JURISDICTION	**:**	CORONER'S COURT OF WESTERN AUSTRALIA
ACT	**:**	CORONERS ACT 1996
CORONER	**:**	PHILIP JOHN URQUHART, CORONER
HEARD	**:**	27 JUNE 2023
DELIVERED	**:**	17 NOVEMBER 2023
FILE NO/S	**:**	CORC 1162 of 2021
DECEASED	**:**	CHILD MD

Catchwords:

Nil

Legislation:

Nil

Counsel Appearing:

Counsel Assisting	:	J. TILLER assisted the Coroner.
Counsel	:	G. BECK appeared on behalf of the Department of Communities, Child and Adolescent Health Service and North Metropolitan Health Service.

Case(s) referred to in decision(s):

Nil

Coroners Act 1996
(Section 26(1))

RECORD OF INVESTIGATION INTO DEATH

*I, Philip John Urquhart, Coroner, having investigated the death of a male child referred to as **CHILD MD** with an inquest held at Perth Coroner's Court, Central Law Courts, Court 85, 501 Hay Street, Perth, on 27 June 2023, find that the death of **CHILD MD** occurred on 12 May 2021 at Perth Children's Hospital, 15 Hospital Avenue, Nedlands, from multiorgan failure in a boy with clinically suspected sepsis and Cockayne syndrome in the following circumstances:*

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LIST OF ABBREVIATIONS

Abbreviation	Meaning
the Act	*Children and Community Services Act 2004* (WA)
the Armadale District	the Armadale District of the Department of Communities
CAHS	Child and Adolescent Health Service
CEO	Chief Executive Officer of the Department of Communities
the Department	the Department of Communities
the Guideline	Children's Antimicrobial Management Program Guideline for Sepsis and Bacteraemia: Paediatric
ICU	intensive care unit
KEMH	King Edward Memorial Hospital
PCH	Perth Children's Hospital
PEG	percutaneous endoscopic gastrostomy
the Review	Mortality and Morbidity Review Committee's Mortality Review

SUPPRESSION ORDER

Suppression of the deceased child's name from publication and any evidence likely to lead to the child's identification.

The deceased is to be referred to as Child MD.

INTRODUCTION

"Some are bound to die young. By dying young a person stays young in people's memory. If he burns brightly before he dies, his brightness shines for all time."
Aleksander Solzhenitsyn - author.

1 Child MD died at Perth Children's Hospital (PCH) on 12 May 2021. He died from multiorgan failure with clinically suspected sepsis and Cockayne syndrome, a rare life-limiting condition. Child MD was two months shy of his third birthday.

2 At the time of his death, Child MD was in the care of the Chief Executive Officer (CEO) of the Department of Communities (the Department). Accordingly, immediately before his death, Child MD was a "*person held in care*" within the meaning of the *Coroners Act 1996* (WA) and his death was therefore a "*reportable death*".[1]

3 In such circumstances, a coronial inquest is mandatory.[2] Where, as here, the death is of a person held in care, I am required to comment on the quality of the supervision, treatment and care the person received from the Department whilst in that care.[3]

4 I held an inquest into Child MD's death at Perth on 27 June 2023. The following witnesses gave oral evidence:

(i) Dr Rebecca Cresp (General Paediatrician at PCH[4]);

(ii) Dr Benjamin Kamien (Consultant Clinical Geneticist at Genetic Services of Western Australia);

[1] *Coroners Act 1996* (WA) s 3
[2] *Coroners Act 1996* (WA) s 22(1)(c)
[3] *Coroners Act 1996* (WA) s 25(3)
[4] This was Dr Cresp's position at the time of Child MD's death

(iii) Dr Katherine Douglas (Consultant, Paediatric Intensive Care Unit, at PCH); and

(iv) Mr Glenn Mace (Executive Director, Services and Delivery, at the Department).

5 The documentary evidence at the inquest comprised of two volumes which were tendered at the commencement of the inquest as exhibit 1. On behalf of Child and Adolescent Health Service (CAHS), Ms Beck tendered at the inquest a letter from the Chief Pharmacist at PCH dated 26 June 2023, which became exhibit 2. Ms Beck also handed up an additional statement from Dr Katherine Douglas dated 26 June 2023. This statement (with attachments) was placed in exhibit 1 and marked tab 17.4. Ms Beck also tendered on behalf of CAHS a document titled "Sepsis Pathway" which is currently being used at PCH. That document became exhibit 3.

