COUNTING THE COST OF LIVING WITH DIABETES

Community
Consultation Findings

November 2024



Diabetes Australia acknowledges the Traditional Owners of the lands on which we live and work. We recognise their connection to land, waters and culture. We pay the utmost respect to them, their cultures and to their Elders past and present. We recognise that Australia is made up of hundreds of different Aboriginal and Torres Strait Islander peoples, each with their own culture, language and belief systems. Their relationship with country remains of utmost importance as it is the foundation for culture, family and kinships, song lines and languages.

Executive summary

As the rising cost of living continues to impact Australians, people living with diabetes are struggling with the financial burden that comes with managing the condition.

Diabetes management is costly. It involves regular medical consultations, supplies for blood glucose monitoring, insulin or other necessary medications. For many people, these expenses are made worse by rising costs associated with food, housing, and transportation. This can lead to difficult decisions as people are forced to choose between maintaining their health and meeting other essential needs, leading to serious health outcomes.

Financial concerns loom large for individuals with diabetes who spend an average of \$4,000 annually managing their condition, before the added costs of any complications.

More than 90 percent of people surveyed who are living with diabetes said they are feeling anxious about the rising cost of living.

Three quarters of people worry that managing their diabetes will become unaffordable in the future; and around half say cost of living pressures are hurting the ability of the people they care for to manage their diabetes, placing their health at major risk.

In September 2024 Diabetes
Australia undertook a national
survey of people living with
diabetes and those who care for
and support them.
The results clearly demonstrate
that because of the rising cost of
living, Australians living with
diabetes are doing it tougher
than ever.



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If people living with diabetes can't afford regular access to health care and medication to manage their condition, the risk of diabetes-related complications increases. This also places significant burden on the health care system, as more people are hospitalised with lifethreatening complications.

A third of those living with diabetes report having cut back on costs relating to how they manage their diabetes, and 44 percent are turning to cheaper, less healthy food options.

Living with diabetes is hard enough without people having the added stress or worry of how they are going to afford to manage their health. Significantly, 60 percent of people living with diabetes agreed that they would like to be better connected to support. It's not just about cost. Australians living with diabetes are also finding it hard to access the right information and support.

The intersection of increasing everyday costs and diabetes management is a complex challenge that demands urgent attention. Recent data from Victoria University shows the percentage of Australians impacted by diabetes is higher than other chronic conditions including heart, stroke and vascular disease. The *Australia's Health Tracker: Chronic conditions by socioeconomic status* report also shows that chronic diseases like diabetes continue to have a bigger impact on disadvantaged communities, and that the health divide between advantaged and disadvantaged communities is widening.

Amidst rising cost of living pressures, this is a major concern for the most vulnerable groups in society.

It is imperative that we find real solutions to support people living with diabetes, and their carers, wherever they live.

A person's postcode or bank balance should not be a barrier to accessing good health care and support.



THE COST OF LIVING WITH DIABETES

When it comes to management, cost is the biggest concern for the people living with diabetes surveyed, as well as carers. These concerns are mostly related to the cost of medicine and technology, or access to healthcare more broadly.

On average, people living with diabetes spend \$4,000 managing the condition each year. Worryingly, both people living with diabetes and their carers identified that the amount they spend on diabetes management is more than what it was five years ago (68 percent and 82 percent).

The cost of accessing medicines and technology was listed as the biggest challenge in their diabetes management for 61 percent of people living with diabetes and 72 percent of carers.

People living with type 1 diabetes are spending nearly twice as much as those living with type 2 diabetes and those in higher socioeconomic postcodes are, not surprisingly, spending more on their diabetes management.

It is clear that increased spending on diabetes management is having an impact on daily life.

"I am at a permanent financial disadvantage and it makes affordability of other things, especially housing, a lot more difficult."

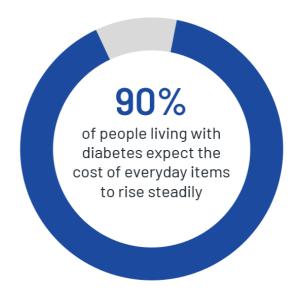
- Person living with diabetes

"This is an expensive condition.

Not sure how my child will cope
financially without my help."

Stress and anxiety

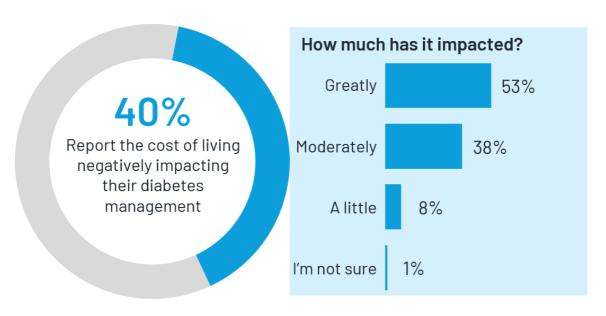
Stress and anxiety caused by the cost of living is a significant burden for people living with diabetes and their carers.



