IN THE CORONERS COURT
OF VICTORIA
AT MELBOURNE

Court Reference: COR 2021 005536

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:	Andrew William Barr
Date of birth:	14 November 1966
Date of death:	17 October 2021
Cause of death:	1(a) Complications of pelvic and spinal fractures sustained in a fall in man with Downs syndrome
Place of death:	Wantirna Hospital, 251 Mountain Highway, Wantirna, Victoria
Key words:	*Disability, decision-making capacity, medical treatment decision maker, advance care directive, guardian, advance care planning*

INTRODUCTION

1. On 17 October 2021, Andrew William Barr was 54 years old when he passed away in hospital from complications following a fall. He usually resided in his childhood home in Burwood.

2. Mr Barr was the only child of Mavis and William Barr. He was born with Downs syndrome (Trisomy 21), which resulted in significant cognitive impairment and health issues.

3. Mr Barr lived at home for most of his life, largely cared for by his beloved mother. His cousin, Clem Peeler, recalled:

> *Aunty Mavis applied a lot of effort over his years in skilling Andrew in communication along with teaching him to spell and read. Andrew was always obedient to his parents and most others. Andrew was very quietly spoken, and his communication was good if he felt at ease with you. If direction was clear and straight forward, he responded well.*

4. In 2006, Mr Barr's parents engaged Burke and Beyond to assist with his care, with the intention that Mr Barr would continue to live in the family home with the help of Burke and Beyond following the deaths of his parents.

5. Mr Barr's father passed away in April 2015 and his mother passed in January 2021.

6. Deannh Ray, Community Services Manager at Burke and Beyond, stated, "*Prior to her passing Mavis had said she was ready (to pass away) and told me that I could look after him from now on. I took this request seriously …".*

7. Mr Peeler stated that his Aunt Mavis had much trust in Burke and Beyond and that Ms Ray had advocated on behalf of Mr Barr and his mother. Mr Barr's finances were managed by State Trustees.

8. Following his mother's death, and in accordance with her wishes, Mr Barr continued to reside in his family home with the support of his carers from Burke and Beyond who provided around the clock care.

9. At about this time, Melbourne East Disability Advocacy contacted the Office of the Public Advocate (**OPA**) on behalf of Mr Barr for advice regarding the appointment of a guardian to support Mr Barr remaining at home following his mother's death. OPA advised it was

unnecessary to appoint a guardian at that point in time as there were no decisions to be made on behalf of Mr Barr.

10. However, Mr Barr's physical health also began to decline at about this time, and he was diagnosed as suffering from Alzheimer's Dementia. His general practitioner, Dr Kopiyawattage Perara at Burwood Health Care, noted that Mr Barr had recurrent presentations to his clinic and Eastern Health for various infections.

11. On the morning of 14 February 2021, Mr Barr experienced a witnessed fall at home. He was transferred to Box Hill Hospital where he was found to have sustained comminuted (multiple fragments) sacral fracture involving bilateral sacral alar and S1/2 bodies with an additional right L5 transverse process fracture. He remained at Box Hill Hospital while his fractures were treated conservatively with analgesia and physiotherapy.

12. On 16 February 2021, Melbourne East Disability Advocacy contacted OPA about concerns with Mr Barr's discharge planning and the suitability of his accommodation. OPA advised Melbourne East Disability Advocacy should consider the ability to support Mr Barr's needs through property renovations or amending services being provided to him. These decisions could be made informally, or with the State Trustees administrator. OPA advised that guardianship could be considered if alternative accommodation was required in the future and a decision needed to be made to move Mr Barr.

13. On 22 February 2021, Mr Barr was transferred to Peter James Centre for ongoing pain management, physiotherapy, and discharge planning. Following a seizure, he was transferred back to Box Hill Hospital on 1 March 2021 for further investigation. A CT brain scan reported no changes, and it was thought that Alzheimer's was the cause of the seizure. Mr Barr was started on anti-epileptic medication. During this admission, he developed urinary incontinence, diarrhoea, groin rashes, and a chest infection.

14. On 23 March 2021, Mr Barr was transferred to the Peter James Centre for ongoing care. During this admission, there was an issue with the electronic medical records and so Mr Barr returned to Box Hill Hospital on 26 March 2021 for continued monitoring of his sacral fractures. Further CT scans showed stability and ongoing healing of the fractures. However, as he was non-weight bearing, Mr Barr became deconditioned and experienced weight loss.

