You can even ask
   them to remind you to check your
   levels (if that's something you'd
   be comfortable with).
- You might find that your blood glucose level rises too high after having a drink that contains carbohydrate, like spirits mixed with regular soft drink or cordial, sweetened liqueurs or large amounts of beer. You may also find that you eat more when you drink alcohol. Where possible, choose a diet soft drink as a mixer and keep an eye on your food intake.

#### SMOKING AND VAPING

People with T1D who smoke can face serious health consequences. They have a much higher chance of complications such as eye disease, heart disease, stroke, nerve damage and kidney disease. It also increases the risk of impotence in men.

Like smoking cigarettes, vaping comes with many health risks. There hasn't been much research specifically done on vaping and T1D, but some studies have shown that vaping can increase blood glucose levels.

If you don't smoke or vape, you shouldn't start now. If you already smoke or vape, it's going to be tough to quit, but there couldn't be a better time to give it up.

Talk to your endocrinologist or diabetes team about strategies you can use to quit. As smoking can cause insulin resistance, you may need to reduce your insulin when you stop or cut back smoking.

You can also visit **quit.org.au** or call the Quitline on 13 78 48 for advice and tips.

### **ILLICIT DRUGS**

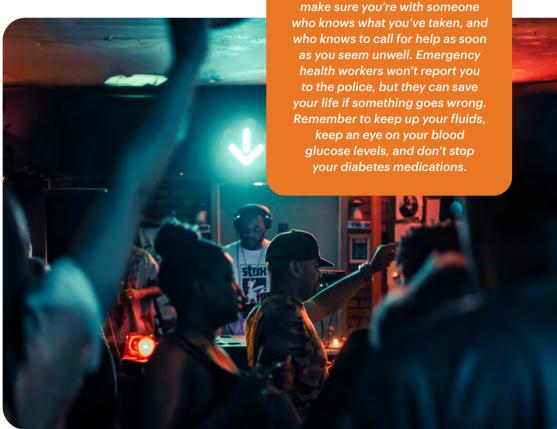
Taking any drug other than those prescribed by your doctor can be risky for anyone, but even more so if you have diabetes. Things get even more complicated if you mix different drugs

or combine them with alcohol. These combinations can increase the risk of shortness of breath, vomiting, fainting, impulsive or dangerous behaviours, accidents and overdoses.

Add diabetes to this and it can quickly become a deadly situation, especially if you forget to take your insulin or don't eat and drink.

You should always wear medical ID that tells people you have T1D, like a bracelet or necklace, or even a well-placed tattoo. This could be helpful in an emergency.





#### TYPE OF DRUG POSSIBLE EFFECTS

### **Depressants**

Depressants are substances that slow down processes in the body. Examples include:

- alcohol
- benzodiazepines
- codeine
- fentanyl
- heroin
- inhalants
- marijuana
- methadone
- morphine

### You might notice:

- altered eating habits and changes to hormone production, leading to low or high blood glucose levels
- drowsiness and confusion
- forgetfulness
- slowed breathing

### **Hallucinogens**

These drugs cause hallucinations. Common examples include:

- ketamine
- LSD
- · magic mushrooms
- PCP

### You might notice:

- abnormal behaviour
- panic attacks
- paranoia

#### **Stimulants**

Stimulants are substances that speed up processes in the body. Examples include:

- cocaine
- crystal meth
- ecstasy (MDMA)
- speed

#### You might notice:

- breakdown of muscle, which can lead to kidney damage (MDMA)
- changes to insulin action and hormone production, leading to high blood glucose levels
- increased blood pressure and body temperature
- increased risk of hypoglycaemia
- loss of appetite
- rapid, slow or irregular pulse
- reduced hypoglycaemia awareness

### **TRAVELLING**



T1D should never stop you from doing the things you want to do – and this includes travelling. Whether you want to head overseas or check out all Australia has to offer, you'll be able to do it all.

Planning ahead is the key to any successful trip, but this is even more important for people with T1D. Being prepared will take you a long way and help keep you healthy once you're there – and let you avoid unnecessary stress, too.

Be sure to get any required vaccinations before you go! The Australian Department of Health recommends all travellers see their GP 6 to 12 weeks before heading off. This gives you time to deal with any possible side effects and to build up full immunity.

### IN THE WEEKS BEFORE YOU LEAVE

### **SEE YOUR HEALTH SPECIALIST**

Visit your GP or endocrinologist for a check-up several weeks before you leave for a holiday.

Discuss your itinerary with your diabetes team. Work out a plan for meals and medication together, especially if you're travelling through different time zones.

It's also important to plan ahead and work out a strategy for sick days, as well as how to adjust your insulin dose if required.

#### **BUY THE RIGHT INSURANCE**

Travel insurance is a must. All travellers are prone to infectious illnesses as they travel through new countries. You're also more likely than usual to have problems with unexpected low or high blood glucose levels when you're out of your normal routine and eating different things.

It's very important that you can access good quality healthcare if you need it. Not all travel insurance policies cover T1D, so make sure you choose one that does.

### PREPARE YOUR DOCUMENTS

Get a letter from your doctor that states you have T1D. The typed letter should explain:

- the devices you use (if you're using an insulin pump or CGM, the letter should also include instructions that the device/s must not be removed)
- the importance of carrying your medications with you
- the related prescription medications you take
- the type of insulin you take
- · your dosage regimen.

Also ask your GP or pharmacist for a list of your medications, including the generic names and doses. Be sure to take that list with you, too.

### **GET IDENTIFICATION**

Take identification that explains you have diabetes in case you're unable to give instructions yourself. Consider getting a MedicAlert emblem (bracelet or necklace) that shows you have T1D.



# ESSENTIAL ITEMS TO PACK MEDICATION, FOOD AND DIABETES SUPPLIES

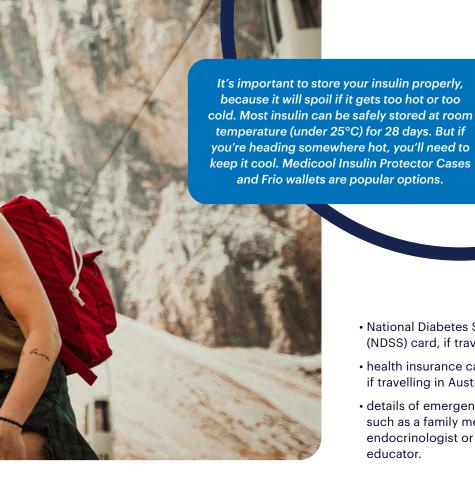
Take extra medication, supplies and hypo food with you in case of theft, loss or accidental destruction. Make sure all your strips and medications are in date!

Insulin and other medication must display a pharmaceutical label clearly identifying what it is, as well as your name. As the prescription label is usually on the outside of the box, it's best to carry medications in their original, labelled boxes.

When it comes to packing your supplies, experienced T1D travellers shared the following advice.

 Divide your medicines and diabetes supplies and pack them in at least 2 places. This will help if you lose a bag. Use insulin pens? Pack a spare.
Use an insulin pump? Take a back-up option, like syringes or a pen with needles, and short- and long-acting insulin. Talk to your doctor about what to do in those situations.

- Make sure you have your insulin, hypo fix and checking supplies in your carry-on luggage. If you use a pump, make sure you carry a spare infusion set, inserter and batteries too.
- Because insulin is affected by extreme temperatures, it should never be stored in the baggage area of an aeroplane. The temperature in the hold is too low and the insulin will freeze, so it won't be effective. Keep it with you instead.
- Pack plenty of snacks in your carry-on bag. Your departure or meal could be delayed, or the meal might not have enough carbohydrate.



### **DOCUMENTATION**

Aside from your passport, ticket and itinerary, there are a few other important documents to pack.

Make sure you take several copies of the letter from your doctor, as well as your list of medications. You should also take the actual prescriptions for all the medications you're carrying. They must include your name, the name of the medication and contact details of your medical practitioner.

Also remember to take your:

- Medicare card if you're overseas, the Australian Government has arrangements with some countries that will provide benefits similar to Medicare
- travel insurance details, if travelling overseas

- National Diabetes Services Scheme (NDSS) card, if travelling in Australia
- health insurance card or details, if travelling in Australia
- details of emergency contacts, such as a family member, your endocrinologist or diabetes educator.

#### SHARPS CONTAINER

If your trip is short, you might want to keep your used needles and sharps and get rid of them when you get home. For longer trips, you can purchase small containers that store or disintegrate needles and syringes.

Going on a cruise? Make sure you pack lots of anti-nausea and anti-diarrhea medication. Gastro and vomiting can lead to low blood glucose levels and hypos.

### **TIPS FOR FLYING**

Airport security regulations are strict for everyone, but they can be a little more challenging for people with special circumstances, like those travelling with an insulin pump or CGM.

Allow extra time to check in before your flight, as your items will be thoroughly searched by airport screening officers. Keep the letter from your doctor handy, so you can show it when needed.

People with a genuine medical condition are allowed to carry syringes, lancets, insulin pens, insulin pumps and insulin medication through security screening points, as long as they're not accessible to the public. All diabetes supplies must be carried in your own hand luggage.

Packaging for syringes should be unopened, or the syringes capped and empty. There's no limit on how many empty syringes you can carry through a security checkpoint, but you also have to be carrying insulin medication. The only exception is syringes containing glucagon, as they're pre-filled for emergencies.



### AN IMPORTANT TRAVEL TIP

It's generally recommended that you don't let your CGM or insulin pump go through body scanners or carry-on luggage x-ray machines. (Check the guidelines for your device on the manufacturer's website.) Metal detectors shouldn't damage your insulin, insulin pump, CGM or blood glucose meter.

### **DEALING WITH AIRPORT SECURITY**

- Ask your doctor or healthcare specialist for a letter that specifies your particular T1D device, as well as the relevant guidelines advising that they shouldn't pass through body scanners and x-ray machines.
- Print out information about your devices and their specific advice from the manufacturers' websites.
- The Department of Home Affairs website has a page with information on medical devices and screening technology, titled 'Travellers with special circumstances'. Bookmark it to show staff if needed.
- Be open to any available form of safe, alternative screening, like pat-downs.
   Some people also choose to remove their CGM or pump and pass through the full body scanners (note that security staff can't ask you to do this).
- If you're denied permission to board, or are faced with diabetes-related difficulties while passing through security checkpoints, ask to speak to the security checkpoint supervisor.

### WHILE IN THE AIR

It's very important to monitor your blood glucose regularly while flying. Check it before you leave home, and then again every 4 hours during your journey.

Be aware of time zone changes, and try to schedule your meals and insulin around them.

Having 2 watches, or a watch and mobile phone, can help keep track of time zone changes. If you keep a clock set to the time of the country you've just left, it will be easier to tell when your next dose of insulin is due, and how long it's been since your last dose.