6 Child MD's family foster carer also provided some material to the Court by email dated 13 November 2023 which included a number of photographs of Child MD. I thank the foster carer for this further information which simply confirmed what I had heard at the inquest regarding this lady's outstanding commitment, care and love that she so clearly demonstrated to Child MD during his short life.

7 The inquest focused on the management of Child MD's medical conditions and the involvement of the Department in his life.

8 On the basis that it would be contrary to the public interest, the State Coroner issued a suppression order with respect to Child MD's name on 2 March 2023, pursuant to section 49 (1) of the *Coroners Act 1996* (WA). The terms of that order are set out above.

CHILD MD'S MEDICAL ISSUES

Background [5]

9 Child MD was born at King Edward Memorial Hospital (KEMH), Subiaco, on 1 July 2018. He was born at 37 weeks gestation by an emergency caesarean section. The emergency caesarean section was necessary due to decreased foetal movements.

10 The identity of Child MD's father could not be confirmed due to conflicting information provided by his mother.

[5] Exhibit 1, Volume 1, Tab 12, Department of Communities Report dated 17 September 2021

11 Shortly after he was born, Child MD was admitted to the neonatal intensive care unit (ICU) at KEMH. He was admitted to ICU due to hypotonia (decreased muscle tone) and other congenital abnormalities.

12 On 24 September 2018, Child MD was admitted to PCH with acute bronchiolitis. He remained at PCH until 10 October 2018.

Diagnosis [6]

13 The presence of multiple congenital anomalies raised the suspicion that Child MD had some form of underlying genetic syndrome. These abnormalities included unusual facial features, bilateral vertical talus (club foot), arthrogryposis of his legs and hands (multiple joint contractures), microcephaly (small head), microphthalmia (small eyes), congenital cataracts, severe deafness and undescended testes. Due to these abnormalities, Child MD had growth failure and severe global developmental delay.

14 Dr Benjamin Kamien (Dr Kamien), a consultant clinical geneticist at Genetics Services of Western Australia, initially saw Child MD when he was eight days old. Although Dr Kamien identified that Child MD most likely had a genetic syndrome, it was difficult to diagnose the precise syndrome at such a young age.

15 After seeing Child MD on 9 April 2019, Dr Kamien identified Cockayne syndrome as one of the differential diagnoses. This diagnosis was subsequently confirmed following genetic testing that found two causative faults in the ERCC6 gene, which is the gene that causes Cockayne syndrome.

16 Cockayne syndrome is not a curable condition and those who are diagnosed with it have a limited life expectancy. It is also an extremely rare syndrome, with Child MD being only the second case diagnosed by Genetics Services of Western Australia.[7] Sadly, Child MD had a very severe case of Cockayne syndrome and his life expectancy was expected to be no greater than five years.

17 As Cockayne syndrome causes growth failure, progressive microcephaly and developmental delay, it is followed by progressive behavioural and intellectual deterioration. Individuals will also have dental anomalies, sun

[6] Exhibit 1, Volume 2, Tab 6, Statement of Dr Rebecca Cresp dated 19 June 2023; Exhibit 1, Volume 2, Tab 7.1, Statement of Dr Benjamin Kamien dated 17 June 2023
[7] ts 27.6.23 (Dr Kamien), p.28

sensitivity and a characteristic physical appearance. As explained by Dr Kamien:[8]

> Cockayne syndrome is life limiting because the ERCC6 gene controls DNA repair mechanisms. Specifically, it affects the ability of cells to repair DNA damage caused by normal metabolic processes and environmental factors such as ultraviolet (UV) radiation. The accumulation of DNA damage over time can lead to cellular dysfunction and tissue degeneration, ultimately affecting organ function.

Overview of Child MD's medical treatment [9]

18 As there is no treatment to cure Cockayne syndrome, medical management is mainly supportive and is aimed towards improving quality of life.

19 A number of specialists were involved in Child MD's care and included those practising in the fields of general surgery, paediatric rehabilitation, neurology, ear nose and throat surgery, plastic surgery, ophthalmology, gastroenterology, occupational therapy, physiotherapy, dietetics and speech pathology. Wherever possible, Child MD's care was provided closer to where his foster carer lived, and Boddington Hospital was able to facilitate much of his therapy with support from PCH.

