

Inquiry into Diabetes in Australia

House of Representatives Standing Committee on Health Aged Care and Sport
Committee Secretary, Parliament House
Health.Reps@aph.gov.au

Dear Minister and Standing Committee

Thank you for convening this inquiry and inviting submissions on diabetes. I realise the inquiry is into type 1, type 2 and gestational diabetes. I highlight my specific interest in type 1 diabetes.

Lived experience

[about me] Father, husband, board director, government advisor, public servant, volunteer, sports coach, extreme athlete, real estate professional, high income earner, tax payer, investor, best mate, mentor. **[about my condition]** I was diagnosed with type 1 diabetes in 1986 (age 14).

Recommendation (see next page)

[my request] I'm writing to encourage the standing committee to make three changes that will help all people with type 1 diabetes live longer, healthier and happier lives. (01) a change in policy so new drugs, medical devices and models of care can be in the hands of all Australians with type 1 that choose them more quickly; (02) change the focus to address and research more of the social determinants of health and mental wellbeing so more people get a fair go; and (03) change the language and tone used around the outlook for type 1 diabetes, especially around children, to support their mental health and resilience.

Background

[my luck] People with type 1 diabetes can be successful and live happy and healthy lives, but too often they don't. Diabetes is relentless, there is no long service leave, and it is with you every minute of every single day. Please use your inquiry to focus on what gives people like me with type 1 diabetes and their parents or carers more choice, and more peace of mind.

Continuous glucose monitoring, automated insulin delivery, food labelling, and new insulins have all made my life so much easier. They take some of the thinking, anxiety, planning and multi-tasking away. Despite this positive progress I've nearly given up – several times. What keeps me going is the strong mindset I inherited from my parents; a supportive network of friends and family; amazing health care professionals; my ability to work hard for qualifications from school and university; employment and ability to earn money; and running. All of that brought me choices which so many others with type 1 don't always get – because of their location, their income or circumstance (social determinants). I've worked hard, but I feel lucky.

I'm 51. After 37 years of having type 1 I'm still fit (physically). I've run ultra-marathons through deserts, climbed and cycled over mountains and represented clubs and regions at team sport. I'm working at my career full time, paying my taxes, raising two boys, supporting my family and volunteering my time. It can be done, it is just harder. Although I'm [#fitterforhavingit](#) and have no signs of diabetes complications - mentally I'm starting to weaken. The pictures, stories and language about how grim diabetes is, how the outlook is poor, how the data is stacked against me, how my diabetes is a burden for others are hard to ignore. When will those 'later in life' complications that people mentioned when I was young arrive? Next week? Next year? Never? Most of the time I wash it away, sometimes I don't. Many people with type 1 don't, they've heard it repeated over and over since childhood.

The negative language, poor and unequal access to therapies, limited availability and high cost of counselling, more expensive or hard to get insurance, delayed adoption of new drugs and medical devices, form filling and waiting times don't help. So Steering Committee please help.

Please be kind, fair and courageous in your recommendations and read more about why I think my suggestions will improve the physical and mental health of people living with, or caring for, type 1 diabetes. If I'm correct, and my views are supported by other evidence and your findings, then research effort, investment and activity will be directed into social determinants, new language and mental health services. This will reduce risk of harm and improve economic productivity in Australia from the many people living with or caring for type 1 diabetes.

Yours sincerely,
Duncan Read

30 August 2023

My recommendations in full

My observations and recommendations from over three decades of lived experience will help Australia raise its game in the treatment and management of type1 diabetes. Please consider them and contact me if you'd like any further discussion or information.

Observations from lived experience

People with type 1 diabetes are all different, but all of us want to think less about what we need to do to manage diabetes each day.

Healthy people living with type 1 diabetes contribute to society and the economy more when we are happy and healthy

Language and literacy about type 1 diabetes is critical to good physical and mental health

Recommendation

- 1. Change policy and regulation to give people in Australia faster access and greater choice of global models of care, drugs and medical devices that help living with and caring for type 1 diabetes easier
[Term of reference #05 – Effectiveness of policy and programs]*
- 2. Reset the discussion on cost of care to one about investing in things that help people with type 1 diabetes think less about their condition each day, so they can contribute more to society and the economy. Loads of us do already (see list at Attachment 1).
[Term of reference #03 – Impact on the economy]*
- 3. Encourage the exploration of positive language in research, media and type 1 diabetes education programs, especially as you shape future investment and changes to models of care, research and policy. This will flow on to positive outcomes and better mental health in children and carers.
[Term of reference #02 – Evidence based advances in managing diabetes]*

Attachment 1.

When considering the return on investment to support type 1 diabetes research, education and healthcare, please spare a thought for the hundreds of people who show that giving people with type 1 diabetes the chance to live the lives they want to live can contribute huge social, sporting, business and economic good.

This list is taken from publicly available information:

- Theresa May- Prime Minister of Great Britain
- Sir Stephen Redgrave- Five-time Olympic gold medallist
- Halle Berry - actress
- Peter O'Toole - actor
- Gary Mabbutt MBE- Tottenham Hotspur and England
- Lara McSpadden- Australian Women's National Basketball League
- Sam Reid - Greater Western Sydney Giants AFL
- Verity Charles - West Coast Fever netball
- Nick Jonas - singer, Jonas Brothers
- Sarah Klau - Australian Diamonds and NSW Swifts netball
- Rob Palmer - TV presenter and celebrity
- Brett Stewart - Australia and Manly Sea Eagles rugby league
- Rod Kafer- Australian Wallaby rugby union
- Duncan Read – Ultra marathon runner, team sport, business leader, and dad.

People with type 1 diabetes can be fitter for having it. But the deck is currently stacked against a lot of us. You can find more lived experience at <https://www.fitterforhavingit.com/>