

Submission to the Government COVID-19 Response Inquiry

We are the [REDACTED] surviving children of the late [REDACTED]. Our names are [REDACTED] and [REDACTED]. We write to inform the Inquiry of our experience during the COVID-19 pandemic. This experience was deeply traumatic and has ongoing negative repercussions upon our wellbeing.

Our mother received the AstraZeneca vaccine on [REDACTED]. She did so not only for her own protection but equally out of a sense of duty. Our mother felt it her responsibility to be vaccinated to reduce the impact of COVID-19 on her community, potentially saving the lives of others. In a cruel twist of fate, this decision ultimately led to her death.

[REDACTED] passed away on the [REDACTED] as a result of the vaccine (as certified by her attached death certificate). Shortly after receiving her first dose of Astra Zeneca, our mother developed Guillain-Barre Syndrome as a direct adverse reaction (as certified by the attached death certificate). This is a condition whereby one's immune system attacks the nervous system. The condition caused paralysis from the neck down, extreme pain not treatable with painkillers, and sporadic hallucinations that severely challenged her grip on reality. After enduring these symptoms for 6 weeks, [REDACTED] passed away.

This experience has been immensely traumatic for the family. Our mother's time in hospital was one of intense physical and emotional suffering. We put our lives on hold to support her – missing paid work and being unavailable to [REDACTED]. Our mother died without meeting her newly born [REDACTED] granddaughters, who she was so excited to meet. [REDACTED] lives with disability and was a dependent on [REDACTED]. Her mother's death meant she had to find a new home while processing her trauma and grief, which is ongoing for all of us.

Despite our mother's experience we are not anti-vaccination, in fact we are all fully vaccinated. We understand the very low chance of illness or death due to the COVID-19 vaccinations. While this knowledge gave us the courage to be vaccinated, it is also a source of great distress. To have our mother taken from us due to such a rare occurrence is difficult to accept and incredibly painful. This has not been sufficiently acknowledged by the government.

We found the government's response to people in our situation to be inadequate and, at times, insensitive. We have been an afterthought to the vaccination process. We must repeatedly tell our story to stakeholders to gain recognition, support, and compensation for our emotional and financial losses, thus reliving the trauma over and over again. All this while rebuilding our lives without our mother, who was the keystone to our lives. This lack of support is unacceptable because [REDACTED] death was a direct consequence of the vaccination rollout. The Government has a responsibility to the small minority harmed by COVID-19 vaccines. It should provide adequate financial, administrative, and mental health support for families of those suffering adverse reactions, and compensation that adequately addresses both suffering and loss of life.

Response to Criteria:

Governance including the role of the Commonwealth Government, responsibilities of state and territory governments, national governance mechanisms (such as National Cabinet, the National Coordination Mechanism and the Australian Health Protection Principal Committee) and advisory bodies supporting responses to COVID-19.

The government strongly urged eligible citizens to be vaccinated. At the time, our mother could only access Astra Zeneca, which caused a fatal adverse reaction. There was insufficient supply of alternatives. People over 60 were told Astra Zeneca was safe for their age group. Several cases of severe adverse reaction to Astra Zeneca had already been made public when [REDACTED] received the

vaccine. We believe that, if available, our mother would have chosen a different vaccine that may have been safer. Nonetheless, our mother trusted government advice that the vaccine was safe, a fact that in the larger sense we do not dispute.

Safe vaccines, however, do harm or cause death for a very small minority. The government strongly urged everyone eligible to receive a COVID-19 vaccine and knew a small number of adverse reactions would occur. It is the government's responsibility to care for these people. Sufficient compensation and also administrative, mental health, and financial support should be provided for those currently affected and in future pandemic vaccination programs. This should be relatively inexpensive and easy to administer given the tiny number of adverse reactions.

Broader health supports for people impacted by COVID-19 and/or lockdowns (for example mental health and suicide prevention supports, and access to screening and other preventive health measures).

Our family still suffers from the mental health impacts of our mother's death. We have had to seek help independently at our own personal cost. We must continually recount our story to different health care providers and thus relive the trauma. This exacerbates physical and mental health symptoms. Additionally, we are often disbelieved when explaining the cause of our mother's death. To receive treatment for heart palpitations connected to trauma and grief, [REDACTED] had to change medical clinics because medical staff disbelieved her and generally made her feel like a crazy antivaxxer – this was incredibly distressing. Finding alternative care was difficult as she lives in [REDACTED] area with limited medical facilities. [REDACTED] requested a document from the government to certify the cause of our mother's death but was told to ask her GP, who in this case was the source of the problem.

