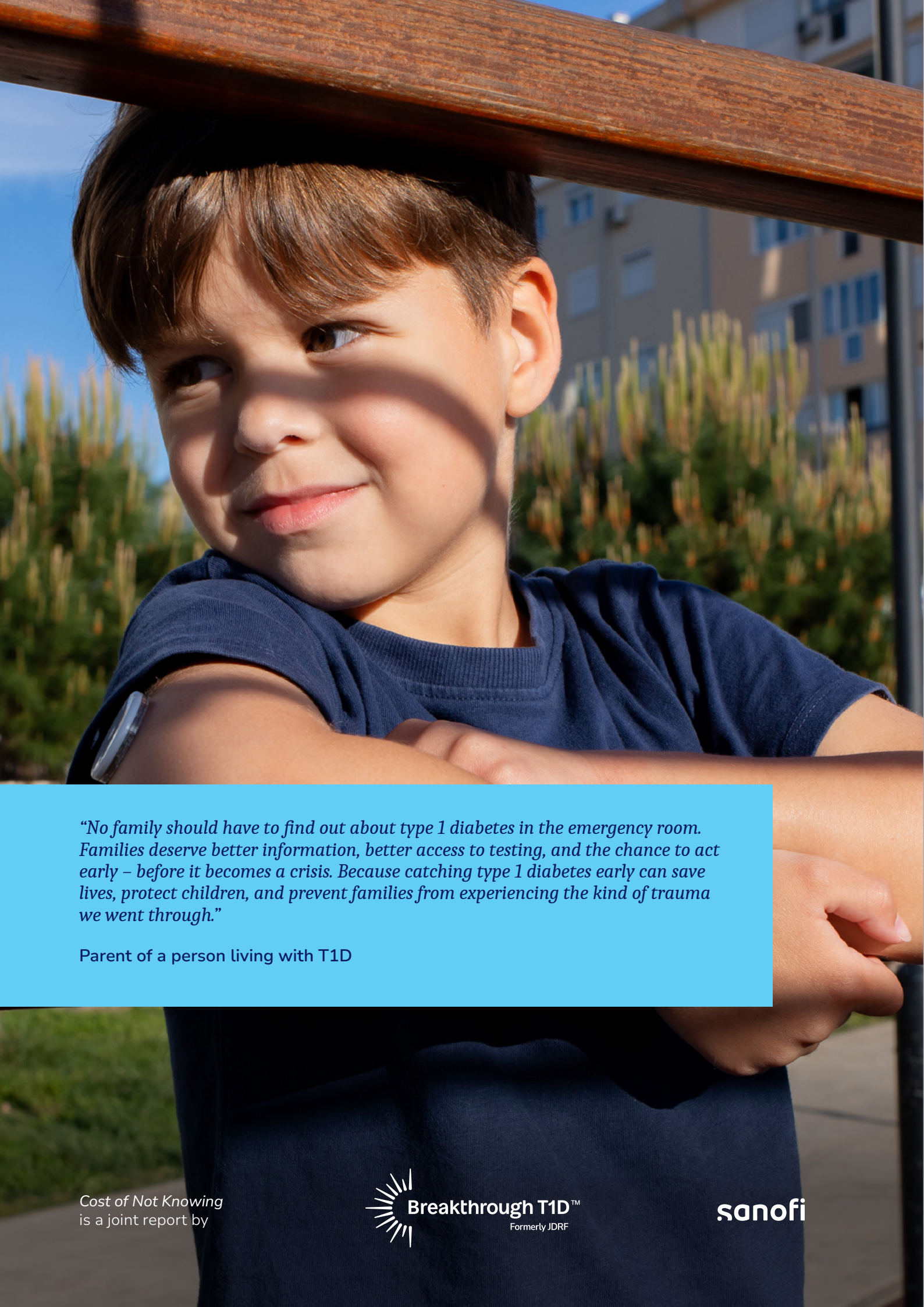
Breakthrough T1D
Formerly JDRF

Cost of Not Knowing

A landmark report into the profound impact of being diagnosed with type 1 diabetes and the opportunity for Australia to lead the world in the early detection of this autoimmune condition.

November 2025



"No family should have to find out about type 1 diabetes in the emergency room. Families deserve better information, better access to testing, and the chance to act early – before it becomes a crisis. Because catching type 1 diabetes early can save lives, protect children, and prevent families from experiencing the kind of trauma we went through."

Parent of a person living with T1D

Cost of Not Knowing
is a joint report by

Breakthrough T1D™
Formerly JDRF

sanofi

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Foreword

Breakthrough T1D's vision is a world without type 1 diabetes (T1D). Our mission is to accelerate life-changing breakthroughs to cure, prevent and treat T1D and its complications.

A cornerstone of this mission is the early detection of T1D before symptoms appear. Once thought impossible, this goal is now within reach. Decades of research have provided evidence to reliably detect T1D in its silent stage, years before symptoms appear and insulin therapy is required.

Australia is globally leading the way in this field, thanks to ongoing Government investment through the Type 1 Diabetes Clinical Research Network. This support underpins Breakthrough T1D's major initiatives, including Type1Screen and the Type 1 Diabetes National Screening Pilot.

