

Kiwis suffering health issues after Covid-19 vaccination want to be heard, but it's complicated



MONIQUE FORD/Stuff

Despite being diagnosed with pericarditis after receiving two doses of the Covid-19 vaccine, Wendy is not anti-vax.

When Wendy* scales back her medication it hurts to breathe. Walking too far can be painful; even doing everyday tasks like putting out the washing or vacuuming is off the cards.

The 44-year-old mother-of-three isn't anti-vax. Despite being diagnosed with pericarditis after receiving two doses of the Covid-19 vaccination, she's trying to figure out how and when she'll be able to get her booster.

The Wellingtonian still wholeheartedly believes the vaccine has served the vast majority of New Zealanders well, and the message from the Government and health officials stands: get vaccinated – it's the best thing you can do to protect yourself and others.

"In this period, public health messaging has been one of the most important things we have had - if not the most important thing we have," Wendy says. "But it's a public health message that bypasses the individual."

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* [Covid-19: Is it dangerous to exercise after your vaccine booster?](#)

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Immunologist Dr Maia Brewerton discusses side effects of the Covid-19 vaccination in a discussion with Roxie Mohebbi for Stuff's Whole Truth project.

[Pericarditis](#) – inflammation of the tissue forming a sac around the heart – is a known, very rare side effect of the Pfizer vaccine. [Myocarditis](#) is the inflammation of the heart muscle.

These conditions are treatable, and in most cases they're mild and short-lived. The sooner you start treatment, the better the outcomes.

Covid-19 is [more likely to cause myocarditis/pericarditis than the vaccine](#) – there's almost four-times higher risk – and the risk of [Covid-19 far outweighs the risk of the vaccine](#).

But those numbers are not much comfort to the small group of Kiwis suffering from this rare side effect.

ALDEN WILLIAMS/Stuff

The Covid-19 vaccine is overwhelmingly safe and effective. More than four million Kiwis over the age of 12 have had two doses of Covid-19 vaccine. Most people experience no adverse event after vaccination.

Wendy is one of a [growing group](#) of New Zealanders [sharing their experience](#) of [adverse responses](#) in the mainstream media, in the hope of being heard, acknowledged and supported.

Last week, a 35-year-old Wellington builder [shared his experienced of being diagnosed with pericarditis](#) after receiving the vaccine. Since having his first dose of the Pfizer vaccine, he's been to hospital about a dozen times. Like Wendy, he's struggled to be heard and get the support he feels he needs.

The discussion isn't an easy one to have. It's a balancing act.

[More than four million Kiwis over the age of 12](#) have had two doses of the Covid-19 vaccine. Most people experience no adverse event after vaccination. Those who do usually experience a mild and temporary reaction.

The 10.9 million doses administered in New Zealand have saved lives, and helped the country avoid the large-scale infections experienced by other populations. And [UK research shows](#) those who've been fully vaccinated are about half as likely to develop long Covid, or long-lasting Covid-19 symptoms.

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Stuff's Whole Truth project has published more than 50 articles examining misinformation about the Covid-19 vaccine. These are the most common themes. (English subtitles.)

[But there are risks](#) – as with any vaccine or medication.

So far, [ACC has accepted 987 claims for vaccine related injuries](#) – 0.009 per cent of the total doses administered.

Among those accepted claims [there are 77 for cardiac injuries like myocarditis or pericarditis](#). And at March 31, a total of 783 reports of myocarditis or pericarditis had been [reported by people after vaccination](#).

Both of these things can be true: the data shows the vaccine is [safe and effective for the vast majority of people](#); meanwhile, some people experience adverse reactions after the vaccine – either directly or indirectly related to the vaccine.

People like Wendy say that in the fight to get the country vaccinated, and counter anti-vax rhetoric and misinformation, the second truth hasn't been properly heard or acknowledged.

For the most part, government officials, healthcare professionals, the media, and some of those who've experienced adverse reactions, have avoided having this conversation – until now.

"I have plenty of people to talk to. But nobody who's had my experience, and that's very isolating," she says.

