



Coroner's Court of Western Australia

RECORD OF INVESTIGATION INTO DEATH

Ref: 29/19

*I, Sarah Helen Linton, Coroner, having investigated the death of **Child KT** with an inquest held at the **Perth Coroner's Court, Court 85, CLC Building, 501 Hay Street, Perth** on **29 July 2019** find that the identity of the deceased was **Child KT [subject to suppression order]** and that death occurred on **23 November 2016** at **Princess Margaret Hospital** as a result of **cardiorespiratory failure in a child with cerebral palsy and epilepsy** in the following circumstances:*

Counsel Appearing:

Sgt L Housiaux assisting the Coroner.

Ms L Bultitude-Paull (State Solicitor's Office) appearing on behalf of the Department of Communities.

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SUPPRESSION ORDER

The deceased's name is suppressed from publication. The deceased should be referred to as Child KT in any external publication

INTRODUCTION

1. Child KT (who I will call Vinnie in this finding, as this was an affectionate nickname given to him for much of his life by his carers and it does not reveal his true name)¹ was born on 20 August 2009. He was his mother's third child. The identity of his father is not recorded.² Vinnie's birth was uncomplicated and he went home to Yalgoo with his mother a few days later.
2. A few weeks after his birth, Vinnie developed pneumonia and was eventually transferred to Princess Margaret Hospital in Perth for treatment. Sadly, during his admission it became apparent Vinnie had serious health issues and was eventually diagnosed with spastic quadriplegia, cerebral palsy and developmental delay. He required a high level of care and medical management.³
3. Due to his high care needs, Vinnie's mother found it very hard to care for him and manage the needs of her other children. Concerns were raised about her ability to continue to care for him due to her social situation and lack of support in remote Yalgoo. To ensure his medical needs were met, the hospital became his primary place of residence.⁴
4. In August 2011 Vinnie was in hospital when he was taken into the care of the Department of Child Protection and Family Services, as it was then known. He was placed from hospital into Lady Lawley Cottage and on 25 November 2011 the Department was granted an order for parental responsibility for Vinnie, which remained in place until his death.
5. The organisation 'Life Without Barriers' assisted the Department to locate suitable specialist foster carers for Vinnie shortly after. When he was not hospitalised, he lived with his foster parents in Perth. Departmental staff regularly assessed his care and found Vinnie's foster parents provided an exceptional level of care to him.⁵
6. Vinnie suffered from chronic respiratory disease and throughout 2015 Vinnie suffered a number of acute respiratory events for which he had a series of hospital admissions in the Paediatric Intensive Care Unit. Specialists concluded that further invasive treatment to prolong Vinnie's life or improve his underlying condition might prolong his pain and discomfort and were likely to lead to secondary problems associated with treatment. In this context, a decision was made that Vinnie should not receive invasive treatment and he should receive palliative care. Forms were signed authorising that he be 'not for resuscitation' and for 'termination of life support', if required.
7. In late October 2016, Vinnie was admitted to hospital for the last time. His health deteriorated over the next month and in the early hours of 23 November 2016 Vinnie died in hospital.

¹ Exhibit 1, Tab 4.

² Exhibit 1, Tab 7.

³ Exhibit 1, Tab 8.

⁴ Exhibit 1, Tab 8.

⁵ Exhibit 1, Tab 8.