20 Child MD required multi-disciplinary treatment and interventions in respect of the following conditions:

a) Bilateral vertical talus, which required surgery by an orthopaedic surgeon on 8 April 2019 and ongoing physiotherapy.

b) Arthrogryposis, which involved regular reviews with rehabilitation medicine, physiotherapy and occupational therapy. Splints were also provided to Child MD's hands and feet to ensure these joints were held in an optimal position. There also was hip monitoring through the orthopaedics clinic.

c) Congenital cataracts and severe visual impairment which involved cataract surgery to both eyes on 12 November 2018, glasses, and management and review by an ophthalmologist.

d) Severe hearing impairment which required regular review and management by surgeons, a bilateral myringotomy and grommet insertion on 31 January 2019, the provision of hearing aids on 12 June 2019 and cochlear implants at the end of 2019.

[8] Exhibit 1, Volume 2, Tab 7.1, Statement of Dr Benjamin Kamien dated 17 June 2023, p.3
[9] Exhibit 1, Volume 2, Tab 6, Statement of Dr Rebecca Cresp dated 19 June 2023

e) Undescended testes which involved review and management by paediatric surgery and a bilateral orchidopexy on 10 August 2020.

f) Global developmental delay which was regularly reviewed by the Paediatric Early Intervention Team and involved input from speech pathology, occupational therapy and physiotherapy at PCH and Boddington Hospital.

21 In August 2020, a PEG (percutaneous endoscopic gastrostomy) feeding tube was inserted, as Child MD was not able to manage feeding when he was unwell.

Child MD's liver function [10]

22 Child MD initially had mildly abnormal liver function test results in September 2018. Abnormal results were again recorded in August 2019. It was noted that on both of these occasions Child MD had a virus. Abnormal liver function testing is common for children in the context of systemic illnesses such as viruses. After the second abnormal liver results, a gastroenterologist reviewed Child MD and determined that the results were secondary to the viral infections and that no further management was required at the time.

23 Nevertheless, further liver function tests in October 2020 showed a worsening liver function. A referral was subsequently made to the Liver Clinic at PCH at the end of 2020. It was felt that Child MD's underlying Cockayne syndrome was the most likely cause for the results of this testing.

EVENTS LEADING TO CHILD MD'S DEATH [11]

24 Of the evening of 25 April 2021, Child MD was taken to Boddington Hospital with increased lethargy, poor oral intake, and vomiting. His blood sugar level was noted to be low, and he was given glucose and orange juice. Child MD was also administered antibiotics for possible sepsis. However, as intravenous access could not be achieved, he was urgently transferred by Royal Flying Doctor Service to PCH, arriving just before midnight.

25 Child MD was admitted straight to the paediatric ICU at PCH. Blood testing showed raised septic markers, acute liver failure, coagulopathy, acute kidney injury and an elevated lactate level. The working diagnosis was sepsis and dehydration.

[10] Exhibit 1, Volume 2, Tab 6, Statement of Dr Rebecca Cresp dated 19 June 2023

[11] Exhibit 1, Volume 2, Tab 6, Statement of Dr Rebecca Cresp dated 19 June 2023; Exhibit 1, Volume 1, Tab 17.3, Report of Dr Katherine Douglas dated 23 June 2021; Exhibit 1, Volume 1, Tab 17.4, Statement of Dr Katherine Douglas dated 26 June 2023

26 Child MD initially made steady improvement. However, on 29 April 2021, he deteriorated with severe cardiorespiratory collapse and multiorgan dysfunction. Although Child MD subsequently had improvement in cardiovascular function, the severe ongoing respiratory failure and renal impairment remained with no signs of meaningful neurological recovery.

27 There were many multi-disciplinary team discussions which involved Child MD's foster carer, his extended family and officers from the Department. On 4 May 2021, it was agreed that Child MD would not be resuscitated in the event of a cardiac arrest. Child MD continued to deteriorate over the following days, and developed further medical complications.

28 Another multi-disciplinary meeting was held on 10 May 2021. By this stage it had become clear Child MD was likely to die from lung disease. Despite maximum support, his oxygen saturation levels were between 43% and 82%. These levels indicated severe hypoxia (reduced blood flow to the brain) that would lead to multiorgan failure.

