Coroners Act 1996
[Section 26(1)]

Western  *Australia*

RECORD OF INVESTIGATION INTO DEATH

Ref No: 45/18

I, Evelyn Felicia Vicker, Deputy State Coroner, having investigated the death of ***SM*** *with an Inquest held at* ***Perth Coroners Court, Court 85, Central Law Courts, 501 Hay Street, Perth****, on* ***10 & 21 December 2018****, find the identity of the deceased child was* ***SM*** *and that death occurred on* ***2 August 2014*** *at* ***Princess Margaret Hospital*** *as the result of* ***complications following Cardio Respiratory Arrest in association with a Seizure in a young boy with Bronchopneumonia on a background of Cerebral Palsy and Chronic Seizure Disorder*** *in the following circumstances:-*

Counsel Appearing:

Mr D Jones assisted the Deputy State Coroner
Mr M Williams (Minter Ellison) appeared on behalf of Joondalup Health Campus
Ms N Eagling (State Solicitor's Office) appeared for Child and Adolescent Health Service and Department of Communities

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SUPPRESSION ORDER

That the name of the deceased and any identifying information be suppressed from publication. The deceased is to be referred to as 'SM'.

INTRODUCTION

The deceased child (SM) was a seven year old Aboriginal boy taken into the care of the CEO of the Department of Communities, then called the Department of Child Protection and Family Support (the Department), on 5 February 2013 at the request of his mother. He came from the Yakanarra Aboriginal Community (Yakanarra) approximately 60kms as the crow flies southwest of Fitzroy Crossing. He had profound disabilities and was only able to smile and vocalise loud sounds, but not words. He was fed by a percutaneous endoscopic gastrostomy (PEG) tube and required 24/7 care. His biological parents had separated and he had extended periods of care at Derby Regional Hospital (DRH) which consultant paediatricians found unsuitable for his situation. Following being taken into care he was transferred to the high needs unit at Lady Lawley Cottage (LLC) in Cottesloe on 18 March 2013 until suitable carers could be found.

The Department used Senses Foundation Australia (Senses Australia) when finding carer parents and ultimately placed SM with a carer family. SM was placed in their care on 28 April 2014. They already had two young children of their own.

Multiple agencies were involved in the provision of care to SM. It was noted his health had been deteriorating since his placement in family care by way of increased seizure activity and respiratory infection, however, he had also increased in weight during that time and appeared to enjoy being part of a family unit.

Immediately prior to his death SM had again been admitted to Joondalup Health Campus (JHC) with a respiratory infection. He was at JHC from 27 July to 31 July 2014 before being discharged back to his carer parents who were reluctant to accept his discharge due to their fatigue and the fact their small children were unwell.

On 1 August 2014 SM's carer father returned him to JHC due to in excess of 20 seizures since he had returned home. Discussions were held with Princess Margaret Hospital (PMH) and it was decided SM would be transferred to PMH. PMH were initially undecided as to where he was best managed and he was eventually admitted under the general paediatric team. Unfortunately SM's condition deteriorated and sometime before 6.20am on 2 August 2014 he became unresponsive. SM was resuscitated and placed in paediatric ICU where he remained while attempts were made to locate his biological mother. These were unsuccessful. Eventually SM was removed from life support and died at 6.15 pm on 2 August 2014.

SM was 7 years of age.

At the time of his death SM was a child in care of the Department and pursuant to the *Coroners Act 1996* (WA) (the Act) (section 3, s 22 (1)(a)) there must be an inquest into the circumstances surrounding the death of a child in the care of the Department's CEO. In addition by way of section 25 (3) of the Act the coroner hearing that inquest must comment on the supervision, treatment and care of that child while in that care.

The evidence with respect to this matter comprised three volumes of documentary evidence, Exhibits 1-3, additional documentary exhibits received during the inquest and the oral testimony of representatives of the Department, a nurse and consultant paediatrician from PMH and an overview by a consultant paediatrician with practices at both JHC and PMH.

BACKGROUND

The Deceased

SM was born on 10 October 2006 and was from the Yakanarra Community which is a two hour drive over difficult terrain south-west of Fitzroy Crossing in the Kimberley. Conditions in the community were often unhygienic due to overcrowding and limited resources.

SM was the youngest child of four to his biological parents. The relationship between his parents was characterised by domestic violence due to his biological father's excessive alcohol use. His mother attempted to act proactively by ending

the relationship and none of her other children from this group of siblings have been in the care of the Department. SM's biological mother did her best to care for SM in her environment, however, found the task too difficult due to the deceased's considerable disabilities. This resulted in her asking the authorities to care for SM on her behalf while she kept her other children safe.

While the Department had been aware of SM's family prior to his birth no interventions had been undertaken and the first concern for SM himself was communicated to the Department on 2 January 2007 when a paediatrician at DRH contacted the Department for assistance for SM. His biological mother had taken him to the hospital three weeks earlier and had not returned. The hospital's concern was in locating his mother to have her return to DRH to discuss the situation concerning SM.[1] Due to the deceased's significant disabilities assistance was sought for his family through the Disability Services Commission (DSC) and the local area coordinator at the Department's Fitzroy Crossing office.

SM's health and medical needs clearly could not be accommodated at Yakanarra where any medical emergency required transport by small plane to DRH.

SM's mother was having great difficulty caring for SM and although she had been able to secure suitable medical intervention when necessary, she was not in a position to

[1] Ex 1, tab 21

continue with what she, and the Department, considered to be appropriate care of SM which was an ongoing and unrelenting situation.

By March 2012 it was made clear to staff at DRH that SM's biological mother could not care for SM and she wanted the Department to take him from her care into a more suitable environment.