Among people living with diabetes, 93 percent, as well as 99 percent of carers, indicated that they were stressed or anxious about the cost of living. The proportion of people living with diabetes who indicated they were feeling very or extremely stressed or anxious was 43 percent.

This stress and anxiety was seen equally amongst socio economic groups, and 59 percent of those in the much younger cohort (18-24 year olds) were significantly more likely to be extremely worried about the cost of living.

Living with diabetes





THE DIABETES BURDEN

For people living with diabetes, **65 percent said** their main life worry was access to medical care, medicines & technologies, and healthy food.

It's also clear that there is significant need for more support. In our survey, people living with diabetes and their carers identified that they would like to be better connected with support (60%). Our community is telling us they want a simple, easy way to access information to help them live well.

Accessing information

Unfortunately for people living with diabetes, they are not sure what information and advice they can trust (69%). This is more the case for people living with type 2 diabetes (72%) compared with type 1 diabetes (56%).

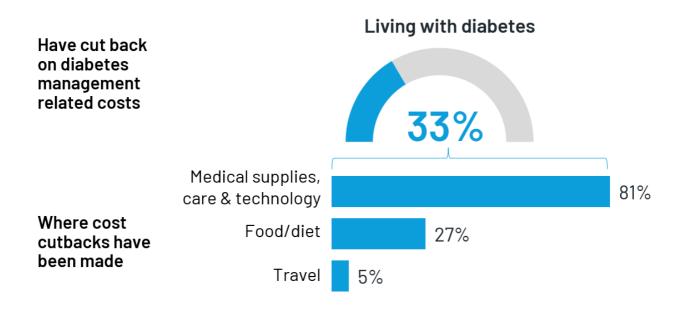
These results are perhaps not surprising considering that 48 percent of those surveyed find it difficult to navigate the healthcare system to find appropriate support, and 40 percent don't know where to access the appropriate resources.

Cutting back on expenses

In a diabetes epidemic, it is concerning to see that a third (33 percent) of people living with diabetes are having to cut back on costs relating to how they manage their diabetes.

These costs are having a profound impact on younger people, with people younger than 40 significantly more likely to have to cut back on related costs (59 percent in comparison to 32 percent of those older than 40).

Of those people surveyed who have cut back on costs, most of the items they are going without are **medical supplies**, **care and technology (81 percent)**. Healthy food and diet was the second main cut that was identified (27 percent).



These statistics are worrying as people are cutting back on the very things which can have the most direct impact on diabetes management: medical supplies, technologies, and healthy food.

If people living with diabetes can't afford regular access to health care and medication to manage their condition, **the risk of diabetes-related complications increases dramatically**. This also places a significant burden on our health care system, as more people are hospitalised with life-threatening complications.

"(Diabetes) just adds to my overall expenses, things I have to buy. Thus I reduce food and energy costs as much as I can to compensate."

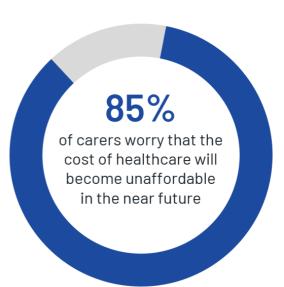
- Person living with diabetes



Concerns about the future

People living with diabetes and their carers are worried about the cost of living, with **90% of people living with diabetes and 94% of carers** indicating that they expect the cost of everyday items to continue to rise steadily in the future.

Carers, perhaps due to the nature of their role, appear to be more concerned about costs and financial stability, with **85 percent of carers** and **74 percent of people living with diabetes** worried that the cost of healthcare will become unaffordable in the near future, and 62 percent of carers (52 percent of people living with diabetes) worried that the cost of managing diabetes will become unaffordable in the near future.



The survey results demonstrate that the cost of living with diabetes is one that is borne not only by the person with diabetes, but also by their carers and families. The emotional and mental costs of living with diabetes and being a carer of someone living with diabetes are both real and significant.

DIABETES AUSTRALIA'S RESPONSE

Diabetes YOUnited

As the national peak body for people living with diabetes, Diabetes Australia is focused on a future where diabetes can do no harm. The cost of living with diabetes is already significant, and those who are living with diabetes should not be further burdened by the increasing cost of good healthcare.

Overwhelmingly, this survey data shows that people living with diabetes want a simple, easy way to access information to help them live well.

Support for people living with diabetes is necessary to bridge the information gap and ensure that people can access essential support on their diabetes journey.

Diabetes Australia is increasing support for people living with diabetes by introducing a new FREE membership program, **Diabetes YOUnited**.