29 At the final multi-disciplinary meeting on 11 May 2021, it was determined that the most appropriate option for Child MD was to withdraw medical care other than what was required to keep him comfortable. As Dr Rebecca Cresp (Dr Cresp), general paediatrician at PCH, noted:[12]

> It was discussed that if he survived, his neurological status would be significantly worse than prior to the illness and that further escalation of care would be against his best interests. A decision to withdraw medical care beyond nasogastric feeding and analgesia/sedation was felt to be most appropriate. This decision was agreed by all attending the meeting, including myself.

30 At 5.30 pm on 12 May 2021 all infusions, apart from fentanyl for pain management, were ceased. Child MD's breathing tube was removed at 6.50 pm and he died at 7.15 pm.

CAUSE AND MANNER OF DEATH [13]

31 On 17 May 2021, Doctor Reimar Junckerstorff (Dr Junckerstorff), a forensic pathologist, conducted a post mortem examination of Child MD's body.

[12] Exhibit, Volume 2, Tab 6, Statement of Dr Rebecca Cresp dated 19 June 2023, p.11

[13] Exhibit 1, Volume 1, Tabs 7.1- 7.3, Supplementary Post Mortem Report, Full Post Mortem Report and Interim Post Mortem Report dated 17 May 2021; Exhibit 1, Volume 1, Tab 8, Toxicology Report dated 16 June 2021; Exhibit 1, Volume 1, Tab 9, Neuropathology Report dated 14 June 2021

32 Dr Junckerstorff noted that Child MD had reduced height and head size for his age and there were signs of medical intervention. His liver was congested, and his brain was reduced in weight. There was also evidence of middle ear effusions in both inner ears.

33 Microscopic examination of Child MD's heart showed no significant abnormalities. His lungs showed focal bronchopneumonia and diffuse alveolar damage (injury to lung tissue), a finding that may be seen in individuals with severe illness, including sepsis. Child MD's liver showed changes of obstruction to blood flow (veno-occlusive disease/hepatic sinusoidal obstruction), a cause of which could not be determined. Child MD's left kidney had a fungal infection, most likely due to his severe illness.

34 Specialist neuropathology examination of Child MD's brain showed findings consistent with Cockayne syndrome.

35 Microbiology testing detected mixed bacteria and a fungus, identified as *Candida tropicalis*, in Child MD's airway and middle ears.

36 A review of x-rays and a post mortem CT scan of Child MD's entire body showed longstanding congenital cerebral abnormalities and generalised subcutaneous oedema.

37 Toxicological analysis detected the presence of medications used in Child MD's hospital care.

38 Dr Junckerstorff also noted:[14]

> The cause of the liver failure in this boy is uncertain. The literature states that individuals with Cockayne syndrome (a neurodegenerative disorder) can have abnormal liver function tests, as was the case in this boy; however, the underlying cause for this is not known. There was a clinical concern of possible liver injury from normal doses of paracetamol; however, the microscopic appearance of the liver tissue was not that of paracetamol toxicity.

39 Dr Katherine Douglas (Dr Douglas) was a Consultant with the Paediatric ICU at PCH who treated Child MD during his final hospital admission. Dr Douglas stated that although Child MD's liver abnormalities were not caused by sepsis, infections were among the cause of liver failure. Dr Douglas also noted that Child MD had some form of an earlier infection as he was experiencing vomiting and diarrhoea in the two days before his admission to PCH on 25 April 2021.[15] However, Dr Junckerstorff reported there was no bacterial infection in Child MD's lungs, blood, spleen and

[14] Exhibit 1, Volume 1, Tab 7.1, Supplementary Post Mortem Report dated 17 May 2021, p.1
[15] Exhibit 1, Volume 1, Tab 17.4, Statement of Dr Katherine Douglas dated 26 June 2023, p.7

spinal fluid. Nor was there any viral infection of his heart, lungs, airways and spinal fluid.

40 At the inquest, Dr Douglas agreed that Child MD's liver was not functioning very well during his final admission at PCH. Although, she added:[16]

> However, it was functioning adequately in that he could maintain normal blood clotting and normal glucose metabolism. So he wasn't in liver failure at the time of his death because we could see the effects in his body of a failed liver. His liver maintained some function at the time he died. I'm sorry that doesn't fit with [the opinion of] the pathologist.

41 At the conclusion of the post mortem examination, and after reviewing the results of the other examinations, Dr Junckerstorff had initially expressed the opinion that the cause of Child MD's death was "*liver failure in a boy with Cockayne syndrome*."[17] This was the opinion from the forensic pathologist that Dr Douglas was referring to in her evidence at the inquest which I have cited above.

