Coroners Act 1996
[Section 26(1)]

Western *Australia*

RECORD OF INVESTIGATION INTO DEATH

Ref No: 17/17

I, Barry Paul King, Coroner, having investigated the death of ***CNR*** *with an inquest held at the* ***Perth Coroner's Court*** *on* ***9 May 2017****, find that the identity of the deceased person was* ***CNR*** *and that death occurred on* ***26 June 2013*** *at* ***Princess Margaret Hospital*** *from* ***heart failure due to chronic rheumatic heart disease*** *in the following circumstances:*

Counsel Appearing:

Ms K E Ellson assisting the Coroner
Ms R N Pajeltak (State Solicitor's Office) appearing for the Department of Child Protection and Family Support, WA Country Health Service and Child and Adolescent Health Service

TABLE OF CONTENTS

SUPPRESSION ORDER

No report may be published of any part of the proceedings or of the evidence given at this inquest that could lead to the identification of the deceased or his family.

INTRODUCTION

1. CNR (**the deceased**) died on 26 June 2013 from heart failure due to rheumatic heart disease.

2. As the deceased was 'a person in the care of the CEO' as defined in section 3 of the *Children and Community Services Act 2004* at the time of his death, he was a 'person held in care' under section 3 of the *Coroners Act 1996*.

3. Section 22 (1)(a) of the *Coroners Act 1996* provides that a coroner who has jurisdiction to investigate a death must hold an inquest if the death appears to be a Western Australian death and the deceased was immediately before death a person held in care.

4. An inquest to investigate the death of the deceased was therefore mandatory. I held an inquest on 9 May 2017 at the Perth Coroners Court.

5. The documentary evidence adduced at the inquest comprised a coronial brief containing seven volumes of material.[1]

6. Oral evidence was provided by

   a) Ms Neroli Samuel, a senior child protection worker at the Department of Child Protection (DCP) in Kalgoorlie from 2013 to 2017;[2]

[1] Exhibit 1, Volumes 1 to 7
[2] ts 6 – 13 per Samuel, N

b) Dr Gervase Chaney, a paediatrician and the chairman of the paediatric medicine clinical care unit at PMH;[3]

c) Dr James Ramsay, a paediatric cardiologist who treated the deceased;[4]

d) Dr Kelvin Billinghurst, the director of medical services for Western Australian Country Health Service, Goldfields;[5] and

e) Mr Andrew Geddes, the acting executive director country services in the Department of Child Protection and Family Support (DCPFS).[6]

7. Under s25(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.

8. I have found that the care provided to the deceased was reasonable and appropriate.

THE DECEASED'S MEDICAL HISTORY

9. The deceased was born at Kalgoorlie Regional Hospital (KRH) on 6 February 1997. He lived with his parents and two siblings in Jameson, or Mantamaru Community, in the Ngaanyatjarra Lands (the Lands) about 125 kms east of Warburton. His parents were loving and supportive.

10. For the first 24 months of his life, the deceased had many presentations to health clinics in the Lands. He was treated for nappy rash, ringworm, scabies sores, ear infections and chest infections. His family were responsive to overt symptoms and immediate health crises.[7]

[3] ts 13 – 23 per Chaney, G
[4] ts 24 – 40 per Ramsay, J M
[5] ts 40 – 48 per Billinghurst, K
[6] ts 48 – 54 per Geddes, A
[7] Exhibit 1, Volume 1, Tab 18

11. Over the next seven years or so, the deceased's parents took the deceased to health clinics in the Lands for treatment of acute symptoms. In 2002 and 2003 he was treated for sores, fever, ear infections and cold/flu symptoms. In 2004 there were no recorded presentations. In 2005 the deceased attended with his father for a shoulder injury sustained while doing somersaults, and later that year an aunt took him to a clinic, with infected eyes and a deep cut on his hand.[8]

12. In January 2006 the deceased parents were attempting to take the deceased to a clinic because he had a high fever, when they became stranded on the road. They were able to enlist the help of passing tourists who took the deceased to the clinic.[9]

13. In February 2006, the deceased's father took him into a clinic with a painful right knee and groin. When his fever did not entirely abate, he was monitored and treated for five days and was then transferred to PMH where he was diagnosed with rheumatic fever. He remained in PMH for a month before being transferred to KRH and home. He was prescribed monthly injections of benzathine penicillin, or bicillin, to prevent the recurrence of rheumatic fever.[10]

14. The deceased's compliance with the monthly bicillin injections was variable over the next year, but he remained asymptomatic for rheumatic fever.[11]

