

# Why young Type 1 diabetes patients pay \$5000 a year to avoid dying

Funding for a high cost lifesaving medical device is being stripped from young Aussies with Type 1 diabetes the day they turn 21.

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Exclusive: It's the 21st birthday present that can kill.

Funding for a high cost lifesaving medical device is being stripped from young Australians with Type 1 diabetes the day they turn 21.

Many young people starting out in low paid jobs or studying can't afford the \$5,000 a year cost of Continuous Glucose Monitors (CGM) when the government subsidy ends.

And it's putting them at risk of dead in bed syndrome when blood sugar levels plunge while they are asleep causing seizures, coma and sometimes death.

The [DANII Foundation](#) estimates six per cent of deaths from Type 1 diabetes in people aged under 40 are linked to the syndrome and the Junior Diabetes Research Foundation (JDRF) is campaigning for the subsidy to be extended to other age groups in the budget.



Casey Macdonald-Smith, who is living with Type 1 Diabetes, lost her eligibility to a Government funded CGM when she turned 21. Picture: NCA NewsWire / Gary Ramage

“A calendar date shouldn’t determine whether you access technologies that are appropriate for your disease, when you turn 21 we don’t take away your cochlear implant,” Mike Wilson, CEO of JDRF said.

Continuous Glucose Monitors (CGM) are used to measure blood sugar and work with an insulin pump to stop “Hypo” attacks when blood glucose levels drop too low.

Using a wire inserted under the skin connected to a transmitter they automatically check blood sugar readings every five minutes and mean a patient does not need to carry out multiple finger prick tests each day.

Without the technology management of Type 1 diabetes is less than optimum placing patients at risk of blindness, limb amputation and other severe outcomes, not to mention the cost to the health system.

The average Australian living with Type 1 Diabetes experiences three hypoglycaemic or ‘low’ episodes blood sugar a week, with a quarter of these resulting in a hospital visit, the foundation said.

A recent survey by the foundation found three in four Australians with Type1 Diabetes who do not own a CGM cite cost as the main reason.

The survey coinciding with the 100th anniversary of the discovery of insulin in 1921, found Australians living with Type 1 Diabetes were spending \$4,777 per year on the devices



Examples of Continuous Glucose Monitors.

“A large number of people reported depression, 40 per cent of people had romantic relationships affected, 30 per cent had careers affected, and a third say no to a spur of the moment event each month, because they can’t be sure of managing their disease in new circumstances,” Mr Wilson said.

While the foundation said everyone living with Type 1 Diabetes should have access to the technology at the very least it says the government should not end the subsidy of people who already have it when they turn 21.

Casey Macdonald-Smith now aged 23 said she was “heartbroken” when the government subsidy for her CGM was withdrawn when she turned 21.

She struggled to pay for it herself and had to give it up this year because the cost was too great.



JDRF CEO Mike Wilson.

This was even though she had an experience where her blood sugar levels plunged so low one night she became unconscious.

“It’s not like a one off payment, it is continuous for the rest of your life,” she said.

“It’s what keeps you alive, day in day out so I don’t think it’s fair and I wish that there was more that could be done to reduce the financial burden of living with Type 1,” she said.

“I had to prioritise do I want to have a deposit for a home, or do I want to have the continuous glucose monitoring system and this year, deposit for the home won,” she told News Corp Australia.

A spokesperson for Health Minister Greg Hunt said over 58,000 people with diabetes able to receive a free Continuous Glucose Monitoring (CGM) device each year and eligibility criteria are designed to target access to people with diabetes who are in most need.

“The Department of Health is currently reviewing the CGM initiative with the goal of further expanding the eligibility criteria for participation in the program to more people with diabetes,” he said.