42 In light of the evidence from Dr Douglas that Child MD was not experiencing liver failure when he died and her observation that infections are a cause of liver failure, I raised these matters with Dr Junckerstorff after the completion of the inquest. Specifically, I asked whether Dr Douglas' opinion regarding the functioning of the liver at the time of Child MD's death altered the forensic pathologist's view as to the cause of death and if it did not, whether the liver failure was due to an infection.

43 At Dr Junckerstorff's request, I provided the relevant material from Dr Douglas.[18] I also provided to Dr Junckerstorff the passage from Dr Douglas' evidence from the inquest that is cited above.[19]

44 After a consideration of this additional information, Dr Junckerstorff was of the view that the cause of Child MD's death would be more accurately described as, "*multiorgan failure in a boy with clinically suspected sepsis and Cockayne syndrome.*"[20]

45 I accept and adopt that conclusion expressed by Dr Junckerstorff as to the cause of death.

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[16] ts 27.6.23 (Dr Douglas), p.48
[17] Exhibit 1, Volume 1, Tab 7.1, Supplementary Post Mortem Report dated 17 May 2021, p.1
[18] Exhibit 1, Volume 1, Tab 17.3, Report of Dr Katherine Douglas dated 23 June 2021; Exhibit 1, Volume 1, Tab 17.4, Statement of Dr Katherine Douglas dated 26 June 2023
[19] Email from the Court to Dr Reimar Junckerstorff dated 8 November 2023
[20] Email from Dr Reimar Junckerstorff to the Court dated 13 November 2023

46 Dr Junckerstorff also expressed the opinion that Child MD's death was due to natural causes and I also accept and adopt that conclusion.

COMMENTS ON CHILD MD'S MEDICAL CARE [21]

47 Following the death of Child MD, PCH's Mortality and Morbidity Review Committee prepared a Mortality Review dated 3 August 2021 (the Review). The Review was completed by Dr Douglas.

48 As to the questions whether there were delays in diagnoses/assessment and initiating treatment when Child MD was admitted to PCH on 25 April 2021, Dr Douglas answered, "*Yes*". She also answered, "*Yes*" to the question whether Child MD's care management deviated from relevant policy or guideline.

49 However, in a statement provided to the Court dated 26 June 2023,[22] Dr Douglas clarified her answers in the Review that stated there were failures by emergency department clinicians at PCH to broaden Child MD's antibiotics and discuss his case with the emergency department's on-call consultant (the consultant).

50 Upon a closer examination of PCH's "*Children's Antimicrobial Management Program (ChAMP) Guideline for Sepsis and Bacteraemia: Paediatric*"[23] (the Guideline), and with the benefit of hindsight, Dr Douglas considered it was a reasonable approach for the emergency department clinicians to treat Child MD with ceftriaxone as the sole antibiotic agent.

51 As to the failure to contact the consultant, Dr Douglas subsequently formed the view that in accordance with the Guideline, the medical records showed that sepsis was the working diagnosis for the emergency department clinicians. In the context of Child MD having none of the criteria for impaired tissue perfusion listed in the Guideline, apart from drowsiness, Dr Douglas expressed the view it was reasonable for the emergency department clinicians to decide not to call the consultant.

52 I accept those explanations from Dr Douglas and I also accept her opinion that treating Child MD with only one antibiotic agent and not calling the

[21] Exhibit 1, Volume 1, Tab 17.2, Mortality Review by Dr Katherine Douglas dated 3 August 2021; Exhibit 1, Volume 1, Tab 17.4, Statement of Dr Katherine Douglas dated 26 June 2023; Exhibit 2, Letter from the Chief Pharmacist at Perth Children's Hospital dated 26 June 2023

[22] Exhibit 1, Volume 1, Tab 17.4, Statement of Dr Katherine Douglas dated 26 June 2023

[23] These are the guidelines used within a hospital to guide appropriate antibiotic therapy: Exhibit 1, Volume 1, Tab 17.4, Statement of Dr Katherine Douglas dated 26 June 2023, attachment KD4

consultant after he was admitted to PCH, did not have any impact on Child MD's overall outcome.[24]

53 Accordingly, I find that Child MD did receive appropriate care and treatment when he was initially admitted to PCH on 25 April 2021.