Type1Screen is an ongoing program, currently offering screening to anyone with a family member already diagnosed with T1D. For those without family history of T1D, we support the Type 1 Diabetes National Screening Pilot, which is comparing simple screening methods to determine the most effective way to offer early T1D detection to every Australian child. Thousands of children have already been enrolled, with promising early results.

Alongside major advances in the clinical development of disease-modifying therapies that can delay or even prevent progression to symptomatic T1D, we are now at a critical inflection point in the trajectory of research into the condition. We now have the tools and evidence to fundamentally change the diagnosis and clinical care of T1D.

The impact of widespread early detection would be profound. Families would no longer face the trauma of a sudden, life-threatening diagnosis. Instead, they would have time to prepare, connect with support services, and access care before they or their child is at the point of stressful complications requiring emergency care, that can result from a late diagnosis.

The benefits extend beyond individuals. Earlier diagnosis and intervention would reduce hospitalisations, easing pressure on the healthcare system and delivering substantial economic savings for Australia.

The science is clear: early detection and screening are critical to a better future for T1D. With continued collaboration, investment and commitment, Australia can lead this global shift and ensure that no one faces T1D without warning.

Dr Dorota Pawlak
Chief Scientific Officer and
Type 1 Diabetes Clinical Research Network Director
Breakthrough T1D Australia

Executive summary

Callum, diagnosed with T1D alongside diabetic ketoacidosis at age nine, says the experience was a “complete explosion”.

When it comes to type 1 diabetes (T1D), being forewarned is forearmed.

Yet for most Australians, this complex and lifelong autoimmune condition strikes without warning. Each year, around 3,000 Australians – many of them children – are diagnosed with T1D,[1] often through a traumatic medical emergency that has lasting consequences for individuals, families and the community.

Cost of Not Knowing, a joint initiative of Breakthrough T1D and Sanofi Australia, lays bare the profound social, emotional and financial costs of a sudden and severe T1D diagnosis.[2]

Informed by the experiences of Australians living with T1D and their carers, *Cost of Not Knowing* explores the significant upheaval caused by an unexpected diagnosis, alongside the immediate and longer-term impacts on employment, education, relationships and household finances.[2]

Critically, the analysis reveals strong support for national T1D screening. Families impacted by T1D overwhelmingly agree that early, pre-symptomatic detection would provide vital time to prepare, help avoid emergency hospital admissions, and support better management of the condition. The ongoing clinical development of treatments designed to alter the disease course and need for insulin[3,4] – an advance many consider “life-changing” – further increases support for early detection.[2]

Once thought to begin when symptoms first appear, research now shows that T1D develops silently over many years. This report explores the shift in the understanding of how T1D progresses, revealing that an estimated 25,000 Australians are unknowingly living with early-stage T1D.[5] Screening could transform the future diagnosis of these Australians from a medical crisis into a managed transition.

A case in point is the story of one Australian family featured in this report, who describe the stark difference between being caught unprepared and being forewarned of T1D. While their story is extraordinary, screening could make this the norm, where prior knowledge helps families avoid life-threatening events such as diabetic ketoacidosis (DKA), while accessing education and guidance well before symptoms present.

With the support of the Federal Government, alongside families, clinicians and researchers, Australia has a unique opportunity to lead the world in making population-wide T1D screening a reality. This would redefine the way the condition is diagnosed for generations to come.

Type 1 diabetes diagnoses

Type 1 diabetes (T1D) is a chronic autoimmune condition that develops when the immune system mistakenly destroys the insulin-producing beta cells in the pancreas.[6] Without insulin, the body cannot regulate blood glucose levels, making lifelong management essential.[6]

More than 140,000 Australians are currently living with diagnosed T1D,[7] and each year around 3,000 new cases are identified – the equivalent of eight Australians every day.[1]

An 'out of the blue' occurrence

T1D can affect anyone, at any age.[6,8] Approximately 90% of people diagnosed with T1D have no known family history, meaning most diagnoses arrive suddenly and without warning.[8]

Family history does, however, play a role. If one family member lives with T1D, the likelihood of a child or first-degree relative developing the condition is increased up to 15-fold.[9,10] The risk of T1D is also elevated in the presence of other autoimmune conditions, such as coeliac disease or autoimmune thyroid disorders, due to shared genetic characteristics.[11-13]

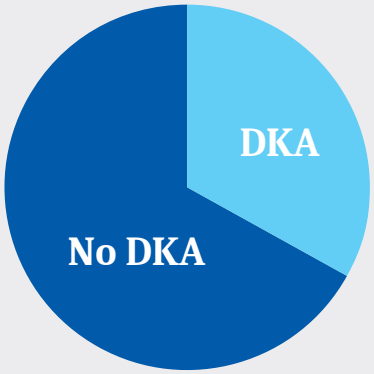
A sudden and severe diagnosis

For many families, a T1D diagnosis involves a medical emergency. The sudden onset of untreated high blood glucose levels can progress to diabetic ketoacidosis (DKA) – a life-threatening complication where the body produces excessive and dangerous acidic ketones due to lack of insulin.[5,14,15]

DKA is a leading cause of hospitalisation among people with T1D, responsible for around half of all admissions.[16,17]

In Australia, more than 30% of new T1D diagnoses in children and young adults involve DKA.[15] This not only places individuals at immediate risk of coma or death, but also has lasting consequences, including:[5,18-23]