If you're travelling east,
your travel day will be shorter.
If you lose more than 2 hours,
you may need to take fewer units of
intermediate or long-acting insulin.

If you're travelling west,
your travel day will be longer.
If you gain more than 2 hours,
you may need to take extra units of
short-acting insulin and more food.

If you're travelling north or south, there's usually very little difference in time. You won't need to make adjustments.

If you choose to sleep while you're onboard, ask the flight attendant to wake you at mealtimes. Airlines usually offer special meals for people with diabetes, but they often don't provide enough carbohydrate. The regular meals are generally okay, but wait until you see your food coming before you take your injection – delays in getting your meal could lead to a hypo.

Try to do some activity on the plane, such as simple stretching exercises in your seat, moving your ankles in circles and raising your legs occasionally. You can also walk up and down the aisle.

Make sure you drink plenty of water throughout the flight, too.

Some people with T1D like to let the cabin staff know they have diabetes, especially if they're travelling alone, just in case any problems arise. But you don't have to if you'd prefer not to – it's up to you.

### ADJUSTING INSULIN FOR CHANGING TIME ZONES

Travelling across several time zones? A regular 24-hour day can be extended or shortened, depending on the direction of your travel. Either way, keeping your blood glucose close to target levels can be a challenge.

You can change the time of your injections and meals by up to 2 hours in a day without adjusting your insulin dose or your meal plan. If you're crossing more than 2 time zones, meet with your endocrinologist or diabetes educator to prepare a meal and insulin schedule before you go.

It might be easier to keep to your usual insulin routine while travelling and then adjust it on arrival. In this case, it's best to have your own supply of food handy – don't rely on airline mealtimes.

A pump is an ideal way to deliver insulin across time zones, as you can pump and dose for meals in the normal way with no real change. Just make sure to adjust the time and date on your pump when you reach your destination. If you're using a 12-hour clock, check that you have the AM and PM right!



### AT YOUR DESTINATION

Plan ahead for situations that will have a big impact on your blood glucose levels, like doing a lot more activity than usual. You'll need to make sure you eat and drink enough to meet your needs. You might need to decrease your insulin if you're going to be extremely active, so make sure you talk about your plans with your diabetes team or endocrinologist before you leave.

Trying different foods is all part of the experience of travelling overseas. Find out the approximate level of carbohydrate in your meal, monitor your blood glucose levels regularly, and carry extra food, water, medication and a hypo kit to be prepared for the unexpected.

In some countries you'll need to be careful to ensure your food and water aren't contaminated. In particular, avoid tap water (including ice cubes made from tap water).

While travelling, wear comfortable shoes and don't go barefoot. Check your feet for problems like blisters, cuts and swelling, and get medical care at the first sign of infection. Also try to avoid sunburn and insect bites.

#### **HOT AND COLD CLIMATES**

Blood glucose levels can be affected by extreme temperatures, increasing your risk of both hypoglycaemia and hyperglycaemia. You always need to keep a close eye on your blood glucose levels when travelling, but it's even more important when you're in hot or cold climates. You may find that you need to make some adjustments to your insulin doses.

Some of your diabetes tools may also be affected by extreme temperatures, so think about how you'll keep your insulin and blood glucose supplies at the right temperature. For example, blood glucose meters won't work in extreme cold, so if you're heading to the ski slopes you might need to carry your meter inside your jacket, next to your body.

# DIABETES AND ISSUES FOR WOMEN

Men and women face different challenges managing T1D. Here are a few medical issues women may need to consider.

### **INFECTIONS**

Vaginal and urinary tract infections are more common in women with diabetes, especially when blood glucose levels are generally too high.

A urinary tract infection can lead to cloudy or bloody urine, a burning sensation when you go to the toilet, and/or a constant feeling that you need to pee. This can lead to a kidney infection if left untreated, so you need to see your GP for an antibiotic prescription when you notice any of these signs. Your pharmacist can provide over-the-counter remedies to reduce any pain.

Vaginal infections, such as yeast infections, can lead to itching, unusual discharge and pain during intercourse. The good news is that they're easily treated, so talk to your GP or pharmacist.

#### **MENSTRUATION**

We all know how powerful hormones can be in controlling menstrual cycles, so it's no surprise they can also affect blood glucose levels.

These changes are due to the hormones oestrogen and progesterone. When these are at their highest level just before your period, they affect insulin, which can cause blood glucose levels to rise. Some women find their blood glucose rises a lot at this time, while others don't notice a difference at all. In yet others, their

levels are lower before and during their periods. Many women say that their fasting blood glucose level before breakfast tends to fluctuate the most.

You need to discover your own pattern, so try to track what happens in relation to your cycle. This will help you be able to adjust your insulin when needed.

### A HANDY TIP

Some women find that being physically active in the week before their period starts helps reduce fluctuations in blood glucose levels.

### **MENOPAUSE**

Women with T1D may go through menopause earlier than others. But no matter when it happens, menopause will make your hormone levels change, which can cause fluctuations in your blood glucose levels. In fact, hypoglycaemia or hyperglycaemia can be an early sign of menopause for many women with T1D.

In the years leading up to menopause, surges and reductions in oestrogen and progesterone might affect you in different ways, such as mood changes, increased PMS signs, and periods that are more or less frequent, or heavier or lighter than they once were. These changes are barely noticeable for some women, but for others, changes in blood glucose levels can mean they need to monitor and adjust their insulin intake more frequently.

Be aware that the symptoms of diabetes and menopause can be very similar. Both can cause dizziness, higher temperatures, moodiness, short-term memory loss and fatigue. The only way to tell if your symptoms are related to menopause or diabetes is to check your blood glucose.

It's important to maintain an active lifestyle when experiencing menopause. Some women find themselves giving up exercise and gaining weight, which affects their ability to absorb insulin and manage their blood glucose levels. Strength exercise is particularly vital for women at this stage, so do some strength and low intensity aerobic exercise every day.

Some women find they have negative side effects such as vaginal dryness and more yeast and urinary tract infections. Talk to your doctor about how to manage these with possible hormone replacement therapy or changes to your insulin.

The key to staying healthy after menopause for women with T1D is the same as it is for women without diabetes. Try to eat regular, well-balanced meals, stay as physically active as possible, and have regular check-ups with your doctor. While there may be times when you ignore some (or all!) of these recommendations, remember that it's what you do most of the time that counts.

### **SEX AND INTIMACY**

Living with T1D can influence your sexual experiences, both physically and emotionally.

### **CONTRACEPTION**

Birth control is an important issue for women with T1D. This is because there are greater risks for a woman with diabetes and her baby when pregnancy is unplanned.

The contraceptive options for people with diabetes are the same as they are for everyone else, and having diabetes

doesn't change how well they work. It all just comes down to your individual preference. You might want to know that:

- blood glucose fluctuations are more likely with combination pills, so some doctors may suggest progestin-only ('mini') pills to avoid this
- intrauterine devices (IUDs) have no impact on blood glucose levels
- using a diaphragm doesn't affect blood glucose levels, but there may be a higher risk of yeast infections for women who have diabetes.

### **LIBIDO**

Persistently high blood glucose levels can influence how much energy you have and make you very fatigued. Unsurprisingly, this can make you less interested in sex. Keeping your blood glucose levels in your target range can help.

#### REDUCED LUBRICATION

Neuropathy (nerve damage) can reduce vaginal lubrication in some women who have had T1D for many years. This can make sex uncomfortable. Water-based lubricants can help improve dryness and sensitivity. Vaginal suppositories can be used for severe cases.

A decrease in lubrication can also happen for many other reasons, such as stress, menopause and birth control pills.

### **OSTEOPOROSIS**

Osteoporosis is a condition in which bones become thinner and more porous. This makes fractures more likely. It's common in all women as they age, but those with T1D have a higher chance of developing it if their blood glucose levels have been high for a long time. Women with T1D may also develop osteoporosis before menopause. As you approach your 50s, your doctor should test for osteoporosis with a bone density scan.

### PREGNANCY, BIRTH AND BREASTFEEDING

Women with T1D can expect to have a healthy baby. Just like all aspects of diabetes management, planning is the key to making it as safe as possible. Just be prepared to put in a bit of extra work so your baby is as healthy as can be.

Women with T1D should try to plan their pregnancies. But if you fall pregnant without planning, don't panic! Just make an urgent appointment with your doctor or diabetes team to review your diabetes and general health, and put a plan in place from there. They'll be able to guide you through all the steps until you meet your precious new bundle of joy.

You'll need a full support team to help you plan a healthy pregnancy, including:

- a diabetes educator
- a dietitian
- a midwife
- a specialist obstetrician
- an endocrinologist.

#### PREPARING FOR PREGNANCY

It's best to plan with your doctor before you become pregnant, if possible. Talk to them at least 3 months before trying to conceive. You can start working on the following goals.

• Try to achieve an HbA1C below 53mmol/mol (7%). If you can do it without having more hypos, you can try for below 48mmol/mol (6.5%). Having persistently high blood glucose levels dramatically increases the risk of abnormal development in babies, so it's best to try to keep to that target range. It's especially important in the first 8 to 12 weeks of pregnancy, when your baby's major organs are developing. If you don't already use an insulin pump, it might be time to consider it.

- Have a medical exam. You'll need check-ups by an endocrinologist before and during your pregnancy. They'll check your blood pressure and immunity to rubella and chicken pox, and screen for complications.
- Start taking folic acid. Discuss an appropriate dose with your doctor.
   They can also let you know if you should consider taking a multivitamin.
- Visit your dietitian. They can give you tips on the most appropriate foods in pregnancy.
- If you smoke or drink alcohol, now is the time to stop. Talk to your doctor if you need help quitting.
- Consider using a CGM, if you don't have one already. CGMs are fully covered by the NDSS for women who are actively trying to fall pregnant or who are already pregnant. Chat about this with your diabetes team to learn more and apply for one.

#### **DURING PREGNANCY**

Keeping your blood glucose levels tightly in target throughout your pregnancy can be very stressful and demanding. It's made even more challenging as your insulin requirements will change as you battle morning sickness and your bump grows.

You might find your usual early warning signs for hypos change or disappear completely. But just remember – it will be worth it! Ask for support and understanding from your partner, family, friends and health professionals.

When you're pregnant, you'll need to visit your endocrinologist and obstetrician more regularly than women without diabetes.



Your doctor will give you a schedule of check-ups. Because certain complications can be made worse by pregnancy, like nephropathy (kidneys) and retinopathy (eyes), you'll be closely monitored.

Your baby's growth also needs to be watched closely. Babies of women with diabetes are at risk of developing macrosomia, which means 'large body'. Babies produce their own insulin from

You can also check out the Australasian Diabetes in Pregnancy Society, or search the NDSS and Diabetes Australia websites for pregnancy fact sheets.

