IN THE CORONERS COURT
OF VICTORIA
AT MELBOURNE

COR 2022 000569

FINDING INTO DEATH WITHOUT INQUEST

Form 38 Rule 63(2)

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

Findings of:	Coroner Paresa Antoniadis Spanos
Deceased:	Ms OS[1]
Date of birth:	16 December 1970
Date of death:	28 January 2022
Cause of death:	1(a) Complications of Huntington's disease
Place of death:	Yooralla, Burwood East, Victoria, 3151
Keywords:	Huntington's disease; Natural causes; Yooralla

[1] The deceased's name has been de-identified in accordance with the family's wishes.

INTRODUCTION

1. On 28 January 2022, Ms OS was 51 years old when she was found deceased at home. At the time, Ms OS lived in a Yooralla disability assisted living facility in Burwood East.

2. Ms OS was born in 1970 and was the middle child of five children. After completing secondary school, Ms OS studied Arts at Latrobe University.

3. In the early 2000s Ms OS was diagnosed with Huntington's disease. At the time of her diagnosis, she remained relatively functional outside of increased depression, mood swings and tiredness. Huntington's disease is a rare progressive inherited neurodegenerative disease that causes the progressive degeneration of nerve cells in the brain. People diagnosed with the disease suffer abnormal movements, disturbed behaviour and cognitive decline. Respiratory issues and seizures are also common.

4. Throughout the 2000s into the 2010s Ms OS remained determinedly independent. She cooked and cleaned for herself and relied on public transport to travel. In 2014, Ms OS's condition progressed and on one occasion she was found on Chapel Street, Prahran displaying erratic behaviour. She was transported to hospital and subsequently stayed in a number of short-term assisted living accommodations.

5. In 2016, residency became available at the Arthur Preston assisted living facility in Burwood East and Ms OS was admitted. The facility specialised in providing living care for residents with progressive neurological disabilities including Huntington's disease. Operation of Arthur Preston was later taken over by Yooralla. Ms OS remained in this facility until her death.

6. In around 2017 Ms OS's condition progressed and she gradually became non-verbal. From this point onwards she relied on a light writer, an electronic communication tool, to communicate.

7. In the context of her Huntington's disease Ms OS suffered anxiety, depression and psychosis. In June 2021 Ms OS attended consultant psychiatrist Dr Brian Leung after multiple attempts to abscond from Yooralla and intermittent episodes of suicidal ideation. The evidence indicates Ms OS also struggled with the COVID-19 restrictions. On review,

she denied any active suicidal plans and indicated she still wished to live.[2] Dr Leung increased her dose of the anti-depressant, venlafaxine, and of her mood stabiliser, valproate.

8. Ms OS was next reviewed by Dr Leung in September 2021 and for the final time in December 2021. On these occasions Dr Leung noted a significant deterioration in Ms OS's cognition, communication and mobility consistent with the progression of Huntington's disease. There were no concerns regarding suicidality at this time, nor were there reports from Yoorolla staff regarding the same.

9. Ms OS's Huntington disease was managed primarily by Neurologist Dr Katya Kotschet in conjunction with General Practitioner (**GP**) Dr Chen Ming Lin of the Glenmount Medical Clinic. Her treating team also included an occupational therapist, speech therapist, physiotherapist, and a nutritionist. At the time of her death, Ms OS's medication regime included:

    i. Trimethoprim 300mg daily.
    ii. Mirtazapine 30mg at night.
    iii. Melatonin 2mg at night.
    iv. Clonazepam 1mg at night.
    v. Sodium valproate 100mg twice daily.
    vi. Lorazepam 1mg if required.
    vii. Propantheline bromide 15mg in the morning.
    viii. Risperidone 100 mg fortnightly.
    ix. Haloperidol 5mg twice daily.
    x. Temazepam 10mg at night if required.
    xi. Venlafaxine 37.5mg daily.

THE CORONIAL INVESTIGATION

10. Ms OS's death was reported to the Coroner as it fell within the definition of a reportable death in the *Coroners Act 2008* (the Act). Reportable deaths include deaths that are unexpected, unnatural or violent or result from accident or injury.
11. The role of a coroner is to independently investigate reportable deaths to establish, if possible, identity, medical cause of death, and surrounding circumstances. Surrounding

[2] Statement of Dr Brian Leung dated 15 August 2022.

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.

12. 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.