While the Government says support is available for those unlucky few who have experienced an adverse reaction to the vaccine, those who spoke to *Stuff* say that's not their experience.

Christel Yardley/Stuff

New Zealand and global data continues to show that Covid-19 vaccines are safe for the vast majority of people. But the small group who do have an adverse reaction say there is a lack of acknowledgement, information and support.

Wendy developed chest pain soon after her first dose of the Pfizer vaccine – her chest felt tight, then it hurt to breathe, walk, lie down. Eventually it subsided, but returned after her second dose in December. She's still experiencing the symptoms, four months on.

Despite her diagnosis, the Ministry of Health denied Wendy's request for a [temporary vaccination exemption](#)

while she [waited for her symptoms to subside, and to ensure the right booster was available](#) to her. If the vaccine mandates were still in place, her lack of exemption could have impacted her job as a teacher.

“It’s easy to feel like there’s nobody who understands, or no health professional who has the answers,” she says.

9NEWS

“Somebody had a real event after receiving the vaccination, and that needs to be recognised, acknowledged, and responded to,” Immunisation Advisory Centre director Professor Nikki Turner says.

University of Auckland’s director of the Immunisation Advisory Centre, Professor Nikki Turner, says individuals have a range of individual responses post-vaccination.

These could be something like a sore arm, or something rare and more serious like myocarditis or pericarditis.

Then there are a range of responses that may or may not be caused by the vaccine, such as tinnitus, migraines, and ongoing heart palpitations. Some of these responses could be due to anxiety related to needles, or to a fear of vaccination, Turner says.

The mandates added another layer. In this environment, those who were anxious, uncertain or against getting the vaccine may have been more likely to experience adverse reactions after receiving their jab.

Regardless of the response, or whether it was caused by the vaccine, those people should be treated with respect and compassion, she says.

“Somebody had a real event after receiving the vaccination, and that needs to be recognised, acknowledged, and responded to.”

Ross Giblin/Stuff

There are online forums riddled with conspiracy theories, misinformation, anti-vaccination statements, fear and grief. This spilled over into the real world, when protesters occupied Parliament grounds for more than three weeks.

When people don't feel heard and supported by the health system, they seek acknowledgement elsewhere. Some have become vulnerable to capture by those pushing an anti-vax agenda.

You don't have to go far to find Facebook groups and websites dedicated to those who've experienced some kind of event after receiving their vaccination. Some of these are pages riddled with conspiracy theories, misinformation, anti-vaccination statements and fear.

On April 11, [the Ministry of Health was notified of the third death](#) considered by safety monitoring officials to be linked to the Pfizer [Covid-19](#) vaccine.

The teenager had myocarditis at the time of their death in December. However, [there was not enough information at the time](#) to determine the potential role of the vaccine.

[In talking about the death](#), Director-General of Health Dr Ashley Bloomfield shared a message from the teen's family: "One thing I do want to say is the family was very clear that they didn't want this death, this unfortunate and very sad death, to in any way put people off from being vaccinated or to be used by groups to try and undermine vaccination efforts in New Zealand."

But in the days since, the teen's death has been weaponised – held up by some as a sort of proof of extremist conspiracies.

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Sanjana Hattotuwa, an independent researcher who works on The Disinformation Project, says countries with high-trust societies are struggling to get to grips with the erosion of social cohesion.

Sanjana Hattotuwa, an independent researcher who works on The Disinformation Project, says experiences and data relating to vaccine-related harm are increasingly being instrumentalised by anti-vax groups.

They prey on people who've had [bad experiences with health services, authority](#), or who are vulnerable due to fear or grief.

Anti-vaccination conspiracy theories were a feature long before this pandemic, but things have escalated.

"We should have known ... We knew what other countries had gone through ... I don't think the health agencies,

institutions and ministries fully appreciated the instrumentalisation of the content they were putting out," Hattotuwa says.

"The broader struggle for countries with high-trust societies is [trying to get to grips with the erosion of social cohesion and trust](#). That has occurred at a pace where countries and institutions simply haven't kept pace."

Amid the infowar surrounding the pandemic, official data has also been misconstrued or intentionally misrepresented by some groups.

