Coroners Act 1996
[Section 26(1)]

Coroner's Court of Western Australia

RECORD OF INVESTIGATION INTO DEATH

Ref: 87 /19

I, Sarah Helen Linton, Coroner, having investigated the death of ***Child TJW*** *with an inquest held at the* ***Perth Coroner's Court, Court 51, CLC Building, 501 Hay Street, Perth*** *on* ***18 December 2019*** *find that the identity of the deceased person was* ***Child TJW*** *and that death occurred on* ***12 July 2018*** *at* ***Perth Children's Hospital*** *as a result of* ***aspiration pneumonia leading to multi-organ failure in a female child with a complex medical history including cerebral palsy, hypoxic ischaemic encephalopathy, microcephaly, seizure disorder and airway obstruction*** *in the following circumstances:*

Counsel Appearing:

Sgt L Houisaux assisting the Coroner.
Ms Omer (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 TJW in any external publication.

INTRODUCTION

1. Child TJW, who I will hereafter refer to as the deceased as I can't use her real name due to the suppression order, was born on 5 June 2011. Her delivery was traumatic and she was transferred to Princess Margaret Hospital (PMH) for specialist medical care as she had a severe brain injury. Withdrawal of life support was discussed with her parents at the time, but they chose to continue with active treatment.

2. She was diagnosed with spastic quadriplegic cerebral palsy and various other conditions that severely affected her health and ability to live independently. Due to these complex health issues, the deceased had very high care needs. She mobilised in a wheelchair and needed assistance with all aspects of her daily living.

3. The deceased lived with her biological family for a number of years with support from the Department. However, in September 2016 concerns were raised with the Department by PMH staff about the family's continued ability to manage the deceased's care. The deceased had been admitted to PMH and she was found to be malnourished and had respiratory distress due to copious upper airway secretions. She had a prolonged admission to PMH, during which steps were taken to bring her into the Department's care. The deceased was placed by the Department at Lady Lawley Cottage on 10 January 2017.

4. She received regular input from a physiotherapist, occupational therapist, speech pathologist and dietitian, as well as ongoing medical care, including numerous admissions to PMH and Perth Children's Hospital (PCH).

5. In June 2017 the Department met with the deceased's biological parents to discuss their resuscitation wishes in the event of a deterioration in the deceased's condition. Doctors advised that the aim of treatment should be to reduce her suffering and promote her comfort. Her family were initially reluctant, but they eventually agreed with the advice of the clinicians and on 9 November 2017 a 'Not for Resuscitation Order' was signed.

6. The deceased was last admitted to PCH on 1 July 2018. She presented with fever, increased respiratory secretion, uncontrolled seizures and respiratory distress. She was diagnosed with a chest infection. Despite treatment her clinical state continued to deteriorate and it became clear that she had reached the end of her life. Multiple meetings were held with the deceased's family and she was treated with comfort measures until she passed away, surrounded by her family, on 12 July 2018.

7. The deceased met the definition of a 'person held in care,' as defined in section 3 of the *Coroners Act 1996* (WA), as she was a child under the care of the Department, so her death was a reportable death. The circumstances of the death were investigated by police and 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 for the coroner.[1]

8. The death of a person held in care requires a coronial inquest be held.[2] I held an inquest at the Perth Coroner's Court on 18 December 2019. The only witness called to give evidence at the inquest was Mr Glenn Mace from the Department of Communities.

OVERVIEW OF CHILD TJW'S LIFE AND HEALTH ISSUES

9. As noted above, the deceased was born in June 2011. She was delivered at 35 weeks' gestation via emergency caesarean section due to placental abruption. Post-delivery she required aggressive resuscitation and was transferred to the Neonatal Intensive Care Unit at Princess Margaret Hospital (PMH) for specialist medical care as she had a severe brain injury caused by a lack of blood to the brain in the uterus due to the placenta detaching from the uterine wall.[3]

10. Brain scans indicated severe brain damage and her long term outcomes were poor. PMH staff discussed the option of palliative care and withdrawal of life support measures, but her family wished to continue active treatment.[4]