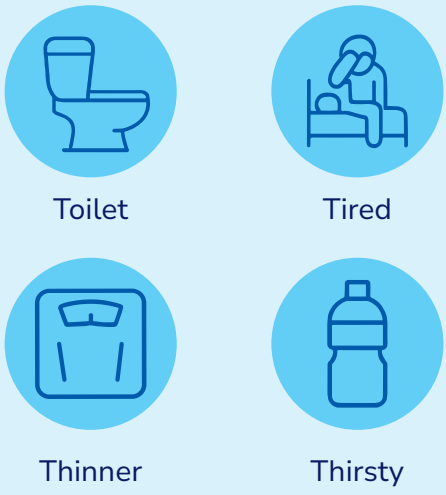
- increased risk of future DKA episodes
- cognitive changes and neurocognitive deficits
- poorer long-term glycaemic control
- higher morbidity and mortality rates.



In Australia, a third of all T1D diagnoses involve diabetic ketoacidosis.[15]

T1D exists before symptoms arise

T1D was once thought to begin when symptoms of high blood glucose levels – frequent urination, excessive thirst, weight loss and fatigue – became apparent.[6]



The 4Ts that signal the onset of symptomatic T1D

Decades of research have since shown that T1D progresses through distinct early stages before symptoms develop, shifting the way the condition and its diagnosis are understood.[6]

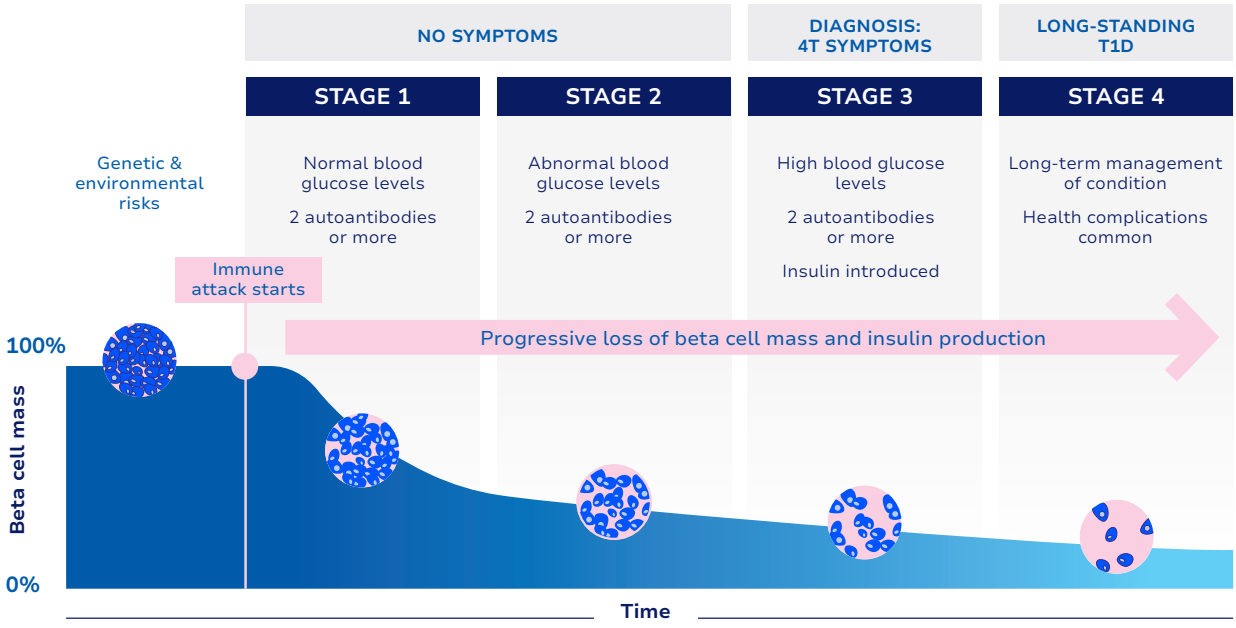
Stages of T1D[6]

- **Stage 1** – no symptoms, normal blood glucose levels, but the presence of two or more islet autoantibodies. Islets are clusters of cells within the pancreas that contain insulin-producing beta cells. At Stage 1, the immune system has begun attacking insulin-producing cells.
- **Stage 2** – continued autoimmune attack and no obvious symptoms. Blood glucose levels have started to become abnormal.
- **Stage 3** – symptomatic stage, with high blood glucose levels. Insulin therapy is required.
- **Stage 4** – long-standing T1D, with many years of insulin treatment and blood glucose level management.

Many Australians are in the early stages of T1D without knowing it.[6] Research suggests that more than 25,000 Australians are currently living with undiagnosed Stage 1 or Stage 2 T1D.[5]

For every one person diagnosed at Stage 3, another eight people are unknowingly in an earlier, pre-symptomatic stage of the condition.[5]

Eight Australians are living with early-stage T1D for every one person diagnosed.[5]



The wider impacts of T1D diagnoses

A T1D diagnosis reshapes daily life for individuals and families. From the outset, people must quickly learn complex skills such as blood glucose monitoring, carbohydrate counting and insulin administration.

This constant management creates decision fatigue, with studies estimating that people with T1D make around 180 extra decisions every day about their condition.[24] Mental health is also significantly affected, with people living with T1D, and their carers, experiencing higher rates of anxiety and depression.[14]

"It has affected absolutely everything. We are exhausted... We have terrible sleep; stress levels are terrible. I am on a mental health plan for stress."