This program will provide easy access to support, from a single trusted source, and it is not dependent on what a person can afford. Everyone who joins the free service will have access to up-to-date information and education tools, personalised guidance, regular news and updates with expert insights and resources, and better connection to and support from Australia's largest diabetes community.

<u>Diabetes YOUnited</u> is available to everyone in Australia living with diabetes and the people who care for and support them.

Unite for Tech



As a key cost of living measure, Diabetes Australia is also calling on the Federal Government to increase subsidies for insulin pumps and continuous glucose monitoring (CGM) devices.

The results of this survey show that these essential technologies continue to be unaffordable for many people living with diabetes.

Diabetes Australia has released a policy paper which outlines the steps needed to create more affordable access to CGM devices and insulin pumps for people with all types of diabetes. The paper includes economic modelling that shows a \$200 million package of investment would support nearly 40,000 people living with diabetes to access these technologies, prioritising those with greatest need.

Increasing subsidies for these technologies was a recommendation of the recent Federal Parliamentary Inquiry into Diabetes and we are engaging with government about how that recommendation can be delivered.

APPENDIX: Breakdown by capital cities

Most difficult challenges with managing diabetes

Biggest challenges in managing diabetes	Melbourne	Sydney	Brisbane	Adelaide	Perth	Canberra
Cost of accessing medicines and technology	66%	65%	64%	49%	56%	70%
Cost of accessing healthcare	58%	53%	45%	43%	27%	38%
Access to medicines and technology	53%	45%	32%	33%	41%	51%
Difficulty keeping on top of my diabetes management	37%	60%	46%	22%	41%	34%
Getting an appointment with my GP and other healthcare professionals	25%	38%	32%	43%	39%	30%
Stigma and discrimination	20%	19%	27%	32%	6%	50%
Access to healthcare	20%	28%	10%	6%	16%	16%
Lack of information and educational support	24%	29%	41%	29%	46%	19%
Other	13%	19%	22%	35%	17%	12%

This table demonstrates the variability in challenges for people living with diabetes throughout Australia. The biggest challenge in managing diabetes, regardless of where a person is located, is the cost of accessing medicines and technology. This was the highest in Canberra and the lowest in Adelaide. Lack of information and support was rated as a bigger challenge compared to stigma and discrimination in all locations except Canberra.

Negative impact of cost of living

Cost of living negatively impacting diabetes management	Melbourne	Sydney	Brisbane	Adelaide	Perth
Yes	42%	44%	34%	30%	46%
No	42%	37%	48%	51%	43%
l'm not sure	16%	19%	18%	19%	12%

This data shows that the cost of living negatively impacts on diabetes management, in Melbourne, Sydney and Perth, more so than in Brisbane and Adelaide.

Cost of living related behaviors

Behaviours due to cost of living	Melbourne	Sydney	Brisbane	Adelaide	Perth
Eating out less	59%	67%	61%	39%	51%
Had to cut back on family holidays	37%	50%	50%	46%	57%
Had to eat cheaper food which is less healthy	46%	52%	40%	49%	47%
Not been able to participate in sports and fitness activities	29%	30%	31%	22%	26%
Had to cook less to reduce energy costs	6%	24%	6%	19%	20%
Borrowed money to pay for medical costs	11%	13%	11%	5%	11%
Been unable to afford travel to medical appointments	5%	9%	9%	5%	9%
Had to use a food bank	3%	6%	4%	15%	12%
None of the above	22%	24%	27%	32%	33%

The survey showed that the most common response to the increasing cost of living is eating out less. The only anomaly to this was Adelaide, where eating cheaper food which is less healthy and cutting back on family holidays ranked higher. Across the board, however, eating out less, cutting back on family holidays, and eating cheaper food which is less healthy were the main behaviours which increased due to cost of living pressures.

Future concerns

% agree and strongly agree	Melbourne	Sydney	Brisbane	Adelaide	Perth
I'm worried about the long-term financial stability of my household due to the cost of living	47%	66%	58%	55%	60%
I expect that the cost of everyday items will continue to rise steadily in the future	89%	88%	85%	85%	81%
I feel confident in my ability to financially support myself despite future increases in the cost of living	38%	36%	44%	25%	34%
I am worried that the cost of healthcare will become unaffordable in the near future	74%	75%	73%	80%	52%
l am worried that the cost of managing my diabetes will become unaffordable in the near future	52%	47%	43%	45%	36%

Across the country, people expect that the cost of everyday items will continue to rise steadily in the future and that people are worried that the cost of healthcare will become unaffordable in the near future. People were also generally less confident about their ability to financially support themseves in the future, with only a quarter of the people surveyed in Adelaide reporting confidence in this area.