8. The fact that Vinnie was a child in care at the time of his death was unfortunately overlooked, so his death was not reported to the Office of the State Coroner. Instead, medical staff at the hospital completed a death notification form, indicating the cause of death was cardiorespiratory failure in a child with cerebral palsy and epilepsy. Vinnie was released to his family for a funeral service to be conducted.
9. Following a Departmental review, the WA Police Coronial Investigation Unit were notified by the Department of Vinnie's death on 18 July 2018. It was acknowledged that Vinnie was a child in care, for the purposes of the *Coroners Act 1996* (WA), at the time of his death, and his death was a reportable death.
10. The circumstances of the death were investigated by police. Significant material was provided by the Department as part of the investigation. At the conclusion of the investigation a comprehensive report of the death was prepared.⁶
11. The death of a 'person held in care,' as defined in section 3 of the *Coroners Act 1996* (WA), requires a coronial inquest be held.⁷ I held an inquest at the Perth Coroner's Court on 29 July 2019.
12. The documentary evidence tendered at the inquest provided a comprehensive summary of the care and supervision provided to Vinnie prior to his death by the Department, and more specifically his foster carers and medical practitioners. The only witness called to give evidence at the inquest was Mr Andrew Geddes from the Department (now known as the Department of Communities). Mr Geddes provided clarification on the initial failure of the Department to advise the Coroner of Vinnie's death, and provided information about the new systems in place to ensure a similar failure is unlikely to reoccur. I am satisfied the new processes described by Mr Geddes are appropriate and should ensure all reportable deaths are reported in a timely manner by the Department.
13. The evidence before me showed that Vinnie was cared for by the same foster carers for many years until his death. His foster carers were committed to providing a safe, supportive and loving environment for Vinnie throughout his relatively short life. They were still caring for him right up until the time of his death. His biological mother also remained a part of his life and was kept involved in decision-making until his death. Vinnie was treated by a multidisciplinary team of doctors, all of whom appear to have provided a high level of medical care. Taking into account all of the circumstances, I am satisfied Vinnie's care and supervision was appropriate and of a very high standard.

⁶ Exhibit 1.

⁷ Section 22(1) (a) *Coroners Act*.

OVERVIEW OF VINNIE'S LIFE AND HEALTH ISSUES

14. Vinnie's health issues originated at birth. As well as cerebral palsy and epilepsy, Vinnie's other medical issues included microcephaly (small head), blindness, asthma and chronic lung disease, gastro-oesophageal reflux, severe osteopenia that led to fractures and recurrent pneumonia. He required regular hospital reviews and full time care. He spent a large majority of his early years in hospital due to chronic respiratory issues.⁸
15. Vinnie's mother, who lived in a remote community and was a single mother with a number of other children, struggled to provide the level of care Vinnie required. He had been referred to the Disability Services Commission, who provided support, and was in a developmental follow-up program through the hospital, but it was still very difficult to provide Vinnie with everything he needed.⁹
16. Accordingly, as noted above, he spent most of his early life in hospital, often as a social admission. It was concluded that Vinnie required a more stable home and higher level of care than his family could provide. During a hospital admission at Geraldton Regional Hospital in August 2011 Vinnie was taken into care by the Department under a protection order, which was formally granted in the Children's Court at an ex parte hearing on 25 November 2011.¹⁰
17. Vinnie was temporarily placed at Lady Lawley Cottage and then was placed into the care of his foster parents. One of his foster parents was a trained nurse and both parents had experience in dealing with children with high needs. Vinnie lived with them for the majority of his life until his death at the age of seven years. It was known by his foster carers that he had physical and intellectual impairments and many complex medical needs. Vinnie was unable to swallow, so he was fed through a PEG tube. He was on a complex medication regime for his health conditions. They were able to manage these requirements and provide a loving home environment.¹¹
18. Vinnie's foster mother recalls that for the first few years that Vinnie was in their care he was "a happy, darling boy and his health was under control."¹² It was difficult to find appropriate education for Vinnie due to his care requirements and vulnerability to illness, but he did attend kindergarten in 2014 and pre-primary in 2015.¹³
19. His health deteriorated in 2015 and in 2016 and he missed significant amounts of school due to his poor health. Vinnie experienced a severe health event in June 2015, including a collapsed lung, which required him to be hospitalised in the Intensive Care Unit and placed on a ventilator. After a

⁸ Exhibit 1, Tab 8.

⁹ Exhibit 1, Tab 9.

¹⁰ Exhibit 1, Tab 8 and Tab 9 and Tab 10.

¹¹ Exhibit 1, Tab 4 and Tab 9.

¹² Exhibit 1, Tab 4, p.1.