11. The deceased had extensive, long term health issues, including:

    - Severe spastic quadriplegic cerebral palsy;
    - Severe global developmental delay;
    - Seizures;
    - Bilateral hip dysplasia;
    - Craniosynostosis (premature fusion of the skull bones); and
    - Microcephaly (small head).[5]

12. She used a wheelchair and required feeding via gastrostomy tube. It was also believed that she had impaired vision. The deceased showed little response to her environment or people around her and was unable to attend formal education.[6]

13. The deceased lived at home with her parents. In 2012 her parents gave birth to a second child and a third followed in 2013. [7]

14. The Department had extensive contact with the young family for a number of years. They were referred to the Best Beginnings program shortly after the deceased's birth, but did not engage with the program. There were difficulties arranging for the deceased to regularly attend her medical appointments, despite efforts to facilitate her attendance through providing

[1] Exhibit 1.
[2] Section 22(1) (a) *Coroners Act*.
[3] Exhibit 1, Tab 10.
[4] Exhibit 1, Tab 10.
[5] Exhibit 1, Tab 10 and Tab 36.
[6] Exhibit 1, Tab 10.
[7] Exhibit 1, Tab 10.

transport, booking multiple appointments for the same day and rescheduling appointments on an emergency basis.[8] A meeting with the family in July 2012 found there were a number of stressors experienced by the family, including isolation, lack of support and family conflict. The family was on the waiting list for assistance from the Disability Services Commission.[9]

15. From that time, the Department maintained close contact with the family to encourage compliance with medical appointments and to ensure that the deceased was safe and receiving appropriate care. The increased attention assisted the family to more closely engage with the medical services available, although child protection concerns remained. There were some issues with accessing specialist medical services, while the family lived with a relative in Albany, so they made plans to move to Perth. This initially presented some new difficulties, as their accommodation in Perth was not permanent, but in July 2013 they found a permanent home in Maddington.[10]

16. There were no major concerns raised again about the deceased's family's capacity to manage her care until September 2016.[11]

TRANSFER TO DEPARTMENTAL CARE

17. On 6 September 2016 a social worker from PMH raised concerns of neglect and it was found the disability service provider had been having limited access to the deceased as the family was not engaging with the service. The deceased was admitted to PMH, where she was found to be malnourished and had respiratory distress due to copious upper airways secretions. She had a prolonged admission to PMH, during which the Department conducted an investigation and determined that the deceased's medical needs had increased and she required 24 hour hospital care. It was felt that her care could no longer be provided at home by her family.[12]

18. On 23 November 2016 the deceased was brought into Provisional Protection and Care under the Department while still a patient at PMH. On 1 March 2018 a Magistrate in the Perth Children's Court granted a Protection Order for the deceased until she turned 18 years, thus making the CEO of the Department her legal guardian.[13]

19. A permanent placement was eventually found for the deceased at Lady Lawley Cottage and she was discharged from PMH to the facility on 10 January 2017.[14]

20. The deceased was supported in the community with regular input from Ability Centre's physiotherapist, occupational therapist and speech

[8] Exhibit 1, Tab 10.
[9] Exhibit 1, Tab 10.
[10] Exhibit 1, Tab 10.
[11] Exhibit 1, Tab 10.
[12] Exhibit 1, Tab 10.
[13] Exhibit 1, Tab 10.
[14] Exhibit 1, Tab 10.

pathologist and with dietitian input from PMH. The deceased required a nasopharyngeal airway (NPA) to support her breathing, supplementary oxygen and normal saline nebulisers and salivary gland Botox injections to improve her upper airways secretions. Despite these measures, she continued to suffer from recurrent respiratory distress, infections and multiple daily seizures.[15] It was noted at the inquest that her care was very difficult to manage, even in this specialised setting, so it is not surprising that her family had eventually been unable to continue to care for her at home.