What is currently needed, and what should be provided in future pandemics, is a specific case manager to help those affected by adverse vaccine reactions. This case manager should in the first instance be an advocate while the afflicted is in hospital. We had to fight tooth and nail for quarantine restrictions to be eased so that we were able to be with our mother in her final hours. This should not be our responsibility. In the event of death, this case manager should facilitate access to mental health support and help navigate the compensation process.

Financial support for individuals (including income support payments).

Our mother's illness and eventual death also drained our personal finances as we put aside everything to support her. [REDACTED] of us forewent paid work to be with her. Pandemic quarantine restrictions made visits by extended family and friends impossible, and we did not want her to face this ordeal alone. [REDACTED] came from [REDACTED] at his own expense, missing work and leaving his [REDACTED] who was suffering [REDACTED] depression, to care for their recently born [REDACTED]. [REDACTED] spent most of her time with [REDACTED] or advocating for medical care, missing work and barely seeing her [REDACTED]. The compensation scheme does not cover loss of income or mental health expenses for families of those who die because of a COVID-19 vaccine. [REDACTED] and [REDACTED] still experience heart palpitations that are frightening, difficult to treat, and which curtail the hours they can work. These expenses should be compensated given they are a consequence of the vaccine rollout program.

We would also like to express our dissatisfaction with the COVID-19 Vaccine Claims Scheme on the following grounds:

- The Non-Dependent Lump Sum Payment of \$70,680.00 for deaths resulting from the vaccine is shockingly low. While it is difficult to place numerical value on a life, this does not come close and is well below comparable standards. This low figure makes us feel that the government does not really value our mother's sacrifice or recognise our loss.

- Compensation covers either Pain and Suffering or Death, but not both – payment for Pain and Suffering is subtracted from compensation for death. We find this insensitive and insulting. The implication is that pain and suffering has no meaning once one has died and is thus unworthy of compensation. Our mother suffered greatly in the 6 weeks before her death. She was paralysed from the neck down, in such pain that being moved by staff caused screams of agony, and had intense hallucinations that severely afflicted her sense of reality. Now that she has died, this suffering has no value according to the current policy. This feels callous, and is quite galling considering that compensation for both Pain and Suffering and Death would be relatively inexpensive given the few people who die from adverse reactions.
- There should be more assistance with compensation claims. Families should be contacted by government representatives to be made aware of the claims scheme and then assisted throughout the process. We wonder how many families have gone uncompensated because they are unaware of the scheme. We have finally submitted our claim over 2 years after our mother's death because we were overwhelmed by the process and needed questions answered. [REDACTED] was promised assistance after contacting her local member and State and Federal Health Ministers but only received an initial phone call and a few emails. Exasperated by this, we contacted [REDACTED] to tell our mother's story and highlight the government's inadequate response. [REDACTED] This [REDACTED] prompted contact from Services Australia but no meaningful assistance. It took another approach to the federal health minister via [REDACTED] local member to receive answers to our questions and sufficient help with our claim.

Mechanisms to better target future responses to the needs of particular populations (including across genders, age groups, socio-economic status, geographic location, people with disability, First Nations peoples and communities and people from culturally and linguistically diverse communities).

[REDACTED] receives a disability pension and has complex health needs. Our mother's death meant she needed to find new housing and may have ended up homeless without the help of her immediate family. People with disabilities have the right to live with dignity and participate actively in their own lives – the government response did not address this or ensure this happened. A case manager should have been assigned to the family, with a particular responsibility to assist [REDACTED] through this difficult and stressful process. A dedicated case manager should also have been available to help [REDACTED] obtain her third vaccination dose. Given our mother's experience, she did not want to receive Astra Zeneca. She approached several healthcare professionals and was informed that she had no choice. [REDACTED] then stepped in and eventually arranged for someone to come to her home and administer a different vaccine. To achieve this, [REDACTED] had to again recount her story to multiple stakeholders, exacerbating her heart palpitations and psychological distress.

Documentation:

We have attached the following documentation to substantiate and provide more detail to our story:

1. A copy of our mother's official death certificate
2. A timeline of events related to our mother's death and our experience since
3. Examples of relevant email correspondence
4. Examples of relevant official letters received

[REDACTED]