IN THE CORONERS COURT
OF VICTORIA
AT MELBOURNE

COR 2024 004859

FINDING INTO DEATH WITHOUT INQUEST

Form 38 Rule 63(2)

Section 67 of the ***Coroners Act 2008***

Findings of:	Judge John Cain, State Coroner
Deceased:	Ivy McGowan
Date of birth:	19 November 1994
Date of death:	5 October 2023
Cause of death:	1(a) Cerebral x-linked adrenoleukodystrophy
Place of death:	706/45-55 Dudley Street West Melbourne Victoria 3003
Keywords:	Specialist Disability Accommodation resident, supported independent living, disability support, reportable deaths, natural causes

INTRODUCTION

1. On 5 October 2023, Ivy McGowan was 28 years old when she passed away at her home in West Melbourne. At the time of her death, Ms McGowan was a National Disability Insurance Scheme (**NDIS**) participant. She received funding to reside in a Specialist Disability Accommodation (**SDA**) enrolled dwelling[1] provided by the then-Department of Health and Human Services. Ms McGowan was receiving these supports due to her diagnosis of cerebral x-linked adrenoleukodystrophy. Her medical history also included pulmonary embolism, neuropathic pain, recurrent urinary tract infections, and Addison's disease.

2. Ms McGowan enjoyed doing project-based contract work twice per week and volunteering once a week. She also enjoyed spending time with family and friends, reading, creating collages, listening to music and attending shows.

THE CORONIAL INVESTIGATION

3. Ms McGowan's death fell within the definition of a reportable death in the *Coroners Act 2008* (**the Act**) as she was a 'person placed in custody or care' within the meaning of the Act, as a person receiving funding for Supported Independent Living (**SIL**) and residing in an SDA enrolled dwelling immediately prior to her death. This category of death is reportable to ensure independent scrutiny of the circumstances leading to death given the vulnerability of this cohort and the level of power and control exercised by those who care for them. The coroner is required to investigate the death, and publish their findings, even if the death has occurred as a result of natural causes.

4. 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.

[1] SDA enrolled dwelling is defined under the *Residential Tenancies Act 1997* (Vic). The definition, as applicable at the time of Ms McGowan's death, is a permanent dwelling that provides long-term accommodation for one or more SDA residents, that is enrolled as an SDA dwelling under relevant NDIS (Specialist Disability Accommodation) Rules in force at the relevant time. An SDA resident means a person who is an NDIS participant funded to reside in an SDA enrolled dwelling, or who receives continuity of supports under the Commonwealth Continuity of Support Program in respect of specialist disability services for older people (from 1 July 2021, the Disability Support for Older Australians program). The definition of SDA resident was amended on 1 July 2024 pursuant to the *Disability and Social Services Regulation Amendment Act 2023* to extend to include persons who are residing, or propose to reside, in an SDA dwelling under an SDA residency agreement or residential rental agreement.

5. 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.

6. This finding draws on the totality of the coronial investigation into the death of Ivy McGowan, including information from the National Disability Insurance Agency (**NDIA**) and the NDIS Quality and Safeguards Commission, as well as a Medical Certificate Cause of Death (**MCCD**) completed by a medical practitioner at Equinox Gender Diverse Health Centre. 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.[2]

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

Circumstances in which the death occurred

7. In late-2022, Ms McGowan experienced a significant increase in the symptoms of her neuropathic pain. She was referred to a palliative care team, who trialled various analgesia options including fentanyl patches, gabapentin, pregabalin and tapentadol, amongst other medications. Ms McGowan also updated her advanced care plan in January 2023. Her general practitioner (**GP**) noted at that time, Ms McGowan was experiencing some cognitive decline, however noted she was "*still in the living well section*". Over January 2023, Ms McGowan also experienced significant anxiety, and she was treated with oxazepam and later clonazepam to manage her symptoms.

8. Over the first-half of 2023, Ms McGowan's condition deteriorated, and she started to experience visual and auditory hallucinations, became very sensitive to noises and experienced a decrease in her cognition. She was prescribed quetiapine to manage her hallucinations, with some effect.

9. By September 2023, Ms McGowan's condition had deteriorated further, and her palliative care team provided a syringe driver to assist with management of her pain, in accordance with her advanced care directive. In early-October 2023, Ms McGowan experienced a significant

[2] 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.

decline in her condition, lost her vision and became very agitated. She opted to cease her regular medications and commence palliative care medications via a syringe driver. Ms McGowan passed away at home on 5 October 2023.

Identity of the deceased

10. On 11 October 2023, Ivy McGowan, born 19 November 1994, was identified by medical practitioner Dr Satu Simpson via review of medical records.

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

Medical cause of death

12. On 11 October 2023, medical practitioner Dr Satu Simpson reviewed Ms McGowan's complete medical history and completed a MCCD. Dr Simpson provided an opinion that the medical cause of death was cerebral x-linked adrenoleukodystrophy.

13. On 18 August 2024, a Medical Liaison Nurse (**MLN**) at the Victorian Institute of Forensic Medicine, reviewed the MCCD at my direction and confirmed that the cause of death was due to natural causes.

14. I accept Dr Simpson's opinion and am satisfied that the death was due to natural causes.

FINDINGS AND CONCLUSION

15. Pursuant to section 67(1) of the *Coroners Act 2008* I make the following findings:

    a) the identity of the deceased was Ivy McGowan, born 19 November 1994;

    b) the death occurred on 5 October 2023 at 706/45-55 Dudley Street West Melbourne Victoria 3003, from *cerebral x-linked adrenoleukodystrophy*; and

    c) the death occurred in the circumstances described above.

16. The available evidence does not support a finding that there was any want of clinical management or care on the part of the SIL provider that caused or contributed to Ms McGowan's death.

17. Having considered all the available evidence, I find that Ms McGowan's death was from natural causes and that no further investigation is required. As such, I have exercised my discretion under section 52(3A) of the Act not to hold an inquest into her death and to finalise the investigation of Ms McGowan's death in chambers.

I convey my sincere condolences to Ms McGowan's family, friends and carers for their loss, and acknowledge the distress caused by the delay in the reporting and investigation of Ms McGowan's death.

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

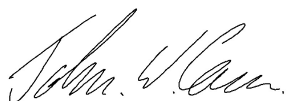
I direct that a copy of this finding be provided to the following:

Yolanda Maxwell, Senior Next of Kin

Enliven Housing Pty Ltd

Equinox Gender Diverse Health Centre

Signature:



Judge John Cain, State Coroner

Date: 08 January 2025

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.