The Australian Breastfeeding Association offers advice on diabetes and breastfeeding. around 15 weeks gestation; if your blood glucose level is high, extra glucose crosses the placenta to your baby, and this stimulates their pancreas to make increased levels of insulin. Because of this, your baby can grow faster and store extra glucose as fat. They may also have problems with low blood glucose levels at birth, as they can continue making extra insulin for a couple of days. Keeping your blood glucose levels in your target range will help reduce these risks. But some babies may still have problems (just like the babies of women without diabetes!).

#### **BIRTH**

Good news: having T1D shouldn't impact your chances of having a regular birth.

Many women with T1D carry their baby to full term and go into labour on their own. But some are advised to have their baby early for various reasons, including difficulties with diabetes or the baby growing too large. It's also slightly more common for women with T1D to have a caesarean.

You'll be able to discuss all your options and make a plan for your baby's birth with your obstetrician.

#### **BREASTFEEDING**

T1D won't stop you from breastfeeding if that's what you'd like to do. Women with diabetes may find their milk slower to come in, but it's still possible to do it – and to keep going for as long as you (and your baby!) want to.

If you'd like to breastfeed, here are some tips to help.

- As always, watch for fluctuations in your blood glucose levels.
- Plan ahead you'll need additional carbohydrates when feeding, especially in the early months.

- Get education and support. You can contact your hospital or obstetrician to ask about going to breastfeeding classes before your baby even arrives.
- After the birth, talk to the hospital midwives and a lactation consultant for more advice.
- Feed as early and as often as possible to stimulate your supply. If your baby needs special care, get support to use a breast pump to express milk to begin with.
- When you're breastfeeding, keep a hypo treatment close at hand. The last thing you want to have to do is look for food while caring for your baby and having a hypo. Keep a well-stocked caddy next to your breastfeeding chair, with lots of bottles of water in easy reach too.

### WILL MY BABY HAVE T1D?

It's natural for people with T1D to worry about passing the condition on to their kids. But it's important to remember that around 90% of people with T1D have no family history of it! Your baby won't be born with T1D, and the chance of them developing it is only about 5% if their mum has it (or 7% if their dad has it).

## DIABETES AND ISSUES FOR MEN

There are a few aspects of living with T1D that are particularly relevant to men.

### **FERTILITY**

There are no specific fertility issues concerned with T1D.

It's natural to worry about passing diabetes on to your children, but it's important to remember that around 90% of people with T1D have no family history of it. As a male with T1D, the chance of your children developing the condition is only around 7%.

### **SEX AND INTIMACY**

Erectile dysfunction, or impotence, means you can't get an erection that allows you to have penetrative sex. Impotence is a common problem for all men, and many experience short-term episodes of it. It's also more common in men with diabetes.

Impotence can be caused by many physical and psychological reasons, including:

- chronically high blood glucose levels
- drinking too much alcohol
- high blood pressure and/or cholesterol
- · low testosterone levels
- performance anxiety
- · problems in relationships
- some medications and operations (such as prostatectomy)
- stress
- · work and family pressures.

Researchers are still working out why men with diabetes are more prone to problems with impotence than others. Some people with diabetes develop hardened arteries, and it's thought this might contribute to impotence by restricting blood flow to the penis. Nerve damage can also play a role. Keeping your blood glucose levels close to your target range can help reduce your chances of it happening.

Men with diabetes can also experience libido issues. There are many treatments for decreased libido and impotence, such as counselling, oral or injectable drugs, and surgery. Talk to your doctor or endocrinologist about your options.

### THRUSH AND BALANITIS

Thrush is a yeast infection caused by excessive growth of a fungus that lives on and in the body.



Men can get thrush orally and on the penis. Symptoms of oral thrush include redness and white spots coating the tongue. Penile thrush can cause inflammation of the head of the penis. This inflammation is called balanitis. In balanitis, the head of the penis becomes red and sore. You may also notice irritation, itching and small red spots. There can be penile discharge, too.

High blood glucose levels can increase your chance of thrush, as well as using antibiotics and asthma inhalers. See your pharmacist for treatment. Your partner should also be treated to stop reinfection. If it persists, see your GP.

### A NOTE ON SEEING DOCTORS OR SPECIALISTS

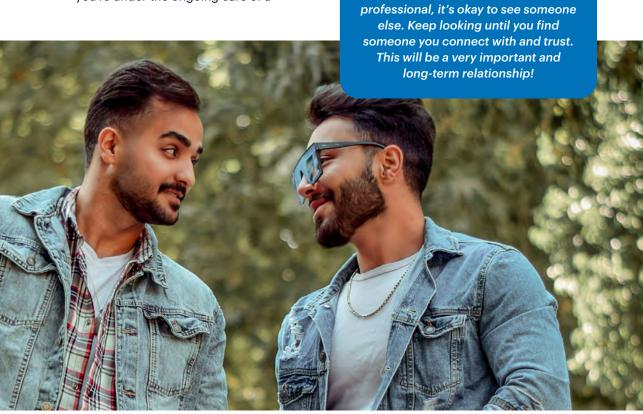
Australian men are stereotypically very reluctant to see a doctor. But now you have diabetes, it's very important that you're under the ongoing care of a diabetes specialist or diabetes team.

Not doing so may affect your long-term health. Many complications of T1D can be prevented or reversed if they're caught early enough. Regular check-ups, even if you feel well, are vital. See page 31 for a list of common tests and checks.

It's also important that you're honest with your healthcare team. They know that other parts of your life – like family and work commitments – can mean that some areas of your diabetes management will be a lower priority at times. Your diabetes team will be able to support you better if you talk to them about what's going on so they can help you manage it all.

Remember: if you don't feel

comfortable with your healthcare



# DIABETES AND ISSUES FOR TEENAGERS



We all know that life can be tough for teenagers at the best of times. Throw T1D into the mix and it's extra challenging - there's no question about that!

As you grow into your later teens, you might notice your diabetes management becoming more of a trigger for family arguments. This can happen for a few reasons. For starters, the hormones that make you grow and mature faster in your teen years can interfere with your insulin's action. This can make it harder to keep in your target range, which can be frustrating for you and your parents or carers.

At this time, you might want to take more responsibility for your own diabetes management. If you were diagnosed with diabetes before you were a teenager, chances are your parents have been mainly managing your diabetes for you. The handover of responsibility can be difficult (and a big learning curve) for everyone involved.

### WHO'S RESPONSIBLE FOR WHAT?

It can be hard to tell your parents you want to start taking over your diabetes management. It can also be difficult to tell them you don't want to take on all the responsibility just yet.

You'll probably do better if your parents stay involved in your diabetes care in some way until you reach your early adult years. You just need to negotiate who's responsible for what – and those negotiations need to be ongoing.

Have a think about how you'd like to divide up the tasks. For example, consider if you or your parents will:

- be responsible for sensor or infusion set changes
- book your clinic appointments
- make sure you don't run out of diabetes supplies (insulin and blood glucose monitoring)
- work out how many carbs you're eating, and how much insulin to take.

If it all gets too hard and you want to hand back some of the responsibility, you can always talk to your parents or diabetes team. You're allowed to change your mind!

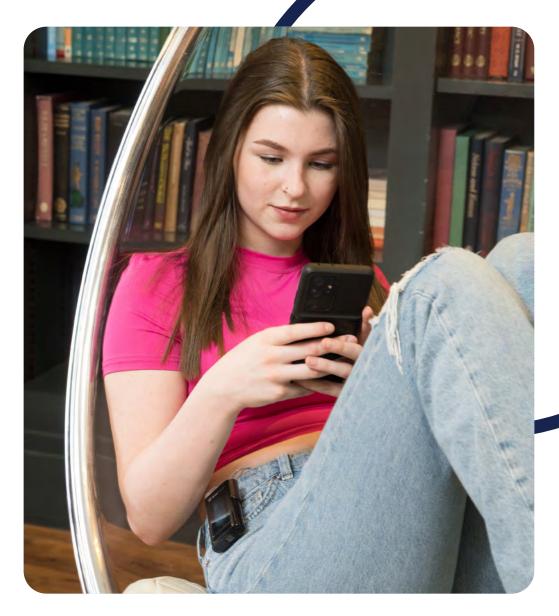
Never be afraid to tell your endocrinologist or diabetes team if you don't fully understand or want to learn more about an aspect of your T1D care. They're there to help!

### TRANSITIONING TO ADULT CARE

Life can get pretty busy and stressful during your late teenage years, so you might prefer to continue seeing your familiar paediatric team until you've finished high school. But if you feel uncomfortable sitting in a waiting room with young children, or you're ready for a change, transferring to an adult-focused team or endocrinologist may be a better option. It's especially helpful if the adult team has some experience with young people with T1D.

It's important that you find a doctor or team you feel comfortable with. You also need to like and trust them. It might take a few false starts before you find someone new who suits you, but it's definitely worth persisting.

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If the hospital system doesn't suit your needs, you also have the option of private diabetes care. There are a lot of health professionals in private practice who work out of a variety of settings. Some even offer home visits and online video calls.

Your new doctors or team will expect you to know about your diabetes history and management, such as when you were diagnosed, the name and dosages of any medications you take (including what insulin you use), and which specialists

you used to see. Write down all this information and take it with you when you go for your first appointment.

Seeing an adult-focused healthcare professional can feel strange at first – after all, they'll be working with you, not your parents. But keeping your parents informed and involved is a good idea. They'll worry less and support your decisions if they know you're looking after yourself.



LOOKING TO THE FUTURE

### RESEARCH IS THE KEY

We know that a type 1 diabetes (T1D) diagnosis may make you worry about the future. But it's important to remember that researchers are committed to finding a cure and improving the lives of those with the condition.

Life for people with T1D has improved a lot over the past few decades. New technologies and treatments have helped with long-term health complications, so people can stay healthier for much longer.

The last few years have also seen rapid acceleration in the development of drugs that can delay the progression of T1D. These are called disease modifying therapies. For example, in 2022, the US Food and Drug Administration approved teplizumab (Tzield®) to delay the onset of T1D in those at risk. This was a major milestone, as teplizumab is the first therapy approved for T1D since the discovery of insulin 100 years earlier. Many other disease modifying therapies are now in the clinical trial stage.

Our vision of a world without T1D can only be achieved through continued research. It will help us uncover new therapies that may reverse the condition. It may also help us find the causes of T1D, so we can eventually prevent it altogether.

### HOW JDRF IS DRIVING PROGRESS

JDRF is the world's leading not-for-profit funder of T1D research globally. We currently fund over 400 projects in 22 countries around the world through almost \$560m in investments.



On top of that, 70 projects have been funded through JDRF Australia's Type 1 Diabetes Clinical Research Network (T1DCRN). This is made possible by the Australian Federal Government, which has committed a total of \$58m (to 2022).