15. On 8 April 2021, Mr Barr returned to the Peter James Centre for further rehabilitation and discharge planning. By this time, Mr Barr had developed a sacral pressure injury which was

being monitored. He developed a further chest infection, likely due to aspiration, and experienced further seizures.

16. Mr Barr's level of function plateaued at this time. It was subsequently decided that in the event of further deterioration, he would be provided comfort care but no active treatment.

17. During his prolonged admission to Eastern Health, a hospital social worker applied to the Victorian Civil and Administrative Tribunal (**VCAT**) to appoint a guardian to make decisions about Mr Barr's care needs and living arrangements as Mr Barr was unlikely to be able to live in his home without extensive renovations.

18. On 31 May 2021, OPA was appointed guardian to make decisions about where Mr Barr lived and the services he required (but not decisions about medical treatment).

19. In about August 2021, there were discussions between Mr Barr's social worker and guardian about the role of Burke and Beyond in his care as they were being provided with information about Mr Barr's clinical course, despite them not having any formal role. It was agreed that Mr Barr had a right to have someone contacted for social and emotional support in an emergency. It was determined that Burke and Beyond would continue providing support to Mr Barr, but it was noted they could not challenge decisions made about Mr Barr's medical treatment.

THE CORONIAL INVESTIGATION

20. Mr Barr'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. Mr Barr's death fell within the latter category, the beginning of his decline being the result of a fall and traumatic injuries.

21. 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.

22. 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.

23. The Victoria Police assigned an officer to be the Coroner's Investigator for the investigation of Mr Barr'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.

24. This finding draws on the totality of the coronial investigation into Mr Barr'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.[1]

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

Identity of the deceased

25. On 17 October 2021, Andrew William Barr, born 14 November 1966, was visually identified by his support worker, Deannh Ray, who signed a formal Statement of Identification to this effect.

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

Medical cause of death

27. Forensic Pathologist, Dr Melanie Archer, from the Victorian Institute of Forensic Medicine (**VIFM**), conducted an inspection on 18 October 2021 and provided a written report of her findings dated 11 November 2021.

28. Examination of the post-mortem CT scan showed dilated ventricles of the brain, malocclusion of the jaw with prognathism, and consolidated lungs. There were no fractures. The original pelvic and spinal fractures appeared to have healed.

29. The post-mortem examination did not reveal any evidence of an injury of a type likely to have caused or contributed to death.

[1] 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.

30. Dr Archer provided an opinion that the medical cause of death was *"1(a) Complications of pelvic and spinal fractures sustained in a fall in man with Downs syndrome"*.

31. I accept Dr Archer's opinion about the cause of death.

Circumstances in which the death occurred

32. On 5 October 2021, Mr Barr was transferred to Wantirna Hospital for palliative care. Eastern Health sought advice from OPA in relation to his palliation.

33. Ms Ray requested that Mr Barr be allowed to return home for end-of-life care, however this could not be facilitated before his death.

34. Mr Barr's health continued to deteriorate. He subsequently passed away at 1.15am on 17 October 2021.

CONCERNS ABOUT CLINICAL MANAGEMENT AND CARE

35. The coronial brief contained statements which outlined concerns about the care Mr Barr received following his mother's death and his fall at home.

36. Mr Peeler stated he believed Mr Barr's rapid decline in health was due to his needs not being properly understood by those treating him. He considered that Box Hill Hospital staff had limited understanding of how to appropriately manage his needs. He stated, *"Andrew was wary of people he didn't know. Especially if they were unable to communicate effectively with him"*.

37. Ms Ray similarly considered that Mr Barr's death was avoidable. In addition to her statement in the coronial brief, Ms Ray also provided a lengthy submission outlining Mr Barr's care following his fall and her concerns about the care he had received at Box Hill Hospital and Peter James Centre and the general lack of understanding of Mr Barr's needs. In summary, these were:

    (a) delayed recognition of additional fractures;

    (b) the onset of seizures, treated as epilepsy without further investigation;

    (c) multiple bouts of pneumonia;

    (d) his general decline in health and cognition;

(e) lack of physiotherapy;

(f) multiple transfers between Box Hill Hospital and the Peter James Centre; and

(g) lack of communication with Burke and Beyond carers despite Mr Barr not having someone to advocate on his behalf.