¹³ Exhibit 1, Tab 8.

couple of days he was extubated as his lung had re-inflated, but within 48 hours his other lung collapsed and he was intubated again.¹⁴

20. Vinnie's foster mother recalls a conversation with the medical staff where they explained it would not be possible to put Vinnie back on a ventilator, should his lungs collapse again, as it would be cruel. Vinnie's foster parents were distressed by this news but understood that the doctors were prioritising Vinnie's quality of life and wishing to avoid him unnecessary pain. They told the doctors to do what they could to ensure that Vinnie had the best possible chance to survive.¹⁵
21. Vinnie was transferred to the ICU, where he remained in a poor condition, His foster mother describes this period as "a terrible time for the little boy and extremely emotional for all involved."¹⁶ Whilst he was in ICU Vinnie's biological mother and extended family were able to come down to Perth and visit him. To everyone's surprise and pleasure, Vinnie eventually rallied and after a long eight week admission he was able to return home.¹⁷
22. During this time the palliative care team spoke to Vinnie's foster parents about an 'end of life' plan, which was discussed in conjunction with Departmental staff. The medical staff at PMH emphasised that further invasive treatment to prolong Vinnie's life would not improve his underlying neurological condition or his quality of life and might actually prolong his pain and discomfort. In July 2015 it was decided in conjunction with Vinnie's foster parents, biological mother, and the Department that Vinnie should be made 'not for resuscitation' to ensure that he would not suffer any unnecessary pain or distress.¹⁸
23. Over the following two years Vinnie received care at his foster parents' home when not in hospital. They both ceased work to ensure that they could care for him together. Vinnie spent about half of this period of time in hospital due to recurrent chest infections and other health issues. When at home, he required oxygen intermittently during the day and always at night and he was on a significant medication regime.¹⁹
24. During the last period that Vinnie was at home he was described by his foster mother as "happy and smiley."²⁰ He was home for 12 weeks, which was the longest spell he had been able to spend at home for a long time.²¹ His foster parents were elated and "started to dare to think ... he was getting stronger."²² Vinnie then became unwell again, but his foster parents did not think it was as severe as in the past, so when he returned to hospital they only anticipated he would be admitted for a few days. However, once in hospital he deteriorated.

¹⁴ Exhibit 1, Tab 9.

¹⁵ Exhibit 1, Tab 4, p. 1.

¹⁶ Exhibit 1, Tab 4, p. 1.

¹⁷ Exhibit 1, Tab 4.

¹⁸ Exhibit 1, Tab 4, 2nd email and Tab 9 and Tab 17.

¹⁹ Exhibit 1, Tab 4, 2nd email.

²⁰ Exhibit 1, Tab 4, 2nd email, p. 1.

²¹ Exhibit 1, Tab 8.

²² Exhibit 1, Tab 4, 2nd email, p. 1.

25. Vinnie's last hospital admission at PMH began on 24 October 2016 and ended with his death on 23 November 2016. One of his foster parents remained with him at all times and participated in his care.²³
26. Vinnie had been admitted due to increased secretions and increased oxygen requirements. He was diagnosed with pseudomonas lung infection and parainfluenza virus. He was treated with oxygen, intravenous antibiotics and hydrocortisone. During this admission Vinnie received input from the complex care, rehabilitation, respiratory, endocrine, physiotherapy and palliative care teams. Unfortunately, his condition continued to deteriorate and he required increasing amounts of oxygen to control his saturation levels.
27. On 3 November 2017 a social worker advised the Department of Vinnie's deteriorating condition and arrangements were made for his biological mother to travel to Perth to visit him.
28. A few days later Vinnie was started on small doses of morphine to manage his increasing breathlessness and to keep him comfortable. As his respiratory distress increased, his morphine was also increased and all non –essential medication was discontinued.²⁴
29. On the Saturday morning of 19 November 2016, Vinnie's foster mother bathed him and changed his clothes before sitting him in his chair. She was talking to him and he was smiling. Vinnie's foster mother then changed his bed linen and returned him to bed. She noted at this time that his breathing became laboured and, despite being on oxygen, he appeared very sleepy. Doctors came to assess him and noted he had developed a decreased respiratory rate unrelated to the morphine he was receiving.²⁵
30. On the Sunday Vinnie did not appear to be doing well and it became clear to his foster parents that his death was imminent. The respiratory and palliative care doctors attended and they did everything to ensure Vinnie was comfortable. Vinnie's foster father stayed with him over the following days and was with him when he passed away at 4.30 am on the Wednesday morning, being 23 November 2016.²⁶ Vinnie's biological mother had also been visiting him regularly during these last few days, as it became apparent he might not survive.
31. On the day of his death, Vinnie's foster mother and a friend met at the hospital and bathed and dressed Vinnie and took him to the chapel of rest. His biological mother had been invited, but was too overwhelmed to assist.
32. Following his death, a memorial service was held in Perth that was attended by the many people from various services who had helped care for Vinnie, as well as family and friends. He was then taken to Yalgoo for his funeral,

²³ Exhibit 1, Tab 4, 2nd email.