We fund research that covers every age and stage of T1D across 2 key pillars: finding cures, and improving the lives of those with the condition. While our ultimate aim is to cure T1D, we recognise the need to keep people healthy enough to fully benefit from the cure when it's found. We also need to achieve our goal of preventing the condition's onset in future generations.

But translating science from the researcher's bench through to the public requires more than just funding. JDRF is uniquely positioned to accelerate scientific progress from every angle, drawing on our extensive and collaborative connections with policy makers, industry members, regulatory bodies, diabetes organisations, healthcare providers and the T1D community.

JDRF not only funds research, but actively moves it – strategically – along the translation pipeline to those who need it most.



### THE LATEST IN AUSTRALIAN T1D RESEARCH

JDRF research funding makes a priority of scientific areas where questions remain, and areas that will deliver the greatest impact for the T1D community. We have a special focus on prevention, precision and progress.

### **PREVENTION**

Prevention research aims to uncover what triggers T1D in the first place, and investigates therapies and strategies that will stop it before it develops. Here are some examples of prevention research projects we fund.

### ENVIRONMENTAL DETERMINANTS OF ISLET AUTOIMMUNITY STUDY

To prevent T1D, we first need to understand the cause and early stages

of the condition. We know that T1D rates can't be explained by genetics alone, which means the environment must play a role in the development of the condition somehow.

That's why we fund the Environmental Determinants of Islet Autoimmunity (ENDIA) study. This is a world-first Australian study that collects a lot of information - like exposure to bacteria and viruses, body growth, factors in the home environment and nutrition to work out if any of these might contribute to or protect against T1D development, with the research starting in pregnancy. Armed with this information, we'll continue to work on therapies that may be able to prevent people at risk from developing T1D in the first place. Some examples include vaccines against viruses, probiotics or other interventions.

### AUSTRALIAN TYPE 1 DIABETES NATIONAL SCREENING PILOT

To prevent T1D, we need to know who has a high risk of developing it, so we can give them preventive therapies as they become available.

We're already able to detect who is in the early stages of T1D, before they have any symptoms. But most people with T1D don't have a family member with it and don't get tested, so they only learn about it when they finally develop the condition.

This is why we support the Australian Type 1 Diabetes National Screening Pilot. This tests the best methods to screen children at risk of developing T1D. Through this pilot, Australia could be one of the first countries in the world to develop population-wide T1D screening.

#### **PRECISION**

People's T1D can develop differently, and their responses to therapies can vary. Precision medicine research aims to deliver tailored and personalised therapeutics to suit each person best.

#### PIONEERING TECHNOLOGIES

We're investing in research that uses cutting-edge technologies, such as genomics, to discover why there's such variation in the development, progression and therapeutic response in people with T1D.

Along with personal preferences, this will let us develop precision medicine for T1D. It will mean the prevention, diagnosis and treatment of the condition can be tailored to individuals, based on their genes, environment and lifestyle. This will provide the right care at the right time to those with T1D.

#### **PROGRESS**

Progress research will accelerate a cure for T1D. This includes:

- expanding the number of clinical trials that promise to delay the development of T1D
- investing in research that focuses on replacing damaged beta cells
- supporting the best and brightest research talent now and into the future.

# AUSTRALASIAN T1D IMMUNOTHERAPIES COLLABORATIVE

JDRF funds the Australasian T1D Immunotherapies Collaborative (ATIC). This globally connected platform delivers world-leading clinical trials in Australia that focus on dampening the immune attack seen in T1D. Through ATIC, we'll expand the number of trials that promise to delay the progression of T1D. This will allow more Australians who live with T1D, or who are at risk of developing it, to access these trials.

#### **BETA CELL INVESTIGATION**

Insulin is produced in the beta cells of the pancreas, and these are the cells destroyed by the immune attack in T1D. A cure could be found by regenerating these cells, or replacing them from a source outside the body. People with T1D could then make their own insulin again.

We support a wide variety of projects that focus on novel sources of beta cells from outside the body, such as animal sources of beta cells, human stem cells and gene therapy. Another possible option is regenerating cells from a person's own pancreatic tissue.

We also fund research that improves how beta cells from outside the body are transplanted into someone with T1D.

### CLINICAL TRIALS: GET INVOLVED IN RESEARCH

Clinical trials are how research discoveries are developed into real world solutions. They're the important final step before new therapies can be made available to those who need them.

Advances in diabetes treatments and technology are only made possible by volunteers who take part in clinical research. Research volunteers play a vital role in clinical research, whether they live with T1D or not. Without research volunteers, clinical trials for exciting and cutting-edge new treatments can't go ahead.

By volunteering for clinical research, you can be part of the process that helps us discover new treatments and therapies to treat, prevent and ultimately cure T1D.

### WHY YOU MIGHT WANT TO JOIN A CLINICAL TRIAL

There has never been more T1D research happening in Australia. People with and without T1D are needed to join clinical trials to make sure the trials are successful. Here are just a few reasons you might want to volunteer:

- you could get access to new therapies as they're tested, before they get to market
- you could help find a cure for the more than 130,000 Australians and millions of people worldwide who live with T1D (and all those who are yet to be diagnosed)
- you'll contribute to making new therapies accessible to others
- you'll help to speed research progress
- you'll learn more about your own T1D and how to manage it best.



### HOW TO KEEP UP TO DATE WITH RESEARCH NEWS

These websites provide links and plain English summaries of research progress.

- JDRF Australia research news: jdrf.org.au/research/research-news
- JDRF Australia research programs: jdrf.org.au/research/exploreresearch
- JDRF International: jdrf.org/blog
- Type 1 Diabetes TrialNet: trialnet.org

### JOIN THE TEAM AND MAKE A DIFFERENCE

JDRF drives innovation, demands action and stands with everyone facing life with T1D – and there are many ways you can join our friendly, passionate community.



JDRF runs events throughout the year to help raise money for invaluable T1D research. Why not show your support by joining our popular One Walk, skydiving to Jump for a Cure, biking through the Barossa Valley in One Ride, attending a formal gala, or making your own fundraising event? It's a great way to make a difference while meeting other people near you who live with T1D. Learn more at bluearmy.jdrf.org.au

#### **BECOME A JDRF ADVOCATE**

With the help of our team of passionate T1D advocates around Australia, we have changed how governments view T1D. In the past decade, this has helped us deliver almost \$500m in new investments in T1D research, creating real change.

Learn more at jdrf.org.au/advocacy

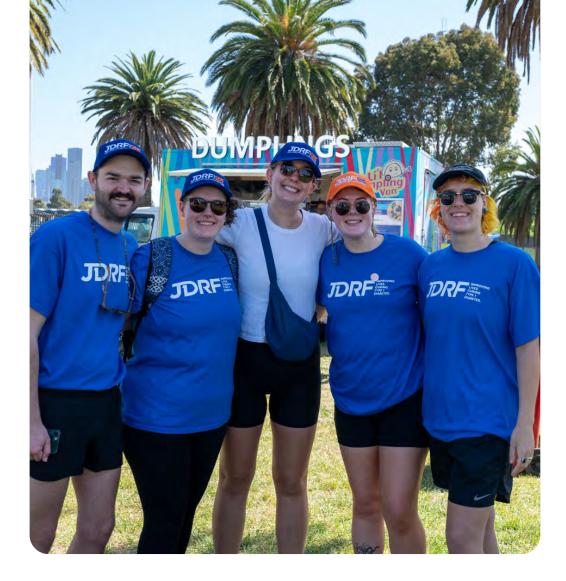
### **VOLUNTEER FOR JDRF**

Volunteering is a great way to meet new people who also live with T1D – and you'll be giving back to your community at the same time. Volunteers have always been at the core of JDRF, and we wouldn't be where we are today without them. Whether you're interested in helping out at an event or can give us a hand in other ways, we'd always love to hear from you!

Get in touch at jdrf.org.au/volunteer



# STORIES FROM OUR COMMUNITY MEMBERS



Being diagnosed with T1D should never prevent you from doing the things you enjoy. And it shouldn't stop you from doing what you want to do with your life, either. Adults with T1D do some amazing things (and we're not just talking about having injecting insulin and checking blood sugars every day!).

Of course it may take some time for you to come to terms with your diagnosis, but in time you might find a silver lining. You might be surprised to learn that, for some people, being diagnosed with T1D gave them a sense of greater purpose

in their lives, a cause they passionately support, and a sense of being a part of a community.

For others, T1D makes them more determined. It can help them focus on achieving their goals – whether it's travel, sport, achieving in their career, or having a family of their own.

There are over 130,000 people in Australia with T1D. Most of them are adults, and all of them are inspirational. Here are some of their stories.



### JACK PERKINS,

**37, VIC** 



Jack is a V8 Supercars driver who regularly competes in the Bathurst 1000. He also commentates and presents races on Channel 7. Jack was diagnosed with T1D at 20.

For me, being diagnosed with T1D in 2006 was an all-new experience. No one in my family had it and my only real experience of it was an older family friend who had it.

Upon reflection, getting that diagnosis was a very daunting experience. Being admitted to hospital where you're told you

have T1D is one thing, but then getting your head around what it all actually means is something else – blood glucose levels, injections, low GI foods, carb counting, finger-pricks, ketones, and more! They're now second nature, but back then it all seemed so daunting.

I'll never forget when I started to really take over my management in hospital. I was offered a Milo and I watched my blood sugars rise – and then the corresponding hypo, where I was handed marmalade jam satchels to treat it.

Since 2006 it's only become easier, from a self-managing point of view. CGMs are the single biggest difference for me. When I was racing before I had my CGM I would prick my finger 20-30 times a day. Now I rarely have to prick my fingers!

The biggest thing that hasn't changed is whose responsibility it all is: it's still mine and really mine only. My endocrinologist, diabetes educator and the like are all very helpful and knowledgeable, however they aren't available 24/7, and I can't imagine there are 2 people with T1D who are exactly the same.

T1D could've ended my racing career before it even started. I was diagnosed in 2006, which was my first year racing V8 Supercars and the famous Bathurst 1000. The diagnosing doctor told me I would never be able to race cars in events longer than 20 minutes. If I'd listened to him and accepted what he'd told me I wouldn't have had a career that still exists today. But I'm lining up later this year in my 19th Bathurst 1000 as someone living with T1D, with a best result (so far!) of third. I'm also a Supercars race winner – I won on the Gold Coast in 2015 with James Courtney, driving for the Holden Racing Team.

From the start, I knew that to race cars with T1D I would need to be very disciplined and ensure the risk of going low into the hypo zone wasn't going to happen. So when I'm racing I eat more carbs than usual, take on less insulin and aim for a blood glucose level of 8-10mmol/L instead of the usual 4-6mmol/L. Everything has an influence in the car: adrenalin, stress, physical exertion – cabin temperatures are 25°C above ambient, so often we race in 50°C while wearing 3 layers of fireproof

SUPERIOR AUT

clothing, losing 2-3kg of body fluids an hour. Any lapse in concentration at 250km/h plus has massive consequences, so fitness plays a big part and you can't be worrying about where your levels are! Thankfully I've had no issues (touch wood), and it's enabled me to race professionally for a long period of time.