38. Ms Day lamented:

> *Andrew was not treated with the dignity and respect he deserved in either hospital setting. Hospital staff are not trained in working with people with disability, and simple things like talking to him so he knew what was happening or closing his door to respect his privacy, were not present. Andrew was more vulnerable due to not understanding what was happening around him or to him and the hospital staff being ill-equipped to deal with his disability. The only time Andrew was treated well and respectfully was in his last days when he was transferred to Eastern Palliative Care Unit, where finally nursing staff spoke to him and treated him as a person who mattered.*

39. Ms Day also criticised delay in having a new National Disability Insurance Scheme (**NDIS**) plan approved despite a significant change in Mr Barr's circumstances, not having a single point of contact at State Trustees who declined to release funding in circumstances where NDIS funding could be used instead, and delayed appointment of a guardian who could make decisions on Mr Barr's behalf.

FURTHER INVESTIGATION

40. In light of these concerns and as part of my investigation, I obtained advice from the Coroners Prevention Unit[2] (**CPU**) regarding the care Mr Barr received at Eastern Health and, more generally, the funding arrangements available to him.

41. For this purpose, I obtained statements from:

(a) Dr Yvette Kozielski, Medico-Legal Officer at Eastern Health;

[2] The Coroners Prevention Unit (**CPU**) was established in 2008 to strengthen the prevention role of the coroner. The unit assists the Coroner with research in matters related to public health and safety and in relation to the formulation of prevention recommendations. The CPU also reviews medical care and treatment in cases referred by the coroner. The CPU is comprised of health professionals with training in a range of areas including medicine, nursing, public health and mental health.

(b) Desmond Lee, State Manager for Queensland Service Delivery at the National Disability Insurance Agency (**NDIA**); and

(c) Renee Surace, Head of Integrated Support at State Trustees.

Medical review of care

42. The CPU noted that on presentation to Box Hill Hospital on 14 February 2021, the injuries identified on CT scan included a significant sacral fracture and a minimally displaced right sided L5 transverse process fracture.

43. Repeat CT scanning on 9 March 2021 confirmed that there was no further pelvic fracture evident and no major changes from previous imaging. The records noted that Mr Barr was not in significant pain and a further CT on 26 March 2021 revealed ongoing healing of the known upper sacral and L5 transverse process fractures with follow up sacral x-rays on 8 April 2021 confirming stable healing fractures.

44. On 30 April 2021, a meeting between carers and medical staff was held and it was highlighted that Mr Barr's condition had plateaued, his functional state was unlikely to improve, he was wheelchair bound and required full care. Mr Barr remained at Peter James Centre for a further five months, in that time he had further seizures treated with anti-seizure medication, episodes of aspiration pneumonia treated with antibiotics, and his general condition deteriorated. While the ongoing plan for Mr Barr was to eventually discharge him home, these medical complications and his gradual decline were significant barriers to Mr Barr's discharge.

45. As regards Ms Ray's concerns, the CPU noted as follows:

Delay in identification of all fractures

46. The CPU noted that the initial sacral alar and L5 fractures were well-described in the medical record from February 2021, and no injury was missed (repeat imaging confirmed the initial injury with no acute changes).

47. The CPU considered that the confusion around this issue may have been due to difficulties with information sharing / communication due to the absence of a medical treatment decision maker (**MTDM**).

Multiple transfers between Box Hill Hospital and Peter James Centre

48. The CPU noted that Mr Barr had multiple medical complications during a protracted admission at Eastern Health across the Box Hill Hospital and Peter James Centre campuses between February and October 2021.

49. The CPU considered that the re-admission to Box Hill Hospital on 1 March 2021 for investigation of new onset seizures was appropriate.

50. The reason given for Mr Barr's re-admission to Box Hill Hospital on 26 March 2021 was initially for safety due to an IT emergency at Peter James Centre. However, the medical records indicate this admission was for orthopaedic reassessment and management.

51. Mr Barr remained at Box Hill Hospital until he was transferred back to Peter James Centre on 8 April 2021 for further rehabilitation and discharge planning.