Parent of a person living with T1D

Cost of Not Knowing findings

The *Cost of Not Knowing* survey of Australians directly affected by T1D sought to better understand the experience of a sudden and unexpected diagnosis, including financial, social and emotional impacts.[2]

Undertaken by YouGov Australia in July – September 2025, the *Cost of Not Knowing* survey of 154 people living with T1D and 125 parents or carers of people living with T1D revealed the following.[2]

A shock diagnosis[2]

For most families, T1D arrived without warning, with 69% of respondents reporting no known family history of the autoimmune condition.

More than half (52%) of participants felt shocked and overwhelmed following diagnosis.

Although T1D usually presents with telltale signs, including thirst, frequent urination, unexplained weight loss and fatigue, these symptoms can be easily mistaken for other common illnesses. This is the case for many people, with the survey finding diagnosis is often delayed.

More than a third (37%) of respondents said they or their child had been unwell for a while, but only 42% of these people suspected T1D.

Alarmingly, 42% only realised something was seriously wrong when the person became very unwell. Of these, just 23% considered T1D as the likely cause.

"Absolutely devastating. Had no idea and broke into tears upon diagnosis. We were all totally shocked and terrified for our child."

Parent of a person living with T1D

"It took the wind out of our sails. A total shock to our family."

Parent of a person living with T1D

"To say it was life changing is an understatement. We were very unaware of what life with T1D would look like... the stress it took on our family in the first six months was incredible."

Parent of a person living with T1D

"It was horrific and devastating. I cried for weeks and I am sure my parents did as well."

Person living with T1D

A medical emergency[2]

For many respondents, a T1D diagnosis presented as an acute health crisis that required urgent medical attention and an extended hospital stay.

More than eight in 10 (84%) required hospital care at the time of diagnosis, and this care was delivered in an emergency setting in more than half of cases (55%).

Diabetic ketoacidosis (DKA), a dangerous and potentially life-threatening complication, was reported in 41% of T1D diagnoses.

The road to blood glucose stabilisation and a return home was not quick.

More than half (54%) of people diagnosed with T1D spent between four and seven nights in hospital, while more than one in five (21%) remained admitted for longer than a week.

Emily was diagnosed with T1D at 14 months. She says her diagnosis came as a huge shock to her parents, as nobody else in their family had T1D. They spent a week in hospital learning everything about how to keep their baby alive and then were sent off with a whole new way of life.

"This has been a massive traumatic experience for all of us. Diagnosed when he was found unresponsive and rushed to hospital in DKA. This has turned all our lives upside down."

Parent of a person living with T1D

"She almost died in the ICU... She was unwell for six weeks prior, with all the symptoms that I missed. Our GP treated her for a UTI, end-of-year school exhaustion, and a virus. It wasn't until she had trouble breathing that we went to the ED."

Parent of a person living with T1D

"It was horrific. We had no idea what was happening. The DKA was intense and we were told if we were a few hours later it could have been fatal. Scariest time of our lives."

Parent of a person living with T1D

"Initially my world was turned upside down. My daughter nearly died and we were following the ambulance to the nearest children's hospital, over an hour away."

Parent of a person living with T1D

"Watching our daughter fight for her life in intensive care, surrounded by machines and medical staff, was deeply traumatic. It is an experience that stays with you."

Parent of a person living with T1D

Cost of Not Knowing findings continued

Jasmine was diagnosed with T1D at age five. She says her life changed forever; that she didn't even know how to tie her shoes properly and had to learn how to inject insulin.

Far-reaching impacts on the individual, family and society[2]

The impact of a T1D diagnosis can be profound and multifaceted.

- Almost nine in 10 respondents (86%) said their emotional and mental wellbeing was affected.
- Two-thirds (67%) were scared for the future.
- More than half (52%) felt shocked and overwhelmed.
- Nearly half (48%) felt unprepared.

Nearly all respondents (99%)

faced challenges immediately following diagnosis.

The most common challenges for people with T1D and their parents was learning how everyday factors affect blood glucose levels (68%), explaining T1D to others (65%), and managing the fear of too much or too little insulin (59%).

More than two-thirds (68%) of people with T1D found managing their condition at work, school, university or in social situations to be the most challenging aspect of their diagnosis.

The diagnosis impact extended to social lives and relationships. Among people with T1D, 31% felt the concern of others limited their independence, while 30% missed out on or avoided social activities, which impacted friendships.

Parents also bore heavy burdens: two-thirds (66%) reported having less time for hobbies and interests, 59% spent less time with other children, and 59% had to cancel plans due to the demands of T1D care. Most parents (85%) reported that the unrelenting nature of managing T1D every day was a challenging part of diagnosis.

"It had a huge impact on me and my husband. I was anxious, angry, scared and overwhelmed. It took me many years to work through these responses."

Parent of a person living with T1D

"I was a young adult with a partner. It saw the breakdown of that relationship. I was living in another state from all my family so I had no support and it was very hard."

Person living with T1D

"It has turned our lives upside down. The emotional toll has been huge, has made every family relationship more difficult."