13. Victoria Police assigned First Constable Klay Patten to be the Coroner's Investigator for the investigation of Ms OS's death. The Coroner's 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.

14. This finding draws on the totality of the coronial investigation into the death of Ms OS 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

15. On 28 January 2022, Ms OS was visually identified by her brother-in-law, who signed a formal Statement of Identification to this effect.

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

Medical cause of death

17. Forensic Pathologist Dr Gregory Young, from the Victorian Institute of Forensic Medicine (**VIFM**), conducted an autopsy on Ms OS on 7 February 2022 and provided a written report of his findings dated 5 October 2022.

18. The post-mortem examination showed changes in the brain consistent with the known history of Huntington's disease, namely mild gyral atrophy; Caudate nucleus head atrophy

[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.

with severe neuronal loss and gliosis; and neuronal loss in the striatum, basal ganglia, thalami and hypothalamic.

19. Pulmonary oedema (a build-up of fluid in the lungs) was observed as were changes to the lungs attributable to chronic aspiration. Dr Young advised many people with Huntington's disease have dysphagia (difficulty swallowing) therefore increasing the risk of food aspiration.

20. There was no post-mortem evidence of any significant injuries which may have caused or contributed to death. The head and neck were unremarkable.

21. Routine toxicological analysis of post-mortem samples detected clonazepam[4] and its metabolite, venlafaxine[5] and its metabolite, mirtazapine[6], risperidone[7] and its metabolite, haloperidol[8] and valproic acid[9]. Dr Young opined the presence of these drugs did not cause or contribute to death.

22. Prior to autopsy, Dr Young was assisted by the initial police report into the death and medical records from the Glenmount Medical Clinic. Following the autopsy and prior to the provision of his report, Dr Young was assisted by further information provided by police that confirmed Ms OS slept with a blanket over her head, and that when she was found deceased a blanket was wrapped tightly around her head and neck.

23. With respect to his findings at autopsy and the known circumstances, Dr Young made the following comments:

> *This woman's death was likely due to respiratory failure in the setting of Huntington disease. Based on the autopsy findings, it is not possible to ascertain the role of the blanket over and around the deceased's head, in contributing to her death. Whilst this may have impeded her breathing, there was no evidence that it had caused compression of the neck. In addition, it is not possible to ascertain the role of any possible seizure in contributing to her death.*

24. Dr Young provided an opinion that the medical cause of Ms OS's death was *1(a) complications of Huntington disease.*

---

4 Clonazepam is a nitrobenzodiazepine indicated for the treatment of seizures
5 Venlafaxine is indicated for the treatment of depression. It is sold under the brand name Efexor
6 Mirtazapine is indicated for the treatment of depression.
7 Risperidone is an atypical (second-generation) antipsychotic drug.
8 Haloperidol is a butyrophenone derivative used therapeutically as an anti-psychotic agent.
9 Valproic acid (dipropylacetic acid, divalproex, sodium valproate) is indicated for epilepsy, and as an adjunct in mania and schizophrenia where other therapy is inadequate

25. I accept Dr Young's opinion.

Circumstances in which the death occurred

26. On 28 January 2022, Ms OS was home in her room at her supported residential facility. Throughout the day Ms OS was cared for by disability support worker Ms Belinda Murka. Records from Yooralla indicate Ms OS received her morning medications.

27. In the early afternoon Ms Murka delivered laundry to Ms OS's room. At the time Ms OS was in bed and greeted Ms Murka as she ordinarily would. Ms Murka believed Ms OS seemed her usual self. As Ms Murka left the room, Ms OS pulled her blanket up over her head which was not unusual as she was known to like sleeping in this way.

28. Ms Murka next entered Ms OS's room at 3.30pm when she assisted with toileting and cleaned Ms OS by rolling her over while she remained in bed. Mr Murka removed some dirty laundry and exited the room. This was the last time Ms OS was seen alive. Progress notes referred to as part of Yoorolla's Practice Review indicate that Ms OS's blanket was not above her head at this time.

29. At 4.35pm, registered nurse Mr Yuxuan Zhao entered Ms OS's room to administer her medications. Mr Zhao attempted to rouse Ms OS vocally but did not receive a response. It was not uncommon for Ms OS not to respond to verbal cues to wake her so Mr Zhao touched her elbows, neck, and shoulder area to wake her but without success.