15. In early October 2007 the deceased's parents took him to the Wanarn clinic with pain from the site of his latest, delayed, bicillin injection. He was flown to PMH and was diagnosed with his second bout of rheumatic fever. He was discharged with a follow-up cardiology review in February 2008 at KRH, but he did not attend the appointment due to transportation problems. The review was moved to June 2008.[12]

[8] Exhibit 1, Volume 1, Tab 18
[9] Exhibit 1, Volume 1, Tab 18
[10] Exhibit 1, Volume 1, Tab 18
[11] Exhibit 1, Volume 1, Tab 18
[12] Exhibit 1, Volume 1, Tab 18

16. In 2008 and 2009 the deceased received 22 of the 24 prescribed doses of bicillin.[13]

17. On 6 January 2010 the deceased's father took the deceased to the Blackstone (Papulankutja) clinic with a fever and weakness in his legs. Three days later his mother took him to the Jameson clinic with leg pains. The leg pains appeared to improve over the next few days, but on 26 January 2010 they re-emerged, with a slight fever and shallow rapid breathing. He was flown to KRH and on to PMH where he was admitted for over four months. He was diagnosed with valvular heart disease and heart failure.

18. In October 2010 the deceased underwent mitral valve and aortic valve repair at PMH. Post-operatively there was poor blood supply to the heart muscle, which caused significant damage. This may have been caused by a ring, which the surgeon had placed around the mitral valve, pressing on one of the coronary arteries.[14] As a result, the deceased developed biventricular congestive heart failure with ongoing aortic and mitral incompetence as well as tricuspid incompetence, with both right and left ventricles contracting poorly.[15]

19. The deceased was in PMH until 24 November 2010, when he was discharged on 10 additional oral medications. Over December 2010 he was inconsistently compliant with the new medical regime.[16]

20. On 12 January 2011 the deceased attended the PMH cardiology outpatient clinic in significant heart failure. After review he returned to the Lands on 20 January 2011 and continued to be inconsistent in complying with the medication requirements.[17]

21. On 2 August 2011 the deceased was transferred from KRH to PMH in diagnosed heart failure after two weeks of

[13] Exhibit 1, Volume 1, Tab 18
[14] ts 28 – 29 per Ramsay, J M
[15] Exhibit 1, Volume 1, Tab 13
[16] Exhibit 1, Volume 1, Tab 18
[17] Exhibit 1, Volume 1, Tab 18

increased symptoms. Once his medication was regularly administered, his condition improved. He was kept in PMH for about 10 days.[18]

22. The deceased was admitted again to PMH from 19 December 2011 to 30 December 2011 and from 30 January 2012 to 1 March 2012 with heart failure related to poor compliance with medications. On the second occasion the heart failure was more severe, with peripheral oedema to the mid-thigh level.[19]

23. From 1 March 2012 the deceased was admitted to KRH for much of the rest of 2012. He was close to his family but they were not able to provide him the complex medical needs he required.[20]

24. The deceased was transferred to RPH in November 2012 for management of atrial arrhythmias by a radiofrequency ablation procedure and the insertion of a pacemaker/defibrillator. He was assessed by the transplant unit as not suitable for cardiac transplantation because of his psycho-social capabilities, and as not suitable for a mechanical heart pump because of the condition of his heart.[21]

25. The deceased was managed in PMH for the first part of 2013. He was in congestive heart failure and required large doses of diuretics to keep his weight gain and peripheral oedema under control.[22]

26. The deceased was discharged to a foster family in Chittering in early March 2013 and was managed for his last few months through outpatient visits and admissions to PMH.

[18] Exhibit 1, Volume 1, Tab 18
[19] Exhibit 1, Volume 1, Tab 13
[20] Exhibit 1, Volume 1, Tabs 12 and 13
[21] Exhibit 1, Volume 1, Tab 13
[22] Exhibit 1, Volume 1, Tab 13

DECEASED TAKEN INTO CARE

27. On 15 March 2012 the deceased's paediatrician at KRH, Dr Christine Jeffries-Stokes, emailed a duty officer at the DCP, now the Department of Communities - Child Protection and Family Support, with significant concerns for the deceased due to his parents' inability to supervise his medication. She stated that he could not return to the central desert and was bored and at risk of cross-contamination in KRH. She suggested that he could obtain a better quality of life in foster care in Kalgoorlie or Perth with medical supervision and, if he were accepted for heart transplant, he would need to live in Perth. She asked that the DCP become involved.[23]

