IN THE CORONERS COURT
OF VICTORIA
AT MELBOURNE

Court Reference: COR 2025 007876

FINDING INTO DEATH WITHOUT INQUEST

Form 38 Rule 63(2)
*Section 67 of the **Coroners Act 2008***

Findings of:	Deputy State Coroner Paresa Antoniadis Spanos
Deceased:	TPK
Date of birth:	2019
Date of death:	11 November 2025
Cause of death:	1(a) Complications of Pelizauez-Merzbacher disease
Place of death:	Victoria
Key words:	Pelizauez-Merzbacher disease, Long-term Care Order, person placed in custody or care

INTRODUCTION

1. On 11 November 2025, TPK was six years old when he died at home. At the time, TPK lived with his foster parents, Mr and Mrs JEP.

2. At birth, TPK was diagnosed with Pelizauez-Merzbacker Disease (**PMD**), which is a neurodegenerative leukodystrophy that causes progressive neurological symptoms, severe disability, and seizures. TPK had profound developmental delay and developmental regression in keeping with his underlying diagnosis. He also had gastro-oesophageal reflux disease, hypomyelination, and vocal cord paralysis.

3. TPK was the third child to his parents. He was a planned pregnancy and all pre-birth appointments and planning had occurred. His parents were unaware of his condition until birth. At this time, TPK's parents decided they were unable to provide the complex care he needed and so worked with the Department of Families, Fairness and Housing (**DFFH**) for the purpose of adoption by parental consent. DFFH's aim was for TPK to be placed within a family.

4. In February 2020, TPK was discharged from the Royal Children's Hospital (**RCH**) to his foster parents, Mr and Mrs JEP.

5. In July 2020, TPK's parents consented to his adoption, which was legally finalised later that month with CatholicCare Victoria, a community service organisation registered for Permanent Care and Adoption Support, becoming TPK's guardian.

6. In October 2021, the Secretary of the Department of Justice and Community Safety (**DJCS**) became TPK's guardian.

7. In November 2021, CatholicCare indicated they were unable to identify a permanent adoptive home for TPK. This in turn impacted TPK's guardianship, which was due to expire on 5 April 2022. As a consequence, Child Protection (part of DFFH) became involved to address TPK's safety and care needs.

8. In March 2022, a Care by the Secretary Order was made with a permanency objective of long-term out of home care. This order was granted for two years.

9. On 18 April 2024, a Long-term Care Order was made pursuant to the *Children, Youth and Families Act 2005* (Vic), which conferred parental responsibility for TPK's care to the Secretary of the DFFH until the age of 18 years.

10. Mr and Mrs JEP had three adult children. They have admirably fostered 140 children over two decades.

11. Mrs JEP stated that TPK became part of their family. He was doted on by their children and grandchildren and had much joy and laughter around him. He loved to be outside and responded fondly to birds and their pet dog and cat. He also loved watching TV from his wheelchair. His favourite shows were Coco Melon and Bluey. Mrs JEP stated, *"We gave him the best life we could."*

12. Mr and Mrs JEP met all of TPK's complex care needs with the assistance of Mackillop Family Services. TPK also had a medical care team, which included a Paediatrician, Palliative Care, NDIS, Kids Plus (including Occupational Therapy, Play Therapy, Physiotherapy, and Speech Therapy), Child Protection, and the MacKillop Family Services Home Based Care Program.

13. According to Associate Professor (**A/Prof**) David Fuller, Consultant Paediatrician at Barwon Health, TPK had multiple admissions to Barwon Health Paediatric Unit for a range of issues including respiratory issues (including aspiration), infection and reduced conscious state, pain management, and feed intolerance. He had escalating problems with pain, feeding, seizures, and with his bowels and required escalating medications to manage pain and seizures.

14. A/Prof Fuller noted that over the course of his lifetime, TPK had a fluctuating conscious state and at times of illness was regularly deeply unconscious, before bouncing back to a more awake state. TPK had never been verbal. At his best he was smiling, interactive, and laughing, with some understanding of spoken language. However, as his illness progressed and his pain relief regime shifted to requiring subcutaneous administration of medication, TPK's conscious state became more commonly reduced.

15. In 2024, TPK took part in a trial of medicinal cannabis for palliative care patients through the Murdoch Children's Research Institute. He responded well to the treatment and continued to receive medicinal cannabis on a compassionate basis via the RCH pharmacy.

THE CORONIAL INVESTIGATION

16. TPK's death was reported to the Coroner as it fell within the definition of a reportable death in the *Coroners Act 2008* (**the Act**). Generally, reportable deaths include deaths that are unexpected, unnatural or violent, or result from accident or injury. However, if a person

satisfies the definition of a person placed in care immediately before death, the death is reportable even if it appears to have been from natural causes.[1] [2]

17. The role of a coroner is to independently investigate reportable deaths to establish, if possible, identity, medical cause of death, and surrounding circumstances. Surrounding circumstances are limited to events which are sufficiently proximate and causally related to the death. The purpose of a coronial investigation is to establish the facts, not to cast blame or determine criminal or civil liability.

18. Under the Act, coroners also have the important functions of helping to prevent deaths and promoting public health and safety and the administration of justice through the making of comments or recommendations in appropriate cases about any matter connected to the death under investigation.

19. The Victoria Police assigned an officer to be the Coronial Investigator for the investigation of TPK's death. The Coronial Investigator conducted inquiries on my behalf, including taking statements from witnesses – such as family, the forensic pathologist, treating clinicians and investigating officers – and submitted a coronial brief of evidence.