### SANDRA WILLIAMS,

**72, SA** 

Sandra was diagnosed with T1D at 57. After coming to terms with it, she's been determined to look on the positive side.

It was recently my 15-year 'diaversary' (anniversary of diagnosis). I could not believe that I've come so far in that time. I remember when I was diagnosed – it was so scary going home with insulin pens and having to face each day, making decisions on what to eat, how much insulin to take and asking myself what to do next.

I was upset at the time of my diagnosis, and I kept thinking "Why me?". But after a while, I changed that way of thinking to "Why not me?!". I'd spent 57 years of my life without T1D, but a little friend was only 10 months old when he was diagnosed – and now he has every day of his life ahead of him with diabetes. I quickly realised how lucky I am.

My youngest daughter was studying medicine when I was diagnosed. She encouraged me to get an insulin pump to help me manage my diabetes, and did not stop nagging me about it! At first I was very hesitant and scared of how I would manage a pump. But eventually I saw a diabetes educator for advice, then started on my first pump. That was 13 years ago, and now I hope I never have to cope without it. Pumps are amazing and the changes I've seen over that time are just incredible, with even more upgrades to come. My pump helps me in every facet of my life: my sleep, the food I eat, my exercise, my sick days, my holidays and the days when I am celebrating. It keeps me safe so I can enjoy my life. And through all the ups and downs, my educator has been there with me, too.



I'm pleased that diabetes has made me adopt a healthier way of eating. I also now exercise every day and have become so much more proactive, especially with my healthcare. I have found "my mob", a large group of people who understand me and my challenges. We help and support each other when others, including families, can't understand. We all have diabetes in common.

The other big benefit diabetes has brought me is the satisfaction and enjoyment I get from volunteering every week with JDRF. I've been doing it since I retired and I love being able to help others with T1D. I make calls from the Adelaide office, chatting to people to make sure they're getting the support they need. I also help as a moderator on JDRF's private Facebook group for adults living with T1D. This group gives a platform to members so they can chat to other people who understand the challenges we all face. Members can swap their stories and ask for advice, learning from the experience of other members.

I also moderate a local Dia-Buddies chat room and organise events for members.

If you're struggling or feeling alone with your diabetes, organise to meet up with others in your area for a coffee, meal, drink or just a chat on the phone. It's so good to sit down with others who understand!

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I've seen many changes in how we manage our T1D over the past 15 years. I believe we are so lucky to be living in this era with so much technology available to us.



# WILL CULLEN, 19. NSW

Will doesn't remember life without T1D – he was diagnosed at age 2. With supportive family and friends around him, he's now an apprentice line worker.

My family has always been very supportive, helping me so diabetes doesn't stop me from doing anything I want to do. I'm lucky to have a great group of friends, too – I've just started going camping and 4x4 driving with my mates, and I love it.

Over the years, Mum and I have taught my friends what to do if I'm too low or sick to help myself, and I've taught my mates and my girlfriend how to use glucagon. They all know they can call my mum if they're not sure what to do. This way I can go





camping and not worry (and my family worries less too). And overall, even though I can do everything that I need to with my diabetes, I know that I have friends and family who can step in for me.

I'm now a second-year apprentice line worker. I was really open about my T1D in my job interview, as they asked me a question about my achievements. I talked about the advocacy I've done with JDRF, and how I went to Washington in 2017 to represent JDRF Australia at the Kids Congress.

At work I carry hypo treatments with me all the time – my work pants have a lot of pockets to stash supplies, so I can treat hypos without too much interruption. I check to make sure my levels are in range before I drive or go up into the bucket. If I need to, I just stop for a bit and have a juice.

It's best to try to stay on top of your T1D when you're working, so it doesn't get in the way and cause issues. I always have my bag with all my supplies, like spare sets, insulin and batteries, so I can manage any problems as they come up.



Try and get as much support around you as possible. You don't have to do it by yourself. 66

On top of everything related to pregnancy, T1D management can really wear you down.
Try to remember that it's impossible to be perfect.
Be kind to yourself, go with the flow and reach out to your diabetes team when you're feeling drained, stressed or worried.



### LAURA HILL, 34, NSW

Laura has been living with T1D since age 12. After having two children, she's learnt a few things about managing her T1D in pregnancy.

I thought I had a great handle on my T1D management before falling pregnant for the first time at age 31. I assumed this meant I was all set for a safe and relatively easy pregnancy and birth. Little did I know that I was in for a steep T1D learning curve... again!

It seemed that as soon as those two lines appeared on the pregnancy test, everything I knew and regularly did to manage my T1D was thrown out the window. I had to continuously (daily!) adjust my pre-bolus timing, insulin rates, exercise schedule and carb consumption to manage my T1D and account for all the changes my body was going through.

Even with this tight management, my blood glucose levels did unexplainable things. Luckily, I had a committed and supportive diabetes team to help me.

One thing I learnt through my pregnancy journey is that everyone believes they are an expert on you/your body/your baby/ your diabetes. In fact, you're the most knowledgeable and the best expert on all these things. Trust your own intuition, do your own research, and ask lots of questions. And if something doesn't feel right, speak up! I learnt that it's most reassuring to ask for more information (such as the benefits, risks and alternatives) so you can make the most informed decisions for you and your baby.

It's easy to feel like our bodies have failed us when we live with T1D. But my pregnancy and T1D journey led me to a newfound love for my body and what it's capable of. It grew and gave life to two of the cutest babies! While my body may not produce insulin anymore, it does so many other amazing things that I'm so very proud of.

### SARAH GILLIES, 31, QLD

Sarah was 28 when she was diagnosed with T1D. Since then, she's become a voice for the community through JDRF's advocacy program.

I was in the supermarket with my 2 sons when I started to feel hot. My heart was racing and my vision and hearing started to fade. I told my eldest son, who was only 5, that I felt like I might pass out. The next thing I knew I was waking up with paramedics, police, my mum, sister, and sons around me. I'd passed out and had a seizure. It took a while to sort it out, but eventually I was diagnosed with T1D.

As I learnt more about my new way of life, I was shocked by how hard it was to access life-saving technology, like CGMs. I couldn't believe they were so unobtainable for the average family.

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Hope and passion keeps us motivated to keep trying to find a cure – and we'll do that through advocacy. I'll continue to be involved with advocacy until our dream of a cure becomes a reality.



To have to decide if I could afford a CGM for a fortnight or if my kids could go to swimming lessons was always hard. But my family's needs always won.

That's when I started looking for an organisation that supports adults with T1D, and I found JDRF. I became a passionate advocate as part of the 'Access For All' campaign, lobbying the government for subsidised CGMs for all Australians with T1D. With JDRF's support, I spoke with my local Member of Parliament about it. I was determined to create change for adults like me who live with T1D, to give us access to life-saving and life-changing technology.

The campaign was successful, and it helped secure a bipartisan commitment to subsidise CGMs for all Australians living with T1D. I was so proud of what we'd achieved. Finding my passion through advocacy, and speaking out to create change for adults living with T1D, has changed who I am.

Learn how you can get involved in JDRF's advocacy program at jdrf.org.au/advocacy

### LEON TRIBE, 50, NSW

Leon was diagnosed with T1D at 43. He's now involved in the international diabetes advocacy community, travelling to conferences around the world. He writes about diabetes at practical diabetic.com.

My diabetes journey began in 2017. I had been feeling exhausted for months, my ankles ached, and my eyesight was acting up. Then I was presenting at a conference and was permanently thirsty and needing to pee every half hour. This was a bit of a problem as I was expected to be on stage for an hour.

When I got home I headed to the doctor. He confirmed my blood glucose levels were sky high and recommended I immediately go to hospital. At the hospital they came to the (wrong) conclusion I had type 2 diabetes. It was my doctor who tested my blood for autoantibodies, finally confirming I have TID.

For the first 11 months I met no one with T1D. This was quite isolating, so I started up a monthly meet-up to chat with others and to learn from them. Their experience and support was invaluable.

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If you are an adult who has been recently diagnosed, I promise you, it is not all despair. Learn as much as you can and get involved in the online communities – and perhaps I will see you at a conference sometime soon!

While no one is glad they have T1D, my diagnosis had some positive aspects. It forced me to think about my lifestyle and made me a much healthier person.

I feel optimistic for the future of diabetes management. I have already seen tremendous advances in technologies to manage diabetes, such as looping systems, which relieve much of the mental burden experienced with managing T1D.

Another aspect of my journey is becoming part of a passionate international advocacy community. Being part of the #dedoc°voices program has taken me to international diabetes conferences, learning about the latest advances. I have even had the opportunity to present.



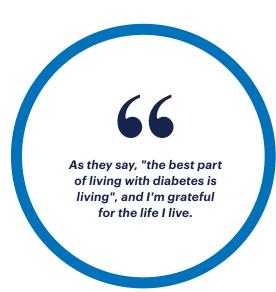


### JENNA CANTAMESSA, 31, QLD



Jenna was 19 when she was diagnosed with T1D. She is now the Australian International Diabetes Foundation Young Leader in Diabetes and runs the popular Instagram account @typeonevibes.

It was during my university exams that I noticed I was losing a significant amount of hair. I put it down to stress, but after a month I decided to have a doctor investigate it further with tests. A week later, my mum and I were sitting in the appointment together when I received my T1D diagnosis. That moment turned my whole world upside down, and life has never been the same. However, it's the card I've been dealt, and I'm so thankful for T1D technology advancements and the unwavering support I have from my beautiful family and partner.



Embracing the silver linings of my diabetes journey, I ventured into the online diabetes community to connect and learn from those sharing similar experiences. In my eyes, no advice can live up to the advice from someone with lived experience.

Keen to have more connections with the online community, I started my Instagram page, and with a background in graphic design, I began creating diabetes drawings. Today they're found hanging in all corners of the globe.

The heartfelt response to my art has given me an entirely new purpose, and I'm so grateful for it. Having diabetes has not only opened doors to various opportunities but has also reinforced the importance of actively accepting the condition as a part of my life.

Read more of Jenna's story (and her mum's perspective about it all) at jdrf.org.au/jenna The reality is diabetes doesn't present a win/win scenario. It requires active acknowledgment and acceptance that it's a lifelong companion (that I didn't ask for). Coming to terms with this reality can be incredibly challenging, and seeking professional support to help foster this mindset can be invaluable. There'll be days when all you want to do is cry, but there will also be amazing days. You only have one life, and you deserve to live a good one, despite the ups and downs that diabetes brings.