52. The CPU considered these transfers between acute and subacute settings were reasonable and although the additional transfer back to Box Hill Hospital on 26 March was not ideal, it was deemed necessary at the time due to issues with the electronic medical records at Peter James Centre.

Weight loss and muscle wasting

53. The CPU noted that throughout his admissions to both campuses, Mr Barr was reviewed by allied health professionals including dieticians, speech pathologists, and physiotherapists.

54. Mr Barr's weight in February 2021 on admission to Box Hill Hospital was 55.5 kilograms (**kgs**). He lost 6.5 kgs over the following months to May (non-weight bearing) when he weighed 48.9 kgs. However, following this he gained five kgs to August 2021 (54 kgs).

55. Mr Barr's last weight documented at Eastern Health was 52 kgs on 19 September 2021 (one month prior to death) with a (not unusual) significant drop in his final weeks resulting in his post-mortem weight being 44kgs.

56. The CPU considered that Mr Barr's weight fluctuations were reasonable considering his clinical condition. Additionally, muscle wasting is not an unusual occurrence in the context of inability to weight bear and Mr Barr's drowsiness and lack of engagement with physiotherapy.

Seizure management

57. The CPU noted that Mr Barr's hospital stay was complicated by new onset seizures which persisted despite reasonable investigation and treatment.

58. The CPU advised that the seizures were thought to likely be related to Mr Barr's Alzheimer's dementia, and they were appropriately treated with anti-epileptic medications. Eastern Health acknowledged that investigation of the seizures was limited due to Mr Barr's inability to tolerate an MRI scan.

Poor nursing care

59. Ms Ray concerns about nursing care included unacceptable hygiene practices (not using soap, delays with pad changes, not washing when replacing continence aids), placing meals out of reach, lack of coordinated care, and a lack of consideration for Mr Barr's specific needs.

60. Ms Ray also submitted these concerns to Eastern Health on 31 March 2021 whilst Mr Barr was an inpatient. An Eastern Health representative[3] held a phone conversation with Ms Ray in May 2021 and discussed all aspects of her concerns.[4] Ms Ray was assured that these concerns were reviewed, and it was acknowledged that staff can have variable degrees of empathy towards patients with a disability and that Eastern Health would continue to work to improve the quality of communication with carers.

61. The CPU considered that while these concerns caused a great deal of distress to Mr Barr's carers, there was no evidence in the post-mortem examination that poor nursing care contributed to Mr Barr's death.

Conclusion regarding medical care provided to Mr Barr

62. Between February and October 2021, Mr Barr's hospital stay was complicated by seizures, drowsiness (unclear aetiology), initial weight loss, dysphagia, recurrent aspiration pneumonia, and delirium. Although Mr Barr was only 54 years old, the combination of his cognitive and physical co-morbidities contributed to his biological age being much older. The initial injury from the fall in February 2021 was significant and resulted in Mr Barr being quite debilitated.

[3] Documentation from Eastern Health regarding the complaint from Ms Ray is redacted. Therefore, it is unclear who dealt with this complaint and what their role within the Health Service was at the time.
[4] Feedback document submitted to the court with Eastern Health statement on 16 October 2023.

This led to further complications resulting in muscle wastage, functional decline and an increased risk of aspiration which ultimately contributed to Mr Barr's decline and death.

63. The barriers to Mr Barr being discharged home appeared related to his declining condition and the delays and difficulties in having a guardian appointed for him.

64. Additionally, the CPU advised it was evident that due to the ambiguity surrounding guardianship and the lack of a clear MTDM, the communication from health care staff to Burke and Beyond carers was inconsistent and distressing for the carers involved.

65. Overall, the CPU considered the medical management of Mr Barr was reasonable and did not identify any prevention opportunities in the clinical management and care provided to Mr Barr.

Review of disability services and support

NDIS' delays in a plan review meeting occurring following a change in Mr Barr's circumstances

66. Ms Ray's concerns described ongoing delays in NDIS holding a plan review meeting, and finalisation/approval of a new plan for Mr Barr. Ms Ray expressed that the lack of a new plan was a barrier to Mr Barr being able to be discharged from hospital to live in his own home.

67. The CPU acknowledged that Mr Barr's care needs were complex and were complicated further by his gradual decline and deterioration.