20. This finding draws on the totality of the coronial investigation into TPK's death, including evidence contained in the coronial brief. Whilst I have reviewed all the material, I will only refer to that which is directly relevant to my findings or necessary for narrative clarity. In the coronial jurisdiction, facts must be established on the balance of probabilities.[3]

MATTERS IN RELATION TO WHICH A FINDING MUST, IF POSSIBLE, BE MADE

Identity of the deceased

21. On 11 November 2025, TPK, born 2019, was visually identified by his medical practitioner, Jill Carter, who signed a formal Statement of Identification to this effect.

22. Identity is not in dispute and requires no further investigation.

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[1] See the definition of "reportable death" in section 4 of the *Coroners Act 2008* (**the Act**), especially section 4(2)(c) and the definition of "person placed in custody or care" in section 3 of the Act.
[2] TPK was considered to be 'in care' by virtue of the Long Term Care Order.
[3] Subject to the principles enunciated in *Briginshaw v Briginshaw* (1938) 60 CLR 336. The effect of this and similar authorities is that coroners should not make adverse findings against, or comments about, individuals unless the evidence provides a comfortable level of satisfaction as to those matters taking into account the consequences of such findings or comments.

Medical cause of death

23. Forensic Pathologist, Dr Joanne Ho, from the Victorian Institute of Forensic Medicine (**VIFM**), conducted an inspection on 13 November 2025 and provided a written report of her findings dated 25 November 2025.

24. The post-mortem examination was consistent with the medical history.

25. Dr Ho provided an opinion that the medical cause of death was *"1(a) Complications of Pelizauez-Merzbacher disease"*.

26. I accept Dr Ho's opinion.

Circumstances in which the death occurred

27. TPK's presentation steadily declined in the months preceding his death. Mrs JEP stated that in the last 12 months of his life, TPK's pain began to increase. She recalled, *"He lost emotion and his energy was drained. He began sleeping during the day which he never did before. Sometimes he would only wake for an hour."*

28. A/Prof Fuller noted that during the last six months of his life, TPK had increasing pain as well as reduction in food tolerance, which indicated emerging gut failure. This necessitated reduction in TPK's enteral feeding and he became progressively weaker as a result of his PMD as well as his reduced feed tolerance.

29. On 20 October 2025, TPK was admitted to University Hospital Geelong with fever and reduced urine output. His treating team discussed the utility of enteral antibiotics at this time. Dr Sidharth Vemuri, Consultant in Paediatric Palliative Medicine at RCH, stated that there was discussion amongst the treating teams that antibiotics would risk prolonging TPK's life without reducing his suffering nor promoting his comfort and would not be in keeping with his goals of care.

30. On 21 October 2025, TPK was discharged home with the support of the Barwon Health community palliative care team. Mrs JEP stated they brought TPK home and kept him comfortable.

31. Later that month, in response to TPK's escalating distress and irritability at home despite reduction in his continuous feeds, TPK was commenced continuous subcutaneous infusions of methadone, midazolam and metoclopramide, with provision for breakthrough doses of

subcutaneous hydromorphone, midazolam and methadone, and buccal clonazepam, which were titrated as needed.

32. The Barwon Health community palliative care team and Victorian Paediatric Palliative Care Program continued frequent contact during TPK's last weeks to keep him as comfortable as possible.

33. TPK subsequently passed away in Mrs JEP's arms on the morning of 11 November 2025.

34. Penny Tripoli, General Manager Barwon and Wimmera Southwest, MacKillop Family Services, noted that TPK had defied his limited life expectancy and stated that this was a testament to the unwavering love and high-quality care provided by Mr and Mrs JEP. A/Prof Fuller and Dr Vemuri echoed these sentiments.

FINDINGS AND CONCLUSION

35. Pursuant to section 67(1) of the Act I make the following findings:

    (a) the identity of the deceased was TPK, born 2019;

    (b) the death occurred on 11 November 2025 in Victoria;

    (c) the cause of TPK's death was s complications of Pelizauez-Merzbacher disease; and

    (d) immediately before death, TPK was a *"person placed in custody or care"* as defined in section 4 of the Act;

    (e) I consider the cause of TPK's death was due to natural causes for the purposes of section 52(3A) of the Act; and

    (f) the death occurred in the circumstances described above.

36. I convey my sincere condolences to TPK's biological and foster family and community for their loss. I acknowledge the dedicated care, love, and support Mrs and Mrs JEP provided to TPK, the support workers who supported his placement and the treating medical teams.

DIRECTIONS

37. Pursuant to section 73(1B) of the Act, I order that a de-identified version of this finding be published on the Coroners Court of Victoria website in accordance with the rules.

38. I direct that a copy of this finding be provided to the following:

Mr and Mrs JEP, senior next of kin

Barwon Health

Secretary, Department of Families, Fairness and Housing

Commission for Children and Young People

Senior Constable Fiona Nation, Victoria Police, Coronial Investigator

Signature:

Deputy State Coroner Paresa Antoniadis Spanos

Date: 7 August 2026

NOTE: Under section 83 of the ***Coroners Act 2008*** ('the Act'), a person with sufficient interest in an investigation may appeal to the Trial Division of the Supreme Court against the findings of a coroner in respect of a death after an investigation. An appeal must be made within 6 months after the day on which the determination is made, unless the Supreme Court grants leave to appeal out of time under section 86 of the Act.