In the case of adverse reactions, the [Medsafe adverse events following immunisation reports](#) have been used as fodder by the anti-vaccination crowd.

[In a comprehensive written statement](#), Ministry of Health group manager of pharmacovigilance, vaccine effectiveness and population protection Dr Tim Hanlon talks about the range of messages and caveats in the Medsafe reports, which contextualise the data, and steer people to trusted sources of information.

[The Medsafe reports](#) advise people not to make any decisions about vaccination based on information contained in the report, and instead say any questions or concerns about receiving a vaccine should be raised with a healthcare professional.

Within the report there are statements like: "the protective

benefits of vaccination against Covid-19 far outweigh the potential risks of vaccination”.

It provides stats to back up this statement. And it notes that a report can be submitted for any cause and is not necessarily associated with the vaccine.

Hanlon says the ministry has proactively communicated safety data as it becomes available, and the way the report is presented has change throughout the pandemic, based on feedback and the practices in other countries,

For example, the Medsafe reports now include the expected versus observed analysis, where the expected number of reports for something like pericarditis are placed alongside the actual number of received reports.

The Covid-19 Vaccine Independent Safety Monitoring Board has also provided expert advice on the safety of the vaccines, and there have been [some proactive media releases](#) from the ministry to communicate information around the safety of the vaccines.

But for those with a limited degree of science literacy, or pre-existing fear or mistrust, these messages and caveats may not go far enough to counter either [unwitting or deliberate misinterpretation](#).

Immunisation Advisory Centre’s Turner says this is not a good enough reason to restrict the flow of information to the public.

"I'm very much in favour of us as a country learning how to do critical appraisal and understand science, not just assume that people can't figure it out."

She acknowledges the presence of a group that's created an industry out of anti-vax misinformation.

"But the answer isn't to start covering up that data. It's to start calling out those people."

[Almost 1 million eligible Kiwis have not yet received their booster shot.](#) Ministry of Health group operations manager for the national immunisation programme Rachel Mackay says some of those people just haven't got around to it yet.

But research by the ministry shows the main barriers for people who say they won't get the booster is because of concerns about the possible long-term and immediate side effects, Mackay says.

Jericho Rock-Archer

Dr Graham Le Gros – the Wellington-based executive director of the Malaghan Institute and head of the Vaccine Alliance Aotearoa New Zealand – thinks it'll take 10 years to get a good understanding of trends, and complete risk profiles.

Dr Graham Le Gros – the Wellington-based executive director of the Malaghan Institute and head of the Vaccine Alliance Aotearoa New Zealand – says New Zealand has a good system for reporting events possibly related to vaccinations, and a high level of engagement from the public and healthcare professionals.

This means trends are quickly identified and information on any emerging risks is proactively released to healthcare professionals and the public.

But Le Gros thinks it'll take about 10 years to get a complete understanding of all the specific risks that come with the vaccine – as is the case with all new vaccines and treatments.

“We still don't know enough about the vaccine and what it can do to the great variety of human beings we have in this country.”

Worldwide, more than 11.4 billion doses of Covid-19 vaccines have been administered. Countries are continuously monitoring any side effects, allergies or adverse reactions, which is constantly adding to the global understanding of how people react to the vaccines.

And, in New Zealand, [there is a new national study](#) to find out if people who developed myocarditis or pericarditis following the Covid-19 Pfizer vaccination had long-term health problems.

Matt Rourke/AP

More than 11.4 billion doses of Covid-19 vaccines have been administered throughout the world. They've saved lives, and are overwhelmingly safe.

Wendy says she doesn't know how the Government or public health officials could have done things differently, or exactly how they should change their messaging to

acknowledge the experiences of people like her.

But she wants information to be readily available to health professionals as well as consumers; she wants support; and she wants to feel heard.

Not just heard by the healthcare professionals she interacts with, but heard by the Director-General of Health Dr Ashley Bloomfield, and the Government.

**Wendy is not her real name. Stuff has agreed not to identify her due to concerns her identity could be used by anti-vaccination groups to further their agenda.*

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