28. On 30 April 2012 Dr Ramsay wrote a letter 'To whom it may concern at DCP Kalgoorlie' in which he outlined the deceased's cardiac problems and the urgent need for him to be placed in a situation outside of hospital where he could obtain dependable and consistent care, probably in a foster home. He stated that the deceased's condition since 2006 had been compromised by poor compliance with medication, and that he was not considered suitable for heart transplant because of his remote location and because his family were unable to comply with his current medication regime.[24]

29. Dr Ramsay said that he understood from Dr Jeffries-Stokes that there may be a family in Kalgoorlie that could care for the deceased in the community and that, if it could be demonstrated over months that the foster family and the deceased could comply with medication administration, it may be possible to refer him for a heart transplant.[25]

30. On 26 June 2012 the DCP received a report from WA Health, KRH that the deceased could be discharged from hospital but that he had nowhere to go because his parents had returned to the Lands. Concerns were also

[23] Exhibit 1, Volume 1, Tab 12
[24] Exhibit 1, Volume 1, Tab 13
[25] Exhibit 1, Volume 1, Tab 13

raised about obtaining consent through his parents for medical procedures.[26]

31. On 12 July 2012 the DCP received a phone call from the regional director of WA Health in Kalgoorlie with concerns that the deceased had been in hospital for 109 days and was at high risk of cross-contamination. That day, the deceased was discharged to spend a week with his family in Warburton and to then return to Kalgoorlie to live at a placement provided by the DCP.[27]

32. The deceased was admitted to the critical care unit in RPH for about a week in August 2012. On his return to Kalgoorlie on 16 August 2012 he was discharged from KRH and began living in a DCP group home.[28]

33. Two days later, the deceased was again admitted to KRH. On 3 November 2012 he was transferred to RPH, where he stayed until 5 December 2012, when he returned to Kalgoorlie and continued living in the group home.[29]

34. On 31 December 2012, Dr Chaney wrote to an officer of the DCP in Kalgoorlie to express the joint view of senior medical staff from KRH, PMH and RPH that the deceased required foster care in order to have the best opportunity for a reasonable quality of life, and to request that the DCP progress the application for foster care.[30]

35. On 5 January 2013 the deceased was admitted to PMH in a deteriorating condition. The DCP considered that, when the deceased was discharged, inconsistent care arrangements and recent changes meant that the group home was not an appropriate place for him to live. The deceased's parents were then in Jameson.[31]

36. On 11 January 2013, Ms Samuel filed an application at the Children's Court of Western Australia in Kalgoorlie for a protection order to place the deceased in the care of the

[26] Exhibit 1, Volume 1, Tab 12
[27] Exhibit 1, Volume 1, Tab 12
[28] Exhibit 1, Volume 1, Tab 12
[29] Exhibit 1, Volume 1, Tab 12
[30] Exhibit 1, Volume 1, Tab 11
[31] Exhibit 1, Volume 1, Tab 12

CEO of the DCP. A magistrate in the Children's Court granted an interim order on 15 January 2013, and on 12 March 2013 the magistrate granted a final protection order pursuant to a minute of consent orders. The deceased's father attended court and consented to the protection order.[32]

THE DECEASED'S TREATMENT AND CARE WHILE IN CARE

37. After the deceased had been taken into care, he was ostensibly staying at the group home in Kalgoorlie, but in fact he was in PMH from 15 January 2013 until 11 March 2013.[33] The DCP arranged for his parents and siblings to stay in Perth so that they could visit him, but they returned to Jameson in February 2013 because they were struggling to cope with life in Perth.[34]

38. On 24 January 2013 DCP officers met with medical staff from PMH and KRH to receive an update from Dr Ramsay on the deceased's condition, which was deteriorating. As a heart transplant was not a feasible option, the focus was on making the deceased comfortable and on providing him with the best possible quality of life.[35]

39. On 11 March 2013 the deceased was placed with high needs foster carers who lived in Chittering. A discharge planning meeting had taken place between the foster carers, DCP and medical staff on 28 February 2013 to ensure that the carers were aware of his medical needs.[36]

40. Ms Samuel continued to work in collaboration with PMH clinicians by way of daily email updates. She was also allocated a co-worker from the DCP Mirrabooka office who filled in for her in Perth. He was the DCP Aboriginal Practice Leader and had connections to Jameson. He was able to engage well with the deceased.[37]

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[32] Exhibit 1, Volume 4, Tab 33
[33] Exhibit 1, Volume 1, Tab 23B
[34] Exhibit 1, Volume 1, Tab 9
[35] Exhibit 1, Volume 1, Tab 23B
[36] Exhibit 1, Volume 1, Tab 23B
[37] ts 12 – 13 per Samuel, N