21. During 2017 the deceased had numerous admissions to PMH, often due to increased secretions and vomiting and acute respiratory distress. In June 2017 the Department's staff met with the deceased's family to discuss their resuscitation wishes in the event of a deterioration in the deceased's condition. The doctors expressed the opinion that the aim of treatment should be focussed on reducing her suffering and promoting her comfort. Initially the deceased's parents still expressed a wish for her to receive full resuscitation, but after continuing discussion her parents accepted the medical advice and the Department took steps for a 'Not for Resuscitation' Order to be signed on 8 November 2017.[16]

FINAL DECLINE IN THE DECEASED'S HEALTH 2018

22. On 2 June 2018 the deceased was admitted to Perth Children's Hospital with an upper respiratory tract infection, blocked NPA and increased seizure activity.

23. On 1 July 2018 the deceased was taken to PCH again with fever, increased respiratory secretions, uncontrolled seizures and respiratory distress. She was diagnosed with a chest infection and administered salbumatol nebulisers. She required multiple changes of her NPA in an effort to ease her respiratory distress. She had sacral pressure sores, which were attend to by the wound care service. Her supplementary oxygen was weaned and her feeds were titrated up.

24. Despite these treatments, the deceased's clinical state continued to deteriorate and it became clear that she had reached the end of her short life. Multiple meetings were held with her family and it was agreed she would receive palliative care. She was treated with comfort measures and was able to have family visits, including with her siblings, until she passed away, surrounded by family, on 12 July 2018.[17]

CAUSE AND MANNER OF DEATH

25. An external post mortem examination was performed on 17 July 2018 by a Forensic Pathologist, Dr Moss. Dr Moss also reviewed the deceased's medical

[15] Exhibit 1, Tab 10 and Tab 36.
[16] Exhibit 1, Tab 10.
[17] Exhibit 1, Tab 10.

records. Toxicology analysis showed the presence of multiple prescribed-type medications, including morphine, in keeping with the medical care provided.[18]

26. At the conclusion of these limited investigations, Dr Moss formed the opinion the cause of death was aspiration pneumonia leading to multi-organ failure in a female child with a complex medical history including cerebral palsy, hypoxic ischaemic encephalopathy, microcephaly, seizure disorder and airway obstruction. I accept and adopt Dr Moss' opinion on the cause of death.[19]

27. I find the manner of death was by way of natural causes.

QUALITY OF SUPERVISION, TREATMENT AND CARE

28. 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.

29. The information obtained during the coronial investigation shows that the deceased faced many challenges in her life from birth. By the time of her death, she had 15 volumes of medical files documenting her extensive medical history.[20] I am satisfied the deceased's medical management was of a high standard. She received appropriate specialist care and multidisciplinary input to manage her complex medical needs.

30. In 2018 it became apparent that the deceased was approaching the end of her life and no further active management was appropriate. After discussion with the various hospital specialists, her parents and relevant staff from the Department, she was appropriately managed with palliative care until her death. Her family were able to be with her at that important time.

31. I am satisfied the Department provided a very high level of supervision, treatment and care to the deceased from the time she was taken into care until her death.

CONCLUSION

32. The deceased was born with severe cerebral palsy, significant global developmental delay and respiratory difficulties. She had complex care needs, which were difficult for her family to manage at home. They were supported by the Department in their attempts to do so for as long as possible, but ultimately she had to be taken into care in 2017.

33. All the evidence before me indicates that the Department worked effectively from that time to provide an appropriate and safe environment for the

[18] Exhibit 1, Tab 6 and Tab 7.
[19] Exhibit 1, Tab 6.
[20] Exhibit 1, Tab 3.

deceased where her complex medical needs could be met. Sadly, her life was drastically shortened by her health conditions, but the Department did its best to provide her with the best quality of life possible over those short years.

34. Her family were still visiting the deceased in her final days and were able to say goodbye to her at the end. At her funeral, the deceased was remembered as a dearly loved daughter, big sister and granddaughter, as well as a special friend to many. Her strength throughout her short life was an inspiration to her family and she was very much loved by them all.

S H Linton
Coroner
20 December 2019