54 The Review also noted there was a medication error when acetylcysteine was incorrectly given to Child MD intravenously rather than by nebulised means (i.e. nasal). This occurred on two occasions. I accept Dr Douglas' evidence at the inquest that it was still safe for this medication to be given intravenously to Child MD.[25]

55 Additionally, I accept the following explanation from Christopher Hopps (Mr Hopps), the Chief Pharmacist at PCH, as to the likely reason for this error:[26]

> Intravenous products are typically provided in glass vials or glass ampoules to be opened by trained nurses. Nebulised products are usually provided in plastic ampoules to avoid the need for patients to undertake the difficult task of opening a glass ampoule in order to administer a nebulised medicine, where they risk cutting their fingers in doing so. It is likely that the nebulised form of acetylcysteine being made available in this case in a glass vial, may have caused nursing staff to assume that it was the formulation that is administered intravenously, given that so many other medicines packaged in a vial are administered intravenously.

56 Mr Hopps also outlined the changes made at PCH regarding the manner in which this medication is now made available to nurses from the automated dispensing machines in clinical and ward areas.[27] Mr Hopps has noted that since these changes have been made, he has not been aware of any further incidents where acetylcysteine solution for nebulisation has been administered intravenously in error.[28] Dr Douglas also gave evidence at the inquest that this change to PCH's procedure will avoid such an error happening again.[29]

57 Having carefully considered the documentary and oral evidence in this matter, I am satisfied that Child MD received quality medical treatment at PCH and Boddington Hospital from dedicated and committed hospital staff. Dealing with small children who are gravely ill will often be a gruelling and emotionally exhausting experience and I am satisfied the care provided to

[24] ts 27.6.23 (Dr Douglas), pp.51-52
[25] ts 27.6.23 (Dr Douglas), p.38
[26] Exhibit 2, Letter from the Chief Pharmacist dated 26 June 2023
[27] Exhibit 2, Letter from the Chief Pharmacist dated 26 June 2023, pp.2-5.
[28] Exhibit 2, Letter from the Chief Pharmacist dated 26 June 2023, p.6
[29] ts 27.6.23 (Dr Douglas), pp.38-39

Child MD by his many health service providers during his short life was professional and compassionate.

THE DEPARTMENTS INVOLVEMENT WITH CHILD MD [30]

Contact with the Department by Child MD's mother before his birth

58 Child MD's mother first came to the attention of the Department in 1994. As of 17 September 2021, she had been named in 90 interactions.[31] As a child herself, Child MD's mother was subject to initial enquiries for neglect in 1994 and physical harm in 2009. Between December 2014 to April 2020, Child MD's mother was named in 16 Family and Domestic Violence Incident Reports involving her ex-partners and relatives.

59 In January 2018, the Department became aware that Child MD's mother was pregnant. On 26 February 2018, due to existing concerns involving mental health, drug use and exposure to family and domestic violence, the Department completed an intake for the as yet unborn Child MD for neglect and commenced pre-birth planning. Contact was subsequently maintained with Child MD's mother in the months before his birth.

Child MD is placed into the care of a foster carer from his family

60 On 2 July 2018, the day after Child MD's birth, the Armadale District of the Department (the Armadale District) commenced a Safety and Wellbeing Assessment.[32] On that day, a decision to take intervention action was made pursuant to section 32(1)(e) of the *Children and Community Services Act 2004* (WA) (the Act).

61 On 3 July 2018, Child MD was placed into the provisional protection and care of the CEO of the Department, pursuant to section 35(1)(b) of the Act.

62 On 4 July 2018, the Armadale District filed an application for a warrant pursuant to section 35 of the Act in the Children's Court and the warrant was granted on the same day.

63 Child MD was able to be placed with a family foster carer whose application had been approved by a District Director from the Department on 23 July 2018. Child MD was placed into her care the next day and he remained with this foster carer until he died.

[30] Exhibit 1, Volume 1, Tab 12, Department of Communities Report dated 17 September 2021; Exhibit 1, Volume 2, Tabs 1-4, Department of Communities Records regarding pre-birth interactions, post-birth interactions, Cockayne syndrome and medical records

[31] An "interaction" is an electronic record detailing the referrer information, details of contact and initial assessment

[32] "A Safety and Wellbeing Assessment" (now known as a "Child Safety Investigation") is undertaken by authorised officers from the Department to determine if harm is substantiated

64 On 15 January 2019, the Children's Court granted a time-limited Protection Order for a period of two years, pursuant to section 48(2) of the Act.