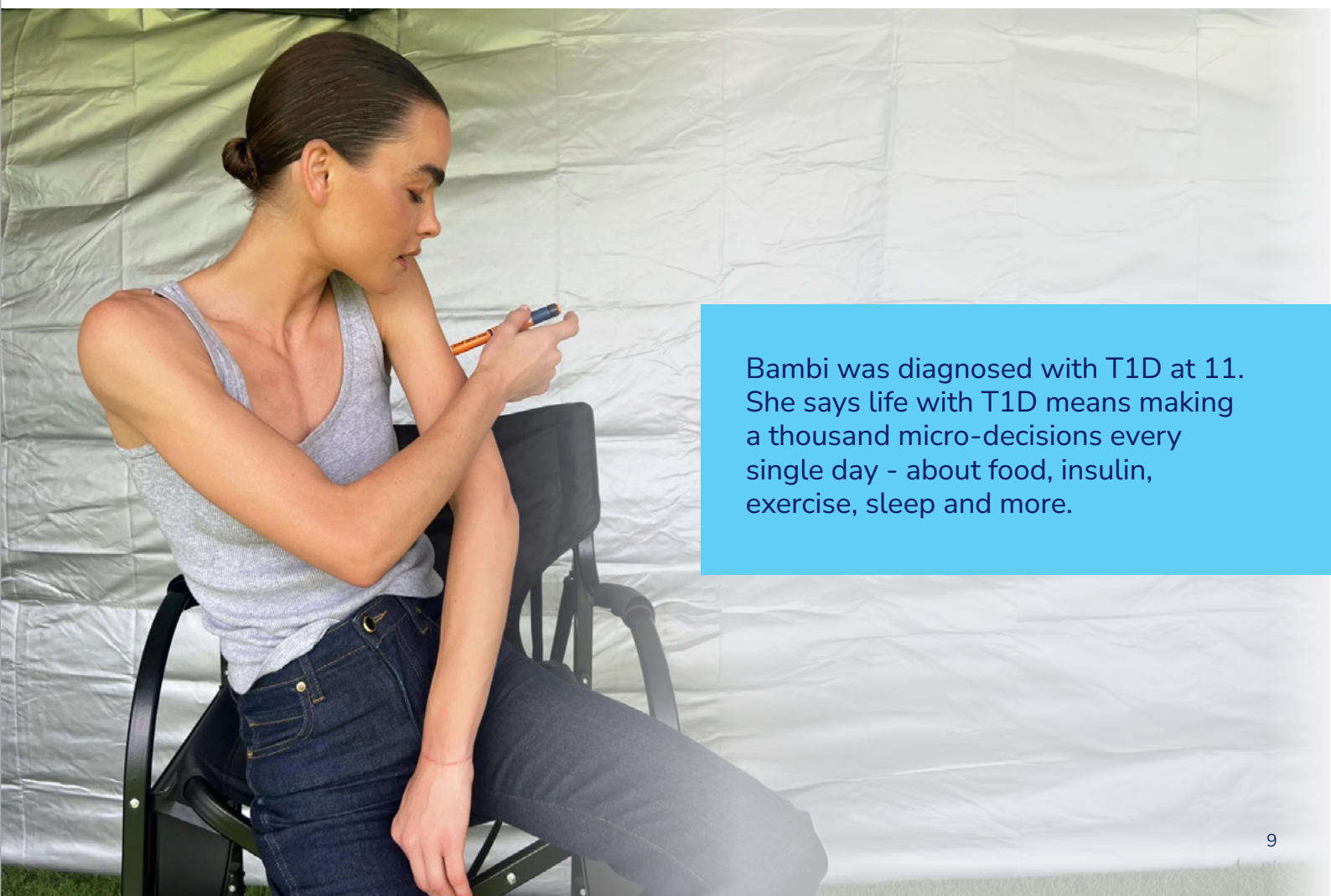
Parent of a person living with T1D

"A complete shock and significant change in our life and household. We suddenly became carers and diabetes experts to manage the care, treatment and needs of our six-year-old son. It was overwhelming, exhausting, stressful and sad."

Parent of a person living with T1D

"I cried for a week, and I sleep less now with a teenager then I ever did when she was a newborn – my life is now my daughter's!"

Parent of a person living with T1D



Bambi was diagnosed with T1D at 11. She says life with T1D means making a thousand micro-decisions every single day - about food, insulin, exercise, sleep and more.

Cost of Not Knowing findings continued

A significant impact on finances and productivity[2]

The cost of T1D is not only emotional, but also financial.

For 60% of respondents, their family's financial wellbeing was negatively affected by the diagnosis.

Almost all (94%) reported new expenses, including essential medical technology (71%) and medications (66%), higher grocery bills (58%), ongoing specialist visits (50%) and private health insurance (48%).

Work and study were also disrupted.

Among parents, 82% reduced their hours or left work to care for their child.

Two-thirds (65%) of people with T1D said their schooling, study or career was adversely affected.

"I quit my job as I wasn't coping and didn't feel I could support my daughter while working."

Parent of a person living with T1D

"While it was a while ago, I remember my diagnosis very clearly. The emotional, financial and physical effects were overwhelming to our whole family and continue to this day!"

Person living with T1D

"They were two-and-a-half-years-old when diagnosed so I had to stop working to learn how to care for them, and didn't return to work until seven years later."

Parent of a person living with T1D

"Our life has been turned upside down. I've had to stop working to care for her. Her school has had to obtain funding for more teachers to allow them to care for her at school."