²⁴ Exhibit 1, Tab 8.

²⁵ Exhibit 1, Tab 4, 2nd email and 3rd email.

²⁶ Exhibit 1, Tab 4, 3rd email.

which was attended by his biological family and the local community, as well as Vinnie's foster parents.²⁷

CAUSE AND MANNER OF DEATH

33. Vinnie's death was certified at 5.30 am on 23 November 2016. Dr Mark Bengson at Princess Margaret Hospital completed a Medical Certificate of Cause of Death on the same day. Dr Bengson recorded the cause of death as cardiorespiratory failure, which had commenced approximately one month prior to his death. Antecedent causes noted were Gross Motor Function Classification System V (GMFCS V) Cerebral Palsy and epilepsy.²⁸ It was later noted in other documentation that he suffered acute respiratory deterioration on a background of chronic respiratory disease secondary to cerebral palsy.²⁹
34. As noted above, notification of Vinnie's death was not provided to the Coroner's Court as his doctor mistakenly thought that his death was not a reportable death.³⁰ By the time his death was reported there was obviously no opportunity for any further enquiry to be made into Vinnie's cause of death.
35. Based upon the medical records, I find that the cause of death was cardiorespiratory failure in a child with cerebral palsy and epilepsy. The manner of death is by way of natural causes.

QUALITY OF SUPERVISION, TREATMENT AND CARE

36. Under s 25(3) of the *Coroners Act 1996*, where a death investigated by a coroner is of a person held in care, the coroner must comment on the quality of the supervision, treatment and care of the person while in that care.
37. The information obtained during the coronial investigation shows that, despite the many hardships Vinnie faced in life, he was a much loved little boy who survived for many years against the odds. All the people who were involved in his life loved him and did everything they could to support him and keep him comfortable and happy.
38. Due to his complex medical needs, the Department had placed Vinnie in the care of foster carers who not only had the necessary skills to manage his medical needs but were also able to provide him with a loving and emotionally supportive environment throughout his short life. The Department facilitated contact with Vinnie's biological mother as much as possible given they were geographically separated. Vinnie was also well supported in the community through his school, the Department and the Disability Services Commission.³¹

²⁷ Exhibit 1, Tab 4, 4th email.

²⁸ Exhibit 1, Tab 5.

²⁹ Exhibit 1, Tab 5.

³⁰ Exhibit 1, Tab 5.

³¹ Exhibit 1, Tab 9.

39. Vinnie's medical management was of a high standard. He received appropriate specialist care at Geraldton Hospital and Princess Margaret Hospital and his complex medical needs were managed via a multidisciplinary team.
40. In 2016 it became apparent that Vinnie was approaching the end of his life and no further active management was appropriate. After discussion with the various hospital specialists, his biological mother, foster parents and the Department, he was appropriately managed with palliative care until he died on 23 November 2016. In those final days he was never left alone, but was always in the company of a foster parent and also his mother at times. His foster father was at his side when he passed away.
41. I am satisfied the Department provided a very high level of supervision, treatment and care to Vinnie from the time he was taken into care until his death.

CONCLUSION

42. Vinnie was an Aboriginal boy from a regional community who was born with life limiting disabilities. Due to his high care needs, he was taken into the care of the Department from a young age and cared for by specialist foster carers when not in hospital. Vinnie's early death had been anticipated and it had been agreed by all involved in his care that his life should not be prolonged unnecessarily through medical intervention, although there was a preference for him to be kept alive as long as he could be kept comfortable. He died in hospital following an ongoing decline in his health.
43. I have noted on previous occasions in other inquests that the community is very fortunate to have people like Vinnie's foster carers, who are prepared to take on the great responsibility of caring for a child with significant health needs. The love and care they provided, with the support of the Department, his doctors and other agencies, enabled Vinnie to have a high quality of life despite his significant physical and mental impairment. Sadly his early death was an inevitable consequence of the serious health issues he was born with, but everything was done to ensure he had the highest quality of life possible for the term of his short life.

S H Linton
Coroner
30 July 2019