68. Following Mr Barr's change in circumstances (the death of his mother, his fall, and resultant hospitalisation), co-ordination of Mr Barr's funding arrangements appeared challenging and potentially protracted due to the multiple stakeholders involved, delays in NDIS replying to requests for meetings, Mr Barr's declining condition and associated requirement for additional assessments (to confirm his support needs following discharge), and the need for appointment of a guardian who could make decisions about his discharge destination.

69. The CPU advised that review of the file and relevant materials indicated that as those involved in Mr Barr's co-ordination of care worked towards confirming his support needs following discharge (including seeking occupational therapy assessment and recommendations), Mr Barr's condition continued to deteriorate and was complicated by bouts of pneumonia and the onset of seizures. In her statement, Ms Kozielski advised that barriers to discharge between April and October 2021 included several chest infections due to aspiration events, and ongoing intermittent seizures.

70. While exhaustion of Mr Barr's NDIS funding during his hospitalisation was unfortunate, in their statement, the NDIA advised that the NDIS are not responsible for funding related to diagnosis and treatment of health conditions, general health or practitioner services, nursing, or medical specialists. Therefore, during his hospitalisation, all treatment, support and care for Mr Barr was the responsibility of Eastern Health.

71. While it was not determined that Mr Barr's disability was an obstacle to reasonable and appropriate clinical management and care, it was acknowledged that the interface between the multiple stakeholders involved (Eastern Health, the NDIS and NDIA, and State Trustees) and the bureaucratic and administrative processes involved with respect to multiple stakeholders, as well as NDIS' lack of timeliness in responding to some requests for plan review meetings, caused delays in approval of a new plan for Mr Barr.

Mr Barr's access to funds managed by State Trustees

72. The CPU noted that Ms Ray expressed that State Trustees declined to provide access to funds for expenses that they deemed 'should' have been paid for by NDIS funding. Ms Ray also expressed frustration that the current system necessitates speaking to a different person at each request, resulting in a lack of understanding of the person and their needs, and ultimately, a delay in Mr Barr being able to be cared for within his own home.

73. The CPU did not identify any issues regarding State Trustees practices. The statement from Ms Surace and the relevant attachments confirmed that from February 2021 onwards, State Trustees released more than $20,000 of Mr Barr's funds to cover 'attendant care fees' during the time that his NDIS funding had been exhausted. Further, a significant amount of money was released for the purpose of completing maintenance and improvements to the home to provide a safe and hygienic workplace environment for Mr Barr's support workers.

74. State Trustees appropriately asked questions to confirm and clarify NDIS' responsibility for funding and queried whether certain funds released by NDIS would be able to be recouped from NDIS.

75. The CPU considered that State Trustees acted reasonably in applying some caution with respect to the potential need to budget for Mr Barr's future and it appeared that they appropriately followed protocols and procedures. Further, in the week immediately prior to Mr Barr's death when he was palliated and discharge planning was ongoing (with a view to Mr Barr receiving 24/7 nursing care to allow him to die within his own home), State Trustees

worked closely with OPA towards this plan, confirming that all requests to access Mr Barr's funds would be approved.

FINDINGS AND CONCLUSION

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

(a) the identity of the deceased was Andrew William Barr, born 14 November 1966;

(b) the death occurred on 17 October 2021 at Wantirna Hospital, 251 Mountain Highway, Wantirna, Victoria;

(c) Mr Barr's death was the result of complications of pelvic and spinal fractures sustained in a fall in man with downs syndrome; and

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

COMMENTS

Pursuant to section 67(3) of the Act, I make the following comments connected with the death.

77. It is abundantly clear that Mr Barr was a cherished child who was lovingly cared for by his parents in the family home until they sadly were no longer able to do so. With the very best of intentions, Mrs Barr made her son the sole beneficiary in her will, leaving him a substantial amount of money that she intended be used for provision of care in Mr Barr's home by people familiar to him. With this intention, she entrusted the staff of Burke and Beyond to continue provision of care.

78. Despite these best intentions, Mrs Barr's enduring wishes for the care of her son were vulnerable. While she had engaged State Trustees to manage Mr Barr's finances, there were no formal appointments made to make decisions about Mr Barr's care and health on his behalf. Mrs Barr's intention for Burke and Beyond to assume this role was significantly limited without the necessary legal standing.