Parent of a person living with T1D

Benjamin (right) was diagnosed with T1D aged four, and James (bottom) was diagnosed with T1D aged three (shown with their parents, Mark and Hayley). Hayley says, "Our hearts broke when Benjamin was diagnosed. We didn't know a great deal about T1D at the time but learnt through some harsh lessons very fast. When James was diagnosed 11 months later, we knew what was coming and our hearts were absolutely shattered."

Forewarned is forearmed[2]

Looking back, the majority of respondents (67%) agreed that greater knowledge and awareness of T1D would have eased the impact of diagnosis. Many (63%) went so far as to describe in vivid detail how they would have benefitted from knowing about T1D well in advance.

Among those who reflected, the message was clear.

86% wished there had been a way to detect early-stage T1D before symptoms appeared and medication was required, giving them time to prepare.

For this group, knowing about T1D well in advance of the onset of symptoms would have been beneficial in many ways: 72% said they would have recognised these symptoms and sought help sooner, 69% would have had more time to learn about daily management, and almost half (48%) would have connected earlier with the T1D community for support.

When asked to describe the benefits of knowing about T1D before symptoms developed and medication was needed, respondents said:

"I wouldn't have been sick for eight months. I was incredibly sick, and it's impacted me significantly. It would have prepared us a bit more and reduced the medical trauma for me and my family."

Person living with T1D

"I would have been able to plan ahead, make alternative career decisions, prepare financially and avoid some of the complications I now have from a later diagnosis."

Person living with T1D

"Time to prepare, to accept, to learn, to cry and adjust. Instead of changes being forced on us immediately, we could have slowly integrated the changes into our lives with the support of a diabetes counsellor or psychologist. It also would have prevented my mad dash to emergency at 4am because he was vomiting and unresponsive."

Parent of a person living with T1D

"It would have provided us with more time to learn and understand the condition without a shock diagnosis. I would have not missed so much school and I would have had the chance to come to terms with the diagnosis, which would have given me the confidence to accept it and explain it to my friends."

Person living with T1D

"It would have been so beneficial. Firstly I wouldn't have had the recovery period I needed after going into DKA. I would have had time to learn about carb counting, technology etc, rather than it all being thrown at me in hospital. My body wouldn't have gone through what it did going into DKA."

Person living with T1D

"For our family, earlier awareness would've meant we could've started learning and preparing gradually – rather than being thrown in the deep end during a crisis."

Parent of a person living with T1D

Cost of Not Knowing findings continued

Strong support for a national T1D screening program[2]

The case for early detection of T1D is well understood and supported by people with firsthand experience of the condition.

The majority of respondents supported a national screening program to detect early-stage T1D before symptoms develop.

Support for nationwide T1D screening rose to 90% if treatment options for early stage T1D were made available.

When respondents who described the benefits of knowing about T1D in advance were asked to imagine a world in which it was possible to detect early-stage T1D and delay the first appearance of symptoms, 82% agreed this would have been "life-changing".

When asked to describe the benefits of knowing about T1D before symptoms developed and medication was needed, respondents said:

"We could have been better prepared and not be smacked in the face with a near-death experience."

Parent of a person living with T1D

"Our daughter... would not have nearly died. The doctors in emergency would have known what was wrong."

Parent of a person living with T1D

"Our life has changed in so many ways. I am still grieving for that old life, for my son's brutal introduction at such a young age to the loss of a carefree childhood."

Parent of a person living with T1D

"It was traumatising [for my parents] trying to give needles to a child that had an arm width smaller than the actual syringe that was being used... I never had a childhood like other kids."

Person living with T1D

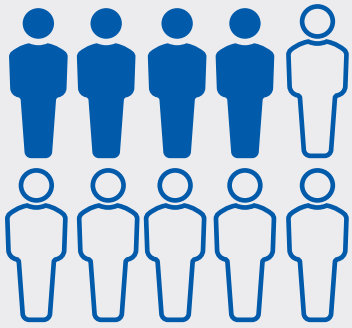
Sophie was diagnosed with T1D at two, and her mum, Bec, says it turned their world upside down. While managing T1D with a young child is incredibly challenging, Bec said they were fortunate to have some understanding of the condition through her husband, diagnosed aged 28.

The diagnosis of T1D is often sudden, severe and a shock to Australian families[2]

Findings of the Cost of Not Knowing Survey

69%

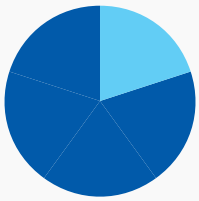
No known family history of T1D



41% were in diabetic ketoacidosis (DKA) at diagnosis

84%

Required hospital care **with more than half of these in emergency wards**



1 in 5

Were in hospital for more than a week

86%

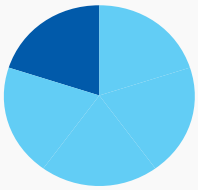
Reported their emotional and mental wellbeing was impacted

60%

Say their financial wellbeing was impacted

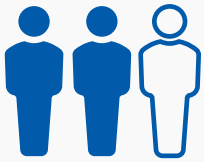
85%

Of parents found the unrelenting nature of T1D challenging



4 in 5

Parents reduced work hours or left the workforce



2 in 3

Reported their education or employment was adversely impacted

86%

Wish there had been a way to detect T1D before symptoms developed*

Knowing about T1D in advance of symptoms would have meant...