### See more of Jenna's art at instagram.com/typeonevibes





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Find an endocrinologist or diabetes educator who works well with you, and learn everything you can from them. The more knowledge and experience you have, the better you can manage on a day-to-day basis.

# JACK RIEK, 25, QLD



Jack is a competitive gymnast, and in 2021 became the Australian national champion on the rings. He's also studying medicine. Jack was diagnosed with T1D at 17.

When I was diagnosed I was very scared because I didn't know how much T1D would affect me. My endocrinologist helped by patiently answering my questions and reassuring me that T1D didn't have to be a barrier, as long as I was willing to put in the work to understand the condition and treat it on a daily basis.

T1D impacts my sporting career in a few different ways. I have to be very careful of lows in particular – not only while training, but also afterwards, because my blood sugar can continue to fall even after stopping exercise. Lows are harder to deal with than highs during training, because it means I might have to stop and rest, as opposed to highs, where I can usually inject some insulin and keep going.

Because of this, I try to avoid lows at all costs, and try to make sure my blood glucose level is trending up prior to starting exercise.

When I compete, I make sure I have everything I need in terms of supplies, and I always try to have extras. I load up my bag with multiple packs of lollies, bars and sugary sports drinks. I always know where my insulin, needles and manual test kit (backup to CGM) are, so I can access them quickly. There's a lot of extra planning involved, but the more I plan, the better I can manage the lows and highs when they inevitably occur.

Over time, I've become much better at managing my levels, as well as my anxiety about my levels during sport events. I put this down to discussing management strategies with my doctor, being committed to learning from my mistakes, and understanding that it's impossible for me to have perfect management all the time. T1D is a lot of work, but it doesn't have to control your life.

# DANIA, 27, NSW

### Dania Ibrahim was 21 years old and studying at university overseas when she was diagnosed with T1D.

Looking back, I started experiencing T1D symptoms a few months before I was diagnosed. I'd visited my GP for some routine blood tests before heading off overseas and my blood glucose level was elevated. I didn't really think much of it at the time. I was so excited about my new adventure that I was subconsciously dismissing my other early symptoms like weight loss, excessive thirst and needing to go to the toilet constantly.

By the time I ended up in a Spanish emergency department, my blood glucose levels were really elevated and I was extremely unwell. Despite this, there was still quite a bit of confusion among the clinical staff about whether I had type 1 or type 2 diabetes. The language barrier certainly didn't help! They referred me to a local diabetes clinic where thankfully I finally received the correct diagnosis and started on my management regimen.

Interestingly, this wasn't the most stressful time for me. I learnt how to manage my condition and my diabetes stabilised quite quickly. It was when I returned home from

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I used to push myself to the limit, but now I try to be a little more disciplined. I listen to my body and try to act on anything that makes my diabetes unstable. my exchange a few months later that I really struggled. I don't think I'd processed the fact that I had a life-long condition until that point, and some of my personal relationships became a little strained. I struggled with the autoimmune nature of my condition – it took me a long time to reconcile that I didn't cause the diabetes.

I had to learn to think a bit differently than your average young adult. It took a while, but I learnt to adjust the way I approach my studies and work commitments. I find that when I take care of my body, I feel better emotionally as well as physically.



# LARA MCSPADDEN,

**24. NSW** 

Lara has been living with T1D since she was 8. It hasn't stopped her from becoming a professional basketball player, and she now plays for the Sydney Flames.

I was always a pretty sporty kid, and to be honest my T1D diagnosis didn't really slow me down at first. It was when I decided to take my sport more seriously when I was in high school that things became a lot more complicated. The combination of increased training and hitting the



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Living with diabetes doesn't stop you doing what you want to do but it does make things more complicated. I think we all deserve recognition for what we achieve despite living with a chronic condition.

teenage years resulted in me becoming a little lax with my diabetes management, which had an effect on my health and sporting performance.

Playing a lot of sport is tough on the body, but having T1D really amplifies things and makes it more difficult to bounce back. The good news is there are things you can do to minimise its impact. T1D isn't always predictable but I focus on managing the things that affect it. To minimise blood alucose fluctuations, I'm very strict with my diet, training regimes and sleep. I eat virtually the same thing every day for breakfast and lunch so I have a good idea of what my blood glucose levels are going to do. I use a CGM, which is really helpful for predicting blood glucose trends and allowing me to intervene before it starts impacting my performance.

I learnt early on that it's really important to have support. My teammates all know about T1D and what to do if something goes wrong. If I drop a ball or awkwardly trip over, they'll remind me to check my blood glucose levels. Of course, it's not always caused by diabetes – sometimes I'm just having a bad day on the court!

# CARL MILLS, 54, QLD

Carl was diagnosed with T1D at 13. After four decades of living with the condition, he has some advice for newly diagnosed adults.

At 13 years old, I was losing a lot of weight. I was playing high level sport, including rugby union, and at the end of each game I was exhausted. I was constantly dehydrated and going to the toilet all the time. My mum knew something was wrong but didn't know what it could be. She took me to the doctor and then I got rushed to hospital. That's how we found out it was T1D.

Over the years, my biggest challenges have been other people's judgement and confusion about what T1D is – from doctors, friends and strangers.

But I love talking about it when asked, and helping others understand it.

My biggest achievement was when I travelled the world by myself at 20. I was still injecting insulin four times a day but had such an amazing time, and seemed to somehow manage it so well.

I now have a 13-year-old daughter, who I love so much. If she does get type 1 I'll love and support her the same way my family supports me. We can't worry about what might happen or if she might get it – we'll just deal with it if it does happen.

Living with T1D can be upsetting, and sometimes even now I ask myself "why me?". But if you worry about it, it will eat you up, inside and out. Accept it, look after yourself, and you'll live a happy life.

My advice for people living with T1D would be to live well, listen, and try new technology when it comes available. Look after yourself and don't rebel against type 1. There are a lot worse diseases out there.





# DR JEREMY ROBERTSON,

45, NSW



# Jeremy didn't always want to be a doctor, but life took an unexpected turn when he was diagnosed with T1D.

I was diagnosed with T1D when I was 31 and working as an international airline pilot for Qantas. I was in LA on a training course when I became extremely thirsty and experienced blurred vision. A high blood glucose result at a local GP indicated I had some form of diabetes and sent me straight home to Australia. I knew enough to know I probably had T1D, which meant my flying career was over. I was on the opposite side of the planet, six weeks out from my wedding and facing a brand new future.

Luckily, my new wife and family were extremely supportive and I was able to

take the time to get back on track – both with my health and my career. I decided I wanted to become a doctor. It wasn't an easy choice, as I hadn't studied any life sciences subjects since high school.

Today, I work as an aviation medicine doctor, which means I can integrate my flight experience with my new skills. Since my diagnosis, the rules have changed and I'm now able to work as a pilot with certain limitations. I occasionally work as a flight instructor and sky diving pilot, too.

I often think about how life may have been different if I hadn't been diagnosed with type 1. While it was a big loss in my professional life, I learnt that I had to also see the opportunity. Today, I'm home every night with my kids, and that wouldn't have been possible in my former career. I believe when one door closes, another will open.

## **GEORGINA PETERS,**

32, VIC

Georgina struggled with body image issues after her T1D diagnosis at 17.
She says that seeing a specialised psychologist changed her life.

I was 17 when I was diagnosed. It was at the start of my Year 12 studies, and 2 different doctors told me that I was just stressed. Luckily, we went camping and the person next to us had T1D and told us to go to the hospital immediately. That random man might have saved my life!

My diagnosis was really tough, and after that I struggled with living with T1D, especially in the first few years. Having lived with an eating disorder prior to diagnosis, T1D felt like a slap in the face to my recovery process. Suddenly I had to be hyper-aware of what I was eating,

Follow Georgina at instagram.com/bodyposibetes

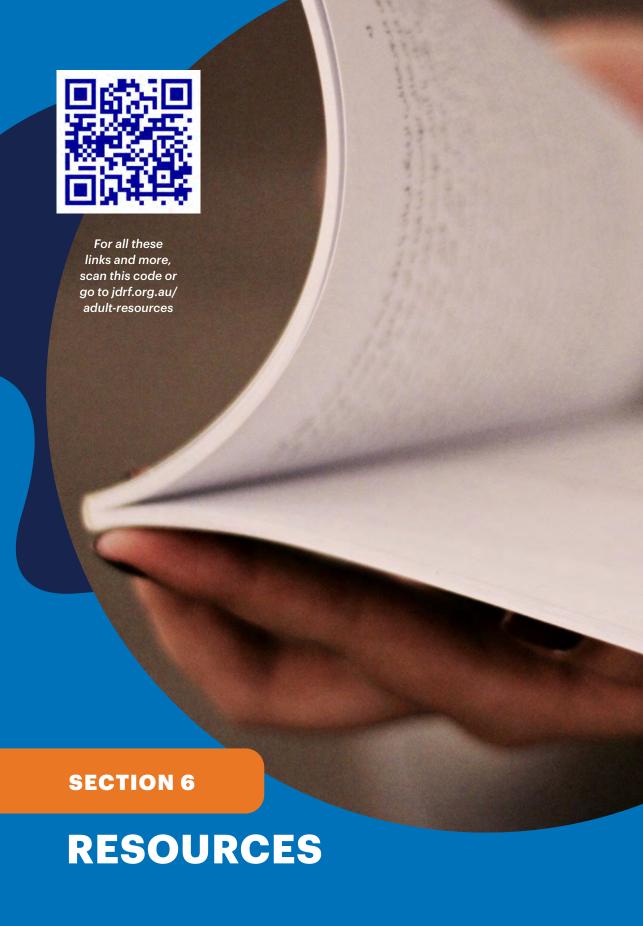
focus on numbers and, what's more, go into a healthcare system that places a huge emphasis on weight! I struggled with insulin omission (diabulimia), but I was privileged enough to be able to access psychological help and go through an intense recovery process. Now I'm doing super well! Technology, and having access to CGMs, has totally changed my life. It's taken so much decision fatigue about my diabetes away from me.

The space that I'm passionate about within the diabetes community in general is around body positivity, neutrality and acceptance. Unfortunately the world we live in is full of diet culture, and that's heightened within our diabetes community. The stigma that people with any type of diabetes face is appalling, and on top of that we're subjected to body stigma from healthcare professionals and other people living with diabetes. It's important that we focus on kindness and compassion for ourselves.

Diabetes comes in all shapes and sizes, and to think otherwise is doing ourselves and others a disservice. By engaging with our community online and promoting another narrative that's not about changing your body or diet, but eating and moving intuitively, and approaching your healthcare in a weight-neutral way, I think we'll start to see real change!

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I have 2 pieces of advice for adults with T1D: be kind to yourself, and see a health psychologist who specialises in people living with chronic conditions. You're trying to be your pancreas – that is NOT an easy job!