Advice from OPA

79. To assist my understanding of the legislative regime in place and the possibilities open to Mrs Barr and her son, I obtained a statement from Matthew Rasmussen, Acting Manager of the Advice & Response Program at OPA. Mr Rasmussen also set out OPA's contact with his carers and disability advocates, which has been incorporated where relevant above.

Advance care directive

80. Where a person has decision-making capacity,[5] they can make an Advance Care Directive setting out their binding instructions, preferences, and values about future medical treatment if they do not have decision-making capacity at a future point in time when they require medical treatment.[6] With some exceptions, health practitioners must follow the directive.

Appointed MTDM or Support Person

81. Persons with decision-making capacity may appoint a MTDM or a Support Person.[7]

82. A MTDM has the power to make medical treatment decisions on behalf of the person. They must make decisions that they reasonably believe the person would have made if they had decision-making capacity and consider the person's values and preferences.

83. A Support Person does not have the power to make treatment decisions. Their role is to support the person to make, communicate, and give effect to medical treatment decisions and represent the person's interests regarding these issues.

Default MTDM

84. Where a person does not have an appointed MTDM or the MTDM cannot exercise their responsibilities, the *Medical Treatment Planning and Decisions Act 2016* (Vic)[8] provides a hierarchy of people who may consent to a medical decision on behalf of the person as follows:[9]

    (a) the person's spouse or domestic partner;

    (b) the person's primary carer (though *not* a paid service provider);

    (c) the person's adult child;

    (d) the person's parent;

    (e) the person's adult sibling.

[5] Section 4 of the *Medical Treatment Planning and Decisions Act 2016* (Vic) defines decision-making capacity.
[6] See Part 2 'Advance Care Directives' of the *Medical Treatment Planning and Decisions Act 2016* (Vic).
[7] See Part 3 'Medical Treatment Decision Makers and Support Persons' of the *Medical Treatment Planning and Decisions Act 2016* (Vic).
[8] See section 55 of the *Medical Treatment Planning and Decisions Act 2016* (Vic).
[9] Appointed MTDMs and guardians appointed by VCAT under the *Guardianship and Administration Act 2019* (Vic) who have the power under that appointment to make medical treatment decisions on behalf of a person take precedence over the default hierarchy.

85. A default MTDM must follow the same requirements as an appointed MTDM when making decisions on behalf of the person.

Providing medical treatment where there is no MTDM

86. When there is no available MTDM, a health practitioner can provide *routine* treatment in the absence of consent. If treatment is *significant*, medical treatment consent is required from the OPA.[10]

Appointed guardians

87. The *Guardianship and Administration Act 2019* (Vic) allows persons to apply to VCAT for an order appointing a person as a guardian.[11] The order outlines the scope of the guardian's decision-making authority.

88. Before making an order, VCAT must be satisfied of the following:

    (a) because of the person's disability, the person does not have decision-making capacity in relation to the personal matter for which the order is sought;

    (b) the person is in need of a guardian; and

    (c) the order will promote the person's personal and social wellbeing.

89. It is important to note that guardianship is considered to be a restrictive approach to a person's decision-making rights. For this reason, where there are few or no medical decisions needing to be made, it may be more appropriate for the MTDM framework outlined above to be utilised. Guardianship orders (where medical treatment decisions are required) are therefore usually limited to the following scenarios:

    (a) the person has a constant need for medical treatment decisions to be made on their behalf, such as due to a medical condition requiring varied treatment; or

    (b) there is conflict between the person's support sources, such as more than one person who would be considered the person's default MTDM.

[10] See section 63 of the *Medical Treatment Planning and Decisions Act 2016* (Vic).
[11] Section 30 of the *Guardianship and Administration Act 2019* (Vic).

Conclusion

90. Whilst still alive, Mrs Barr would have been considered her son's default MTDM. Following her death, it appeared there was no family member who would fall into the default MTDM categories.

91. When Mr Barr was admitted to hospital, Burke and Beyond made attempts to advocate on his behalf regarding his treatment and care plans. A paid carer would not ordinarily have medical treatment decision authority. And it appears that Burke and Beyond were not always included in decisions or informed about Mr Barr's treatment or treatment plans. Frankly, there was no legal compulsion for Eastern Health to do so.