41. On 1 April 2013 the deceased was re-admitted to PMH with acute kidney failure. From that time until his death he spent most of his time in hospital as his condition continued to deteriorate. On 5 April 2013 the DCP formulated a detailed care plan for the deceased's medical and social needs.[38]

EVENTS LEADING UP TO DEATH

42. On 24 June 2013 the deceased was re-admitted to PMH as his weight was extremely high, he was not eating, and his urine output was minimal. By 25 June 2013 he had no urine output, indicating kidney failure. At 5.20 pm on 26 June 2013 he died in his sleep.[39]

CAUSE OF DEATH AND HOW DEATH OCCURRED

43. On 2 July 2013, Chief Forensic Pathologist Dr C T Cooke conducted an external examination of the deceased and found a teenage boy of a large build with scarring to the midline of the chest consistent with past heart surgery. Limited toxicological analysis showed the presence of medications.[40]

44. After reviewing the PMH medical file for the deceased, Dr Cooke formed the opinion that the cause of death was consistent with heart failure due to chronic rheumatic heart disease.[41]

45. Dr Ramsay explained that on 24 June 2013 the deceased was admitted with heart failure. When the heart output is so low that the kidneys are not perfused, the kidneys do not function so there is kidney failure, fluid retention and often liver failure.[42]

[38] Exhibit 1, Volume 1, Tab 23B.8
[39] Exhibit 1, Volume 1, Tab 23B
[40] Exhibit 1, Volume 1, Tab 15
[41] Exhibit 1, Volume 1, Tab 15
[42] ts 36 – 37 per Ramsay, J M

46. On the basis of the information available, I am satisfied that the deceased developed chronic rheumatic heart disease, which led to his death from heart failure.

47. I find that death occurred by way of natural causes.

COMMENTS ON THE QUALITY OF SUPERVISION, TREATMENT AND CARE

48. Each of the clinicians familiar with the deceased's treatment and care who gave oral evidence said that the standard of care received by the deceased was appropriate or high.[43]

49. The evidence establishes beyond any doubt that for several years a considerable amount of medical and social support was provided to the deceased by medical professionals, and a similar level of accommodation, travel resources and case management efforts were provided by officers of the DCP to the deceased and his family. It is apparent that the people involved in providing services and support to the deceased and his family did so with enormous goodwill towards them.

50. In my view, the treatment and care which the deceased received while in care was exemplary, but by then it was too late to overcome the effects of several years of deterioration from rheumatic heart disease and the complications which followed the surgery in 2010 to repair his heart valves.

51. The most pertinent issue that has arisen specific to the deceased's case is whether there was avoidable delay by the DCP in taking the deceased into care to ensure that he received appropriate treatment.

52. Dr Chaney considered that there could have been an expedition of interaction between hospitals and the DCP to allow the health professionals to advocate for DCP intervention. He said that, since that time, he has found

[43] ts 19 per Chaney, G; ts 35 per Ramsay, J M; ts 43 per Billinghurst, K

that escalating a challenging case to a high level where senior officers from the Health Department and the DCP become involved has been helpful.[44]

53. Mr Billinghurst considered that there was tension between the expectations of the medical technicians and the ability of the DCP to assist them in the way they wanted. He explained that in hindsight the deceased's case involved a slowly evolving issue from a loving family from a supporting environment where the deceased actually wanted to be. It was not a case in which he was aggressively abused. But the DCP was also limited in its understanding of the evolving complexity of the deceased's ongoing deterioration.[45]

54. When asked how he saw that tension resolving, Mr Billinghurst said that the establishment in 2012 of multidisciplinary team meetings in which the DCP could explain what it could or could not do under its legislation was successful. He also raised the possibility of what he called an intergovernmental ethics committee which could co-ordinate social and medical support for people subjected to rheumatic heart disease.[46]

55. Mr Billinghurst went on to say that the deceased's case was very much an exception, and that the ongoing working relationships that WACHS in the Goldfields has with DCP officers on a frequent and regular basis does not have the tensions that appeared to be occurring with respect to managing the deceased's treatment and care.[47]

56. Mr Geddes considered that the DCP's determination to seek a protection order could have been done in a shorter time frame. He said that the DCP's efforts were initially to try to identify any medical neglect when probably more weight needed to be on the deceased's emerging medical needs. The main issue at the time was whether the deceased's family or the community was capable to meet those needs.