30. At the time a blanket was wrapped around Ms OS's head. Mr Zhao stated the blanket was wrapped tighter than usual. He removed the blanket from around Ms OS's head and discovered that her eyes were open and dilated. Ms OS was not breathing and did not have a detectable pulse. Mr Zhao immediately called out to other staff members for assistance and lowered Ms OS to the floor.

31. Cardiopulmonary resuscitation (**CPR**) was commenced at 4.38pm and emergency services were called. An automated external defibrillator (**AED**) was applied. Ambulance Victoria paramedics arrived at around 4.48pm and briefly continued resuscitation efforts. Despite all efforts, Ms OS was unable to be revived and she was formally verified deceased at the scene at 4.52pm.

FURTHER INVESTIGATIONS

32. Following a review of the coronial brief and as part of my investigation, I obtained a statement from neurologist Dr Kotschet inviting input about Ms OS's' clinical management

over the 12 months prior to her death, the blanket found around Ms OS's head, and whether Ms OS may have taken action to bring about her own death.

33. Dr Kotschet advised she consulted Ms OS twice in the final 12 months of her life. In May 2021, it was noted that Ms OS was struggling with the change in her routine that resulted from the COVID-19 restrictions. Her mobility and motor function had deteriorated, she was increasingly unsteady and had some minor falls without injury. However, no suicidal ideation was reported.

34. Ms OS was reviewed for the final time by Dr Kotschet on 6 September 2021. Her mobility and stability had further decreased since the last review. Ms OS was still eating and sleeping well and there was no recorded recent suicidal ideation. In her statement, Dr Kotschet referred to Ms OS having a known history of spending time in her room with her face buried in her blankets.

Yooralla Internal Review

35. Following Ms OS's death, Yooralla conducted an internal review into her death. The review identified that Ms OS's death was unexpected to staff although her condition was steadily deteriorating.

36. Interviews with staff revealed that Ms OS had a history of sleeping with a blanket over her head and she had previously been found struggling to breathe as a result. Yooralla identified this as a key issue as there was no alert or mention in any documentation that Ms OS slept with a blanket. Yooralla also identified issues in response to their response to previous falls. As these falls did not contribute to Ms OS's death, I do not propose to investigate them any further.

37. In the final years of her life Ms OS's Huntington's disease had progressed significantly which caused a deterioration in her physical and mental health. The internal review found Ms OS struggled with the COVID-19 restrictions and maintaining quality of life was a focus of care. Overall, Yooralla concluded that their care and clinical management of Ms OS was appropriate and that she was well care for in the period before her death.

38. I am satisfied with the statement from Dr Kotschet and the internal review performed by Yooralla.

FINDINGS AND CONCLUSION

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

i. the identity of the deceased was Ms OS;

ii. the death occurred on 28 January 2022 at Yooralla, Burwood East, Victoria, 3151,

iii. the cause of Ms OS's death was complications of Huntington's disease; and

iv. the death occurred in the circumstances described above.

40. Throughout the course of my investigation, I have been unable to determine the precise effect, if any, of the blanket found wrapped around Ms OS's head.

41. Dr Young advised that there was no evidence at autopsy of neck compression. Although the blanket was noted to be tightly wrapped around her head and that Ms OS had a history of suicidal ideation, given her known history of sleeping with a blanket over her head and no recent recorded suicidality, the evidence does not support a finding that Ms OS intentionally brought about the end of her own life.

42. Accordingly, and on the balance of probabilities, I find that the blanket found wrapped around Ms OS's head on 28 January 2022 did not contribute to her death and that she died from the natural complications of Huntington's disease.

43. The available evidence does not support a finding that there was any want of clinical management or care on the part of Yooralla or Ms OS's treating team that caused or contributed to Ms OS's death.

44. Ms OS's death was reportable by virtue of section 4(2)(c) of the Act because, immediately before her death, she was a person placed in care. Section 52 of the Act requires an inquest to be held, except in circumstances where the death was due to natural causes. I am satisfied that Ms OS died from natural causes and that no further investigation is required. Accordingly, 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 her death on the papers.

I convey my sincere condolences to Ms OS's family for their loss.

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:

Ms OS's family

Yooralla c/o MinterEllison

National Disability Insurance Scheme

First Constable Klay Patten, Coroner's Investigator

Signature:

Coroner Paresa Antoniadis Spanos

Date: 28 April 2023

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.