72% Being aware of symptoms and seeking help before the person with T1D became very unwell*

69% More time to understand and learn about daily T1D management*

48% Connecting earlier with others in the T1D community for support and guidance*

Support national T1D screening

Support T1D screening if early treatment options were available

82%

Say that the early detection and delay of T1D would be life-changing*

Survey findings from 279 people living with T1D or the parents of people living with T1D.[2]

*Of respondents who described the benefits of knowing about T1D well in advance.

Economic impact of T1D and associated complications

The financial burden of T1D in Australia is substantial and increasing.

An economic analysis undertaken in 2020 estimated the average lifetime cost of T1D at $400,000 per person, driven by healthcare costs, reduced wellbeing and productivity losses.[5]

At a national level, T1D and its complications cost Australia approximately $2.9 billion each year through healthcare expenses, lower employment and additional care needs. This equates to $51 billion over the life of individuals who are currently living with T1D.[5]

Direct healthcare costs associated with T1D exceed $1 billion annually, with 51% of this expenditure met by the Federal Government.[5]

T1D complications are costly

The average lifetime cost of treatment for a person with T1D in 2020 was estimated at $143,000, rising to $738,000 for a person with T1D complications.[5] These costs are also likely to be underestimated.

While the prevention of T1D complications requires a lifetime of management, a person's T1D diagnosis experience can have a significant impact on their health in later life. DKA at the time of T1D diagnosis can have a sustained negative effect on blood glucose control, resulting in the increased risk of long-term complications.[5]

Most costs associated with T1D relate to complications arising from suboptimal blood glucose control.[5]

Preventing DKA at diagnosis could significantly reduce hospital costs associated with T1D[25]

Diabetic ketoacidosis is a costly complication of T1D that results in high hospital admissions and significant medical expenses.[25]

New analysis of hospital data over the course of 18 years in NSW reveals government expenditure exceeded $106.8 million for people with T1D who experienced DKA at any point, compared with $44.2 million for those who did not experience DKA.[2]

Covering the longest period to examine the impact of DKA at the time of T1D diagnosis in Australia, the study found that:[25]

Children who experienced DKA at the time of T1D diagnosis were around 33 times more likely to require intensive care than those without DKA.

Children who presented with DKA at diagnosis were 1.2 times more likely to experience recurrent DKA events, leading to a cycle of acute care over nearly two decades of their life.

Within 12 months of T1D diagnosis, 41% of all children who presented with DKA required readmission to hospital, with 30% readmitted within six months.

Within 18 years of diagnosis, 60% of people with DKA at diagnosis had been readmitted to hospital for another episode of DKA, compared to 40% of those without DKA at diagnosis.

Hospital costs per person with T1D for any admission are more than twice as high for individuals with DKA at diagnosis ($20,571) when compared to those who do not experience DKA ($9,743).

The study concludes that preventing DKA at diagnosis could halve hospital costs associated with T1D.[25]

Tilly was diagnosed with T1D aged two. Her dad, James, says he remembers standing in the hallway after a nighttime CGM alarm, wondering how he and his wife would be able to manage this forever.

Angela and James – a tale of two diagnoses

Angela was diagnosed with T1D on her 25th birthday.

Like most Australians with the autoimmune condition, her diagnosis came suddenly and involved an urgent hospital admission. She had lost 15 kilograms, was exhausted, and only avoided DKA because her GP recognised the signs and acted quickly. Angela describes the experience as "life-changing".

Fourteen years later, Angela's son James became one of the first children in Australia to be diagnosed with T1D before symptoms appeared, thanks to his involvement in a landmark Australian T1D research study.

From the time he was 12 weeks old, James' blood was regularly tested for islet autoantibodies. At age three, his results showed an increased risk of T1D. By age 10, James' blood glucose levels began to rise, signalling the transition to Stage 3 of the autoimmune condition.

Because the family knew what was coming, James' diagnosis was completely different from Angela's. He avoided a hospital admission, had no overt symptoms, and was able to continue at school without interruption.

With support from his care team, insulin was introduced gradually, giving James time to adjust to life with T1D.

Angela describes the difference as "like a dimmer switch instead of a light switch".

The gradual approach allowed James and his family to prepare, both practically and emotionally.

"Knowing ahead of time gave James the best possible opportunity to prepare for life with type 1 diabetes," said Angela.

> *"It was like a dimmer switch instead of a light switch – we had time to prepare."*
>
> Angela

Today, James is thriving. He is a competitive boulderer, ranked sixth in Australia for his age, and enjoys swimming and climbing. He has built friendships through advocating with Breakthrough T1D and feels confident managing his condition.

Studying T1D progression from birth

James' early T1D diagnosis was made possible through his participation in the ENDIA (Environmental Determinants of Islet Autoimmunity) study.

Supported by Breakthrough T1D, ENDIA is a world-first Australian study exploring how genetics and early-life environmental factors shape the development of T1D. This pioneering observational study is following 1,500 children with a first-degree relative with T1D from pregnancy through childhood to age 10. While ongoing, ENDIA has already collected more than 167,000 bio-samples, generating invaluable insights into T1D triggers and laying the foundations for future prevention strategies.[26]

Breakthrough T1D advocates Angela and her son James, who both live with T1D.