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[44] ts 20 per Chaney, G
[45] ts 45 per Billinghurst, K
[46] ts 46 per Billinghurst, K
[47] ts 47 per Billinghurst, K

57. Consistent with what Mr Billinghurst said, Mr Geddes said that since the deceased's death there has perhaps been an opportunity to have greater dialogue between health professionals and the DCP. He said that in most regional areas there is a reasonably good relationship between the DCP district director and the director of health or the director of the hospital. However, he agreed that the relationship depended on the people in those positions.[48]

58. From a medical management perspective, Dr Chaney felt that, in hindsight, involving the DCP to arrange for foster care at an earlier stage could have improved the deceased's treatment and care.[49]

59. However, Dr Ramsay thought that having the deceased put into the care of the DCP in April 2012 would not have made a lot of difference to the deceased's clinical course because he was still having medical care in Kalgoorlie under a cardiologist.[50] Dr Ramsay thought that the fact that the heart operation was not as successful as expected was significant, but that they certainly tried to get the deceased the best care that they could.[51]

60. It seems that, in hindsight, it would have been preferable for the DCP to have taken steps to take the deceased into care at an earlier stage, but the reticence to have done so is understandable given that there was no evidence of abuse or malicious neglect of the deceased by his family. To the contrary, though his family were unable to provide the level of care necessary for his complex treatment, on all accounts they loved and supported him. In such circumstances, the concept of removing him from his family to put him into foster care would, as Mr Billinghurst said, 'not have been looked on very favourably'.[52]

61. In addition, though the DCP did not apply for a protection order in early 2012, it did arrange for alternate

[48] ts 51 – 52 per Geddes, A
[49] ts 20 – 21 per Chaney, G
[50] ts 35 per Ramsay, J M
[51] ts 36 per Ramsay, J M
[52] ts 45 – 46 per Billinghurst, K

accommodation with a view to improving the deceased's care, so it was not as if the DCP did not intervene at all. The information available was that the carers in the group home were well-placed to meet the deceased's medical needs.[53] Unfortunately the deceased's placement in the group home did not meet expectations.[54]

62. In the light of the foregoing, I am satisfied that the treatment and care provided to the deceased before January 2013 was appropriate, given the circumstances. I am also satisfied that the current co-ordination of medical services and child protection has improved since that time.

CONCLUSION

63. While it is clear that the deceased received a high level of medical and social care in an attempt to overcome the effects of rheumatic fever and rheumatic heart disease, it is worth noting Dr Ramsay's evidence in relation to rheumatic fever in Western Australia.

64. Dr Ramsay visits the East and West Kimberley regions every six months to conduct clinics. He said that rheumatic fever occurs in Western Australia in Indigenous children aged between five and 14 as frequently as in third world places such as Africa, South America and the Middle East where the incidence of the disease is high. Only 1% of cases in Australia are non-Indigenous.[55]

65. One attack of rheumatic fever will likely lead to some damage of the heart valves in 50% of children. The chances of a second attack occurring is very high, and each time there is a further attack, there is a good chance of heart disease.[56]

66. The only ongoing medicine for rheumatic fever is a monthly bicillin injection and, if the injection is

[53] Exhibit 1, Tab 22.1.2
[54] ts 21 per Chaney, G
[55] ts 25 per Ramsay, J M
[56] ts 25 per Ramsay, J M

administered regularly, a further attack of rheumatic fever is very uncommon. It is crucial that the monthly doses of bicillin are not missed, but 50% of patients do not get 50% of their injections. About 20% of occurrences of acute rheumatic fever are recurrences because patients have missed their injections.[57]

67. Dr Ramsay said that the high incidence of rheumatic fever in Indigenous populations and not elsewhere is probably related to social circumstances and overcrowding, especially in the remote communities. There also appears to be a genetic link.[58]

68. Dr Ramsay said that there has been an effort over the last 10 years to educate medical staff at remote community clinics, and a rheumatic heart disease register was set up in 2009 to assist with returning patients. He said that in the East and West Kimberley there has been a drop in the incidence of recurrences from 30-35% to about 20% in the last five or six years,[59] but that the incidence in 2017 is probably similar to what it was in 1986.[60]

69. That rheumatic fever even exists in Western Australia is a matter of concern, adding to concerns about the well-publicised poor social conditions of a high proportion of Indigenous Western Australians living in remote areas.

70. The evidence adduced during this inquest does not provide sufficient information to allow me to comment on possible improvements that can be made to attempt to eradicate rheumatic fever and rheumatic heart disease in Western Australia; however, it seems clear that addressing poor social conditions lies at the heart of any solution.

B P King
Coroner
28 August 2017

[57] ts 27 and 34 per Ramsay, J M
[58] ts 38 per Ramsay, J M
[59] ts 37 per Ramsay, J M
[60] ts 39 per Ramsay, J M