### **HELPFUL LINKS**



If you ever have questions about any type 1 diabetes (T1D) information you come across, talk about it with your doctor or diabetes team.

### **DIABETES ORGANISATIONS**

- · JDRF Australia: jdrf.org.au
- Australian Diabetes Educators Association: adea.com.au
- Australian Diabetes Society (ADS): diabetessociety.com.au
- Diabetes Australia:
   diabetesaustralia.com.au
- DiaTribe (US site): diatribe.org
- International Diabetes Federation: idf.org
- National Diabetes Services Scheme (NDSS): ndss.com.au

### **Government agencies**

- Australian Government Department of Health and Aged Care: health.gov.au
- Australian Government Private Health Insurance Ombudsman (with private health cover comparison tool): privatehealth.gov.au
- Australian Government Smart Travel: smartraveller.gov.au
- Medicare: medicare.gov.au (or phone 13 20 11)
- National Disability Insurance Agency: ndis.gov.au

### **ONLINE COMMUNITIES**

Online groups of people living with T1D can offer lots of support and helpful advice. Here are a few to check out.

- JDRF Australia's group for adults with T1D (T1D Connect 25+):
   facebook.com/groups/T1DConnect25
- JDRF Australia's group for teens and young adults up to 24 with T1D (T1D Connect 14-24):
   facebook.com/groups/T1DConnect
- JDRF International's forum: forum.jdrf.org
- Search on Facebook to find your local and state-based groups

Would you like to talk to another adult who lives with T1D? Check out JDRF Australia's peer support program:
jdrf.org.au/peer-support

### **HEALTH AND LIFESTYLE**

### **DRIVING**

- AustRoads' Assessing Fitness To Drive: austroads.com.au
- Driving with diabetes:
   diabetesaustralia.com.au/living-withdiabetes/driving
- Emergency ID Australia: emergencyid.com.au

### **EXERCISE**

- Watch videos on how exercise can affect your blood glucose levels: jdrf.org.au/t1d-exercise
- Diabetes UK's information on exercise: diabetes.org.uk/exercise

### PREGNANCY AND BIRTH

- Australasian Diabetes in Pregnancy Society: adips.org
- NDSS information on pregnancy: ndss.com.au/pregnancy



### **FOOD**

- Calorie King Australia (carbohydrate and nutrition listings):
   calorieking.com.au
- · Coeliac Australia: coeliac.org.au
- Dietitians Association of Australia (DAA): dietitiansaustralia.org.au
- The University of Sydney's Glycemic Index Research (including Gl database): glycemicindex.com
- Traffic Light Carbohydrate Counter: trafficlightguide.com.au
- You can also search for carb counters on the App Store and Google Play

### **MENTAL HEALTH AND WELLBEING**

Many of these services and organisations offer phone support and online chat options. Visit their websites to learn more.

- Beyond Blue: beyondblue.org.au
- Black Dog Institute:
   blackdoginstitute.org.au

- Butterfly Foundation (support for eating disorders and body image issues): butterfly.org.au
- · Lifeline: lifeline.org.au
- SANE Australia: sane.org

### RESEARCH

- JDRF Australia clinical trials: jdrf.org.au/clinical-trials
- JDRF Australia research: jdrf.org.au/research
- JDRF International: jdrf.org/impact/research
- Type 1 Diabetes TrialNet: trialnet.org

### **TEENS AND YOUNG ADULTS**

- · Headspace: headspace.org.au
- NDSS Diabetes Youth Zone:
   youth.ndss.com.au
- Reach Out: reachout.com.au

# DIABETES DICTIONARY

**ACE (angiotensin converting enzyme) inhibitor** is a medicine that lowers blood pressure. For people with T1D, especially those with protein (albumin) in the urine, ACE inhibitors help slow kidney damage.

**Adrenalin** is a hormone released by the body in reaction to stress. Adrenalin triggers the liver to break down stored glucose and to release it into the blood.

**Aerobic exercise** is a form of physical activity that makes your heart rate and breathing increase. Examples include brisk walking, swimming or running.

**Albuminuria** is a condition in which the urine has more than normal amounts of a protein called albumin. Albuminuria may be a sign of nephropathy (kidney disease).

Alpha cell is a type of cell in the pancreas. These cells make and release glucagon, a hormone. The body sends a signal to the alpha cells to make glucagon when blood glucose falls too low. When glucagon reaches the liver it tells it to release glucose into the blood to be used as energy.

**Anaerobic exercise** is a form of physical activity that involves short exertion, high-intensity movement. Examples include weight lifting and high intensity interval training (HIIT).

**Antibodies** are proteins that the body produces to fight off foreign substances like bacteria and viruses.

**Atherosclerosis** is the clogging, narrowing and hardening of the body's large arteries and medium-sized blood vessels. It can lead to strokes, heart attacks, and eye and kidney problems.

**Autoimmune disease** is a disorder in which a person's own antibodies destroy body tissues, such as the beta cells in the pancreas.

**Basal insulin** controls blood glucose levels between meals and overnight. It controls glucose in the fasting state.

**Beta cells** make insulin and are found in areas of the pancreas called the islets of Langerhans. In people with T1D, beta cells are targeted and destroyed by the immune system.

**Blood glucose** is the main sugar that the body makes from food. Cells can't use glucose without the help of insulin.

**Blood glucose level (BGL)** is the measure of how much glucose is in your blood at any given time. It's shown as millimoles of glucose per litre of blood (mmol/L). After people eat, their blood glucose levels increase. Maintaining blood glucose levels within a particular range is a key goal of T1D management.

Blood glucose meter is a small, portable machine used by people with diabetes to check their blood glucose levels. After pricking the skin with a lancet, a drop of blood is put on a strip, which is then entered into the machine. The meter displays the blood glucose level as a number on the meter's digital display.

To learn more T1D words and terms, visit jdrf.org.au/t1dictionary

**Blood glucose monitoring** is how people with diabetes know how much glucose is in their blood.

Blood pressure refers to the pressure exerted by blood flow on artery walls. Blood pressure is shown as a ratio (for example, 120/80, read as '120 over 80'). The first number is the systolic pressure (the pressure when the heart pushes blood into the arteries). The second number is the diastolic pressure (the pressure when the heart rests). People with T1D should aim for a blood pressure of 130/80mmHg or lower. High blood pressure can cause heart attacks, strokes and kidney problems.

**Blood sugar** is a term also used to refer to blood glucose.

**Brittle diabetes** is a term sometimes used to describe T1D that has wide variations (or 'swings') in blood glucose levels. In brittle diabetes, blood glucose levels can go from too high to too low very quickly.

**Bolus insulin** is an extra amount of insulin taken to cover an expected rise in blood glucose, often related to having a meal or snack.

**Carbohydrate** is a major source of kilojoules in the diet. It comes primarily from sugar (found in refined fruits and vegetables) and starch (found in grains and legumes). Carbohydrate breaks down into glucose during digestion and raises blood glucose levels.

**Carbohydrate counting** (or carb counting) is a method of meal planning for people with diabetes, based on counting the number of grams of carbohydrate in food.

**Carbohydrate exchange** is a way of measuring carbohydrate. Most diabetes centres around Australia use 15g of total carbohydrate as a carbohydrate exchange. A sandwich slice of bread and 250ml

of milk each have around 15g of carbohydrate and are examples of a carbohydrate exchange.

**Cholesterol** is a type of fat that occurs naturally in our bodies and is also found in animal fats. Too much saturated fat and dietary cholesterol may be associated with heart disease and stroke.

**Chronic** refers to a disease or disorder that's present over long periods of time.

Closed-loop systems are an automated way of delivering insulin. They consist of a continuous glucose monitor (CGM) connected to an insulin pump. The CGM feeds real-time information about blood glucose levels into a special mathematical formula, which calculates the amount of insulin needed. It then instructs the insulin pump to deliver the insulin.

**Coeliac disease** is a digestive disease that damages the small intestine and interferes with absorption of nutrients from food. People with coeliac disease can't tolerate a protein called gluten, which is found in wheat, rye and barley.

**Complications** are harmful effects of diabetes, such as damage to the eyes, heart, blood vessels, nervous system, teeth and gums, feet, skin, and kidneys. Studies show that keeping blood glucose, blood pressure and LDL cholesterol levels close to normal can help prevent or delay complications.

### Continuous glucose monitoring (CGM)

is a means of measuring glucose levels continuously. CGMs are inserted under the skin and worn separately to an insulin pump.

**C-peptide (connecting peptide)** is a substance the pancreas releases into the bloodstream in equal amounts to insulin. A test of C-peptide levels shows how much insulin the body is making.

**Creatinine** is a waste product from protein in the diet and from the muscles of the body. Creatinine is removed from the body by the kidneys; as kidney disease progresses, the level of creatinine in the blood increases.

Counterregulatory hormones are hormones that oppose the action of insulin. They include glucagon, adrenaline, cortisol and growth hormone. Counterregulatory hormones raise the level of glucose in the blood. In healthy people, these hormones are a main defence against hypoglycemia, and levels are expected to rise as glucose levels fall. Persistent elevation can reduce a person's sensitivity to insulin.

**Dawn phenomenon** is the early morning (4-8am) rise in a person's blood glucose level.

**Diabetes** is a condition in which the body either can't produce insulin or can't effectively use the insulin it produces.

**Diabetes educator** is a healthcare professional who can help people learn about taking insulin, blood glucose monitoring, foot care, physical activity, shift work adjustments and more.

**Diabetic ketoacidosis (DKA)** is a condition in which ketones accumulate in the blood, making the blood acidic. Symptoms of DKA include nausea, vomiting, abdominal pain and rapid breathing. It can quickly become very dangerous.

**Diabetic retinopathy** is a disease in which the small blood vessels (capillaries) in the back of the eye (retina) may bleed or form new vessels. Left untreated, it can lead to blindness. It can be caused by long-term high blood glucose levels.

**Dietitian** is an expert in nutrition who can assist people plan the kinds and amounts of food that promote a healthy lifestyle.

**Endocrine gland** is a group of specialised cells that release hormones into the blood. For example, the islets in the pancreas, which secrete insulin, are endocrine glands.

**Endocrinologist** is a doctor who specialises in treating people who have problems related to the endocrine system, which includes diabetes.

**Erectile dysfunction** (impotence) refers to the inability to have an erection sufficient to have sexual intercourse.

**Fasting blood glucose test** is a check of a person's blood glucose level after the person hasn't eaten for 8 to 12 hours (usually overnight).

Fat is the most concentrated source of kilojoules in a diet. Saturated fats are found mainly in animal products, while unsaturated fats come from plants. Excess fat intake, especially saturated fat, can increase the risk of heart disease and stroke.

**Fibre** is a type of material within foods that's mainly found in vegetables, fruits and cereals. It adds bulk to the diet, aiding digestion.