Picture: Martin Ollman / Newspix

From emergency diagnoses to early detection

Historically, T1D has only been diagnosed once symptoms appear, often as part of a medical emergency.[6,14,15]

Thanks to advances in research and diagnostic technology, it is now possible to detect the early stages of T1D before overt symptoms develop.[6] A simple blood test can identify islet autoantibodies, early markers that signal the immune system is damaging insulin-producing cells and indicate the likelihood of progressing to symptomatic Stage 3 T1D.[6]

Australian researchers are leading the way towards population-level T1D screening, with two major initiatives funded and supported by Breakthrough T1D and the Australian Government's investment in the Type 1 Diabetes Clinical Research Network: Type1Screen and the Type 1 Diabetes National Screening Pilot.

Type1Screen

Australians with a family history of T1D can now determine their risk of the autoimmune condition through Type1Screen, a national program that enables early detection via simple, accessible blood testing.

Led by Professor John Wentworth, to date the program has screened more than 3,500 Australians, with 178 individuals testing positive for T1D autoantibodies. Of these, 56 have been diagnosed with Stage 1 T1D and another eight with Stage 2 T1D.[27]

People identified as being at-risk are monitored closely and, if they develop T1D, receive proactive education and early specialist clinical care, helping to prevent serious complications and avoid emergency diagnoses. So far, none of the 19 people who developed T1D during follow-up in Type1Screen developed DKA.

Many participants are also offered opportunities to join clinical studies focused on preventing or delaying T1D, contributing to vital scientific research.

Supported by a national network of healthcare professionals and researchers, Type1Screen represents a vital step towards embedding population-level T1D screening into Australia's preventive health framework while giving families an all-important head start.[27]

Type 1 Diabetes National Screening Pilot

The Type 1 Diabetes National Screening Pilot, led by Dr Kirstine Bell, compared a range of ages and simple screening methods to determine the best way to offer routine T1D screening for every child in Australia.

The groundbreaking pilot has already screened approximately 6,700 children. Of those, 325 have been identified as having an increased genetic risk of T1D.[28]

Results from the pilot presented at the 2025 Australasian Diabetes Congress confirm that population-wide screening for T1D is both feasible and acceptable, with strong support from parents and healthcare professionals, as well as high follow-up rates.[28-31]

> *"The opportunity to alter the trajectory of a type 1 diabetes diagnosis is within reach. This would dramatically change lives in the community, protecting families against medical and emotional trauma and placing Australia at the forefront of type 1 diabetes care and intervention globally."*
>
> **Dr Dorota Pawlak, Chief Scientific Officer and Type 1 Diabetes Clinical Research Network Director, Breakthrough T1D**

Type 1 Diabetes National Screening Pilot

A 2025 review of the Australian Type 1 Diabetes National Screening Pilot revealed:

Strong parental support for T1D screening: 98% of parents of the children screened for T1D agreed that screening is worthwhile and should be widely available.[28]

Health professional support: 91% of surveyed health professionals supported screening, believing it should be government-funded (90%) and available to all children (84%), not just those with a known family history of T1D.[29]

High follow-up rates: Most infants identified as being at high genetic risk of T1D attended follow-up testing at 12 months (74% of infants and 55% of newborns), well above participation rates in international programs.[30]

Insight into a preferred screening pathway: Screening uptake was higher when offered at times and locations convenient for families (e.g. part of routine newborn checks or offered in schools).[28]

These outcomes present a compelling case for a national T1D screening program, potentially preventing thousands of cases of DKA and hospitalisation, and shifting the nature of a T1D diagnosis from a medical emergency to one of early, pre-symptomatic detection and preparation.

Importantly, newborn genetic screening for T1D has been shown to be within the range of the Australian Government's cost-effectiveness threshold, at approximately $50,000 per quality-adjusted life year gained.[31]

Preventing emergencies and enabling education

For many, a diagnosis of T1D involves emergency hospital admission for DKA, a traumatic and potentially fatal medical episode.[6] Early detection through screening holds the key to preventing DKA episodes, avoiding emergency and extended hospital admissions, and enabling a safer, more gradual transition to insulin therapy.[6]

Early detection also provides families with the opportunity to seek proactive T1D education, emotional support and connection to diabetes care teams.

Research shows that rates of DKA at Stage 3 T1D can be reduced by up to 90% when early detection is matched with health follow-ups and education.[6]

Screening to support emerging therapies

The value of early detection extends beyond preventing emergency hospital admissions and providing pre-symptomatic educational and emotional support.

Importantly, screening for early-stage T1D could also unlock opportunities for early intervention.[6] Treatments designed to alter the disease course and need for insulin are now in clinical development.[3,4]

Breakthrough T1D believes these therapies have the potential to be the most significant advancement in care since the discovery of insulin more than 100 years ago.

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Disclaimers

This report was prepared by Ethical Strategies on behalf of Breakthrough T1D Australia and Sanofi Australia and New Zealand.

This report has been developed as a product-agnostic document examining the current healthcare environment in Australia for type 1 diabetes and is intended for general information purposes only.

The *Cost of Not Knowing* survey was commissioned by Breakthrough T1D and Sanofi Australia and New Zealand and funded by Sanofi Australia and New Zealand.

YouGov conducted the survey in July - September 2025, with findings from 279 people living with T1D or the parents of people living with T1D.

YouGov is an international online research data and analytics technology group.

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