92. Ms Ray evidently recognised this when she noted:

> *As Andrew had no known family next of kin, he had no one to advocate on his behalf. Despite Burke and Beyond being the only people who knew Andrew and had been willing, and in fact requested many times that they be informed at any time of the day or night, of any changes or issues, this was rarely the outcome for Andrew. Both hospital settings felt they were in a better position to make decisions for Andrew and that as Burke and Beyond had no formal appointment they did not need to respect what we had to say on Andrew's behalf.*

93. In the months preceding his death, there were a multitude of people and services involved in his care and treatment. I have no doubt their intention was to do what was best for Mr Barr, however, there was no 'one voice' who could co-ordinate and advocate on his behalf.

94. An application for guardianship was eventually made and a guardian was appointed in May 2021. Importantly, the appointed guardian was *unable* to make decisions about medical treatment. It appears that the application did not request authority over medical treatment decisions. Rather, the application was to support Mr Barr's discharge from Eastern Health to make decisions regarding his accommodation, care, and lifestyle.

95. It is possible that a guardian could have been appointed for Mr Barr with medical treatment decision-making authority before his death.

96. Advance Care Planning Australia advise that advance care planning conversations should be a part of routine quality care for persons with disability.[12] Advance care planning allows a person to be involved in decisions about their future health care and medical treatments, including what should happen if they become seriously ill or injured.

97. A person with decision-making capacity will be able to make these plans for themselves, as discussed above. Where a person does not have decision-making capacity, a family member or healthcare professional can record medical treatment preferences on a person's behalf in a document titled *What I understand to be the person's preferences and values*.[13] This document is not legally binding but can be useful to inform care decisions.

98. OPA has also published a resource for carers of persons with disability titled *Securing Their Future: Planning for the future when you care for a person with disability.*[14] This booklet outlines arrangements a carer may put in place to support the person they are caring for in the event they are unable to continue providing that care. Importantly, it recommends obtaining legal advice about these issues.

99. Mr Barr's case highlights the importance of advance care planning, especially when persons with a disability have few or no family members or other formal supports.

100. In ideal circumstances, Mr Barr's advance care planning would have occurred while Mrs Barr was alive so that she could have appropriate input in these decisions, inform Mr Barr's treating clinicians/carers of her/their intentions, and even sought legal advice regarding their options. Mrs Barr took some legal steps, such as creating a will and organising for State Trustees to manage Mr Barr's finances.

101. However, it is unclear in circumstances where she wanted Burke and Beyond to continue to care for her son whether she also understood the need to make those specific legal arrangements before her death and what would happen to her son without formally appointed

[12] Advance Care Planning Australia, Advance care planning and disability, https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-areas/advance-care-planning-and-disability, accessed 24 September 2024.
[13] See for example the one used at Northern Health, https://www.nh.org.au/wp-content/uploads/2020/05/Preferences-and-Values-form-for-another-person.pdf. Advance Care Planning Australia also provide a form titled *Advance care plan for a person with insufficient decision-making capacity*, https://www.advancecareplanning.org.au/__data/assets/pdf_file/0029/178427/advance-care-plan_full-name.pdf.
[14] Office of the Public Advocate, Securing Their Future: Planning for the future when you care for a person with disability, https://www.publicadvocate.vic.gov.au/your-rights/planning-another-s-future-care/securing-their-future-planning-for-the-future-when-you-care-for-a-person-with-disability.

substitute decision makers. It is unclear whether anyone had raised this with her despite her early engagement with State Trustees, the NDIA, and even Burke and Beyond.

102. For the purpose of highlighting the need for advance care planning and to assist the public's understanding of these issues, I direct that this finding be published on the Court's website.

103. I convey my sincere condolences to Mr Barr's family, carers, and community for their loss.

PUBLICATION OF FINDING

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

DISTRIBUTION OF FINDING

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

Deannh Ray, senior next of kin
Eastern Health
Burke and Beyond
Office of the Public Advocate
Melbourne East Disability Advocacy
State Trustees
National Disability Insurance Agency
Senior Constable Katherine Isherwood, Victoria Police, Coroner's Investigator

Signature:

Deputy State Coroner Paresa Antoniadis Spanos

Date: 21 August 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.