**Gestational diabetes** develops in pregnancy. It disappears after birth. Women who've had gestational diabetes are at a higher risk of developing type 2 diabetes later in life.

**Glucagon** is a hormone produced by the pancreas. It stimulates the liver to break down glycogen and release it into the bloodstream as glucose. It can be given by injection to treat hypoglycaemia. An injectable form of glucagon, available on prescription, can be used to treat severe hypoglycemia.

**Glucose** is a simple form of sugar that acts as fuel for the body. It's produced during digestion of carbohydrate and is carried to the cells in the blood.

**Glycaemic index** is a ranking of carbohydrate-containing foods, based on the food's effect on blood glucose compared with a standard reference food.

**Glycogen** is the main carbohydrate storage material, which is stored in the liver and muscles for use when energy is needed.

**Haemoglobin** in the red blood cells carries oxygen and glucose to the cells of the body.

**Haemoglobin A1c (HbA1c)** is a test that reflects the average amount of glucose a person had in the blood over the past 3 months.

HDL cholesterol (high-density lipoprotein cholesterol) is a fat found in the blood that takes extra cholesterol from the blood to the liver for removal. HDL cholesterol is sometimes called 'good' cholesterol.

**Honeymoon period** often occurs after a T1D diagnosis, when the dose of insulin may need to be reduced due to remaining or recovered insulin secretion from the pancreas. This period can last weeks, months or years.

**Hyperglycaemia** is a condition caused by greater than normal levels of glucose in the blood. Symptoms include thirst, frequent urination, weight loss and fatigue.

**Hypoglycaemia** is a condition in which blood glucose levels drop too low. Symptoms include sweating, trembling, hunger, dizziness, moodiness, confusion, blurred vision and hunger.

**Hypoglycaemia unawareness** is a state in which a person doesn't recognise or feel hypoglycaemia symptoms. People who have frequent hypoglycaemia may no longer experience the warning signs.

**Hormones** are the substances released into the bloodstream from a gland or organ. Hormones control growth and development, reproduction, sexual characteristics and blood glucose levels. They also influence the way the body uses and stores energy.

**Impotence** (erectile dysfunction) refers to the inability to have an erection sufficient to have sexual intercourse.

**Injection site rotation** is changing the places on the body where insulin is injected. Rotation prevents the formation of lipodystrophies.

**Insulin** is a hormone manufactured by the pancreas, which helps glucose leave the blood and enter the muscles and other tissues of the body.

Insulin-dependent diabetes (also known as type 1 diabetes or T1D) is a condition in which the body's immune system destroys the cells in the pancreas that produce insulin. Insulin allows glucose to enter the cells of the body to provide energy. People with T1D must take daily insulin injections.

**Insulin pen** is a device for injecting insulin using replaceable pen fills.

Insulin pump is a small computerised device that delivers a slow continuous level of rapid-acting insulin throughout the day. A pump can be programmed to give more insulin exactly when it's needed, or less insulin to help prevent blood glucose levels dropping too low. The pump can also be used to give a surge of insulin with food or if blood glucose levels are too high.

**Insulin resistance** partially blocks the effect of insulin.

**Insulin-to-carb ratio** refers to the number of units of rapid or short-acting insulin needed to cover each carbohydrate exchange eaten at a meal or snack.

Intensive insulin therapy is a treatment for diabetes in which blood glucose is kept as close to normal as possible through frequent injections or use of an insulin pump, meal planning, adjustment of medicines, exercise based on blood glucose check results, and frequent contact with a person's healthcare team.

**Intermediate-acting insulin** is a type of insulin that starts to lower blood glucose within 1 to 2 hours after injection. It has its strongest effect 6 to 12 hours after injection, depending on the type used.

**Islets** (also known as islets of Langerhans) are groups of cells in the pancreas that make hormones that help the body break down and use food. For example, alpha cells make glucagon and beta cells make insulin.

Islet cell autoantibodies (ICA) are proteins found in the blood of people newly diagnosed with T1D. They're also found in people who may be developing T1D. The presence of ICA indicates that the body's immune system has been damaging beta cells in the pancreas.

**Islet transplantation** is an experimental procedure in which islets are moved from a donor pancreas into a person with T1D. Beta cells in the islets make the insulin that the body needs for using blood glucose.

**Kilojoule** is a measurement of energy from food or drinks. The sources of kilojoules are carbohydrate, protein, alcohol and fat.

**Ketones** are the breakdown product of fat that accumulates in the blood when there's not enough insulin or kilojoule intake. A build-up can be dangerous as it can lead to diabetic ketoacidosis. Ketones can be tested with a blood glucose meter or urine ketone monitoring strips.

**Ketonuria** is a condition that happens when ketones are present in urine. This is a warning sign of diabetic ketoacidosis.

**Lancet** is a spring-loaded device used to prick the skin with a small needle, creating a drop of blood that can be used to check a person's blood glucose level.

### Latent autoimmune diabetes of adults

(LADA, also known as type 1.5) is a type of diabetes. People with LADA have features of both type 1 and type 2 diabetes. Their immune system attacks the cells of the pancreas that produce insulin, but they may also have insulin resistance.

### LDL (low-density lipoprotein)

**cholesterol** is a fat found in the blood. It takes cholesterol around the body to where it's needed for cell repair, and also deposits it on the inside of artery walls. LDL cholesterol is sometimes called 'bad' cholesterol.

**Lipohypertrophy** is the build-up of fat below the skin, causing lumps. It can be caused by repeatedly injecting insulin in the same spot.

**Long-acting insulin** is a type of insulin that starts to lower blood glucose within 4 to 6 hours after injection. It has its strongest effect 10 to 18 hours after injection.

**Macrovascular disease** is disease of the large blood vessels, such as those in the heart. Lipids and blood clots build and can cause atherosclerosis, coronary heart disease, strokes and peripheral vascular disease.

**Microvascular disease** is disease of the smallest blood vessels, such as those in the eyes, nerves and kidneys. The walls of the vessels can become thick but weak, causing them to bleed, leak protein and slow the flow of blood to the cells.

**Millimoles per litre (mmol/L)** is a measure of how much glucose is present in the blood.

**Macrosomia** means 'large body'. It refers to a baby that is larger than normal.

**Nephropathy** refers to diabetic kidney disease.

**Neuropathy** refers to diabetic nerve damage.

**Nutrients** include carbohydrates, fats, proteins, vitamins and minerals provided by food and drinks. They're necessary for growth and the maintenance of life.

**Ophthalmologist** is a medical doctor who specialises in the treatment and care of eyes.

**Optometrist** is a non-medical health professional who specialises in eye care of the eyes.

**Pancreas** is the fish-shaped gland that secretes substances such as digestive fluid, insulin and glucagons. It's divided into a head, a body and a tail, and is about 13cm long in adults.

**Periodontal disease** is a disease of the gums, a potential complication of diabetes.

**Peripheral neuropathy** is nerve damage that affects the feet, legs or hands. It can cause pain, numbness or tingling.

**Photocoagulation** is a treatment for diabetic retinopathy. A laser is used to seal bleeding blood vessels in the eye, and burn away extra blood vessels that shouldn't have grown there.

**Podiatrist** is a health professional who diagnoses and treats disorders of the feet.

**Post-prandial blood glucose** is the blood glucose level taken 1 to 2 hours after eating.

**Pre-mixed insulin** is a commercially produced combination of 2 types of insulin.

**Pre-prandial blood glucose** is the blood glucose level taken before eating.

**Protein** is a major source of kilojoules in a diet. Found in meats, eggs, milk and some vegetables and starches, protein provides the body with material for making blood cells, hormones and body tissue.

**Proteinuria** is the presence of protein in the urine. It indicates that the kidneys aren't working properly.

**Rapid-acting insulin** is a type of insulin that starts to lower blood glucose within 5 to 10 minutes after injection. It has its strongest effect 30 minutes to 3 hours after injection, depending on the type used.

**Rebound hyperglycaemia** (also known as the Somogyi effect) is a swing to a high blood glucose level after having a low level.

**Retina** is the light-sensitive layer of tissue that lines the back of the eye.

**Sharps container** is a special container for the disposal of used needles and syringes. They're made of hard plastic so the needles can't poke through.

**Short-acting insulin** is a type of insulin that starts to lower blood glucose within 30 minutes after injection. It has its strongest effect 2 to 5 hours after injection.

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**Sugar** is a simple form of carbohydrate. It provides calories and raises blood glucose levels.

**Subcutaneous injection** is putting a fluid into the tissue under the skin with a needle and syringe.

**Type 1 diabetes** (also known as T1D and insulin-dependent diabetes) is a condition in which the body's immune system destroys the cells in the pancreas that produce insulin. Insulin allows glucose to enter the cells of the body to provide energy. People with T1D must take daily insulin injections.

**Type 2 diabetes** (also known as non-insulin-dependent diabetes) is a condition in which the body either makes too little insulin or can't properly use the insulin it makes to convert blood glucose to energy. Type 2 diabetes may be controlled with diet and exercise, but can also require oral medications and/or insulin injections.

**Urine tests** measure substances present in the urine, like blood glucose or ketones.



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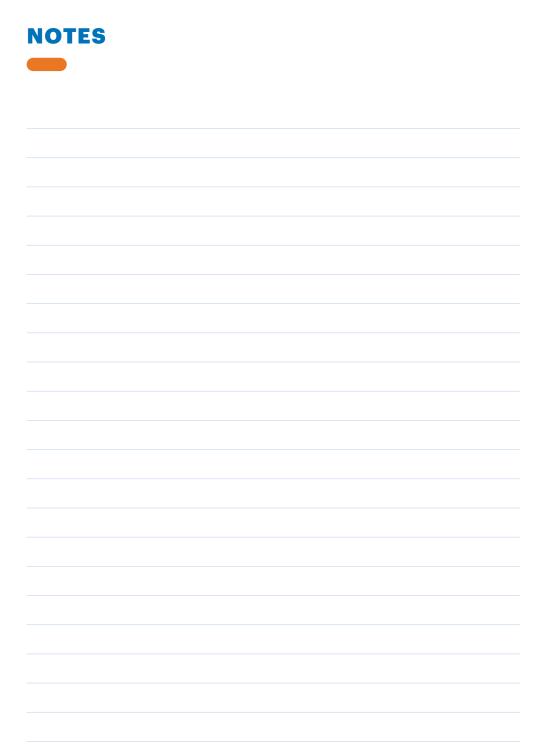
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# **NOTES**



Straight to the Point is the must-have book for every Australian adult living with type 1 diabetes. Whether you were recently diagnosed or have been living with the condition for years (or even decades), you'll find information and handy tips that will help you thrive.

This latest edition features new and updated content, including sections on diabetes technology, the stages of type 1 diabetes, body image, stories from our amazing community members and lots more.

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