65 On 11 January 2021, the Armadale District filed an application, supporting affidavit, and Written Proposal for the Child in the Children's Court. The application sought orders that the time-limited Protection Order made on 15 January 2019 be revoked and replaced by a Protection Order until Child MD had reached the age of 18 years. Given the lack of engagement by Child MD's mother to work towards a future reunification with her son, the Department decided to make the application for this Protection Order.[33]

The Department's care, supervision and treatment of Child MD

66 I am satisfied it was appropriate for Child MD to be brought into the provisional protection and care of the Department's CEO following his birth. Sadly, there was a sound basis to substantiate the likelihood of neglect, emotional abuse and physical abuse should he have remained in the care of his mother. In addition, I am satisfied it was necessary for the application to be made that Child MD was to remain in the protection and care of the Department's CEO until he had reached the age of 18 years.

67 I am also satisfied that the decision to appoint the family member who became Child MD's foster carer was commendable. She was clearly a dedicated and committed carer for Child MD. From 1 August 2018 to 18 March 2021, she took Child MD to no less than 89 appointments at PCH.[34] Each trip from Boddington to PCH and back was about 260 km.

68 In my time as a coroner, I have never encountered the extent of the praise given to Child MD's foster carer. As Mr Glenn Mace said at the inquest, she was, "*an incredibly committed foster carer who, under very difficult circumstances, provided fabulous care, and from what I can see, we couldn't have asked for more of the carer.*"[35]

69 Dr Cresp was able to observe that Child MD, "*seemed to bring joy to his carer, and she joy to him*."[36] And she described Child MD's foster carer as:[37]

> She was amazing. She was one of the most amazing and incredible foster mothers that I have ever had the privilege of working with. She always put his care first, needing to come to appointments, needing to do so much stuff in Perth, impacted so much on her life and on the other things that were going on

[33] ts 27.6.23 (Mr Mace), pp.64-65
[34] Exhibit 1, Volume 1, Tab 12, Department of Communities Report dated 17 September 2021, pp.17-18
[35] ts 27.6.23 (Mr Mace), p.66
[36] ts 27.6.23 (Dr Cresp), p.12
[37] ts 27.6.23 (Dr Cresp), p.21

> for her and she always did it. And any care that needed to be given to him, she was always very considerate of whether that care [was] really necessary and always asked really intelligent questions around what we needed to do and why was that appropriate. She was just absolutely amazing.

70 On the basis of the evidence contained in exhibit 1 and the oral evidence from Mr Mace, I am satisfied that the care, supervision and treatment provided to Child MD by the Department and his foster carer was of a very high standard.

CONCLUSION

71 Child MD was born with a rare disorder known as Cockayne syndrome. It is a life-limiting condition associated with global developmental delay, growth impairment, microcephaly and visual impairment. It is not only incurable but, sadly for Child MD, he was at the most severe end of this syndrome and only had an estimated life expectancy of five years.[38]

72 Despite a broad range of treatments and many hospital admissions during his short life, including a number of surgical procedures, Child MD eventually succumbed to complications from Cockayne syndrome. He died in the arms of his much loved foster carer on 12 May 2021.

73 It was clear to me that a very special bond existed between Child MD and his foster carer. This bond was described by Dr Cresp at the inquest:[39]

> … this little boy was loved, and he loved back, and he had a short life, but I do think he had an impact on a lot of people. With his short life, he was a lovely special little boy, and he had an amazing special foster mother.

74 And in the words of Child MD's foster carer:[40]

> He had a beautiful smile, a cheeky attitude and I took one day at a time. With [the] condition that he had, they told me that he might not live a full life so I made every day so special for him … and I will treasure every moment that I had with him.
>
> He's free to run with the angels, no more pain, no more operations. … He was my son even though we never had the same DNA, but he was my son and I, his mother.

75 On behalf of the Court, I extend to the family members and loved ones of Child MD, and particularly his foster carer, my sincere condolences for their sad loss.

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[38] Exhibit 1, Volume 1, Tab 17.3, Report of Dr Katherine Douglas dated 23 June 2021, p.1
[39] ts 27.6.23 (Dr Cresp), p.22
[40] Email to counsel assisting from Child MD's foster carer dated 11 November 2023

P J Urquhart
Coroner
17 November 2023