Both DRH and the Department worked together and sought accommodation for SM at LLC Respite Facility in Cottesloe, but LLC was adamant it was unable to provide long term accommodation without there being full cooperation between the Department and DSC. After some toing and froing between the various organisations and SM's mother, it became apparent it was unrealistic for SM's mother to continue to care for him in the environment in which she and her family lived. While there were no concerns with her attempts to care for SM it was clear it was totally impracticable and eventually, following entirely appropriate intervention by Dr Stephen Bilkey, Paediatrics Senior Registrar Kimberley Region, Broome Health Services, it was conceded SM's continued long term stay at DRH was detrimental to any possible development for SM.[2] A referral was also provided to LLC for a respite period of six months.

SM was returned to his mother pending the respite placement on 3 September 2012, however, he was returned to DRH on

[2] Ex 1, tab 21 attachments 2 & 3

22 September 2012 because SM's mother was unwell and unable to care for him. SM remained at DRH until 15 November 2012 when DRH again raised concerns about SM remaining hospitalised and the difficulty in accessing a suitable respite placement for him. It was unrealistic for the Department to expect SM's mother to care for him, despite her wish he be well looked after and raised with some cultural awareness.

SM's biological mother clearly understood the implication this would see SM removed from her care and the Department would take responsibility for his future needs. It was impossible for her to look after SM as he needed to be looked after, no matter how willing she may have been.

SM was taken into provisional care of the Department and on 5 February 2013 a protection order until SM was 18 years of age was granted.[3]

SM was then placed at LLC on 18 March 2013, while the Department sought long term carers for SM suitable to his needs and requirements. The Fitzroy Crossing office remained responsible for SM's case management and had a co-working arrangement with the Joondalup office while the Department sought a suitable placement for SM through Senses Australia.

[3] Ex 1, tab 3

Medical Context

SM was born on 10 October 2006 in Derby Hospital by emergency caesarean section due to foetal distress. He required intubation and ventilation at birth and investigations showed extensive ischaemic changes to his brain on both RMI and EEG studies.

SM was diagnosed with severe spastic quadriplegia, cerebral palsy with profound intellectual impairment, seizures likely to increase as he aged and recurrent chest infections resulting in the need for regular aspiration. It was essential this was done in hygienic conditions. He also had a right hip dislocation, significant scoliosis of the spine and muscle contraction. His lack of mobility necessitated 24 hour care. He was unable to vocalise with words, but people in contact with SM noted he was capable of smiling and responded to adverse or positive conditions.

SM's various diagnoses and lack of mobility made him extremely vulnerable to aspiration and therefore chest infections, for which he required regular suctioning and repositioning to assist with his breathing and vulnerability to the developing of pressure sores. He needed to be fed by a PEG tube directly through his abdominal wall to his stomach due to his inability to swallow appropriately. This also required his medications be administered through the tube. Prior to SM being taken into care in February 2013 he had spent the majority of the previous 18 months at DRH with trips to PMH when specific surgery or treatment was required for his many

conditions. It was impossible for his biological family to manage these difficulties as SM grew.

Once SM was taken into care the Department needed to find carers for SM who would be able to provide him with the living interventions he required, but preferably in a family environment due to the consultant paediatricians' view that hospitalisation was not conducive to SM's continued wellbeing.

Once transitioned to LLC SM's medical needs were supervised by PMH and he had regular access to a range of appropriate medical consultants including in gastroenterology, rehabilitation, diet and orthopediatrics.[4]

SM was registered with a general practitioner (GP) at Mosman Park Medical Centre and in August 2013 his medical needs were coordinated by the Ambulatory Care Coordination (ACC) program to develop integrated health care plans for SM. The intention was the plans would be regularly updated and provided to all carers involved in SM's ongoing development. They included a strict medication regime and physical therapy.

SM was registered with the Department for Disability Services and he had an allocated local area coordinator. The Cerebral Palsy Association was involved to address his therapeutic needs by the provision of physiotherapy, occupational and speech therapy. He was provided, or assessed for therapeutic supports to enable those caring for him to better coordinate his

[4] Ex 1, tab 11

requirements. He also underwent plastic and reconstructive surgery to improve his physical wellbeing.

The intention was that once suitably managed there would be a clear care plan for all the many parties involved in caring for SM appropriately.

DEPARTMENT OF COMMUNITIES (THE DEPARTMENT)

Once under the care of the CEO for the Department in February 2013 until the age of 18, a number of Government agencies worked together in an attempt to find a suitable environment for SM's continued care and development. It was not possible to find a culturally appropriate environment to take care of SM, however, efforts were directed towards finding carers who would facilitate SM's continued contact with his cultural heritage. Meanwhile SM stayed at LLC.

Senses Australia was selected as a service provider in the Disability Services area to facilitate a suitable placement for SM.

Eventually Senses Australia carers were located who were prepared to offer SM a place in their family in Butler. The family had two biological children and had been registered with Senses Australia since February 2014, after an assessment process providing registration on the Foster Carer Directory of Western Australia as Foster Carers. SM was provided with a

full time alternative family carer under a disability placement and support program on 8 April 2014.

Jodi Perkins, Senses Australia Manager Service Development – Community Living Services was involved in support for the family and their Departmental Child Protection Worker (DCPW) in Fitzroy Crossing was Natasha Walker, with the Joondalup DCPW being Mima Comrie.[5]

SM commenced primary school at Butler Primary School and the school also assisted the family in accessing occupational therapy and speech therapy through the school therapy services. The carer family was provided with a care plan which had been implemented by Senses Australia, PMH and SM's GP in Mosman Park to provide practical and emotional support to the carer family around their needs to enable them to care appropriately for SM. Additional support by way of resources and the acquiring of appropriate equipment was also funded through the Department and on his placement with the carer family all those assisting with the care of SM were provided with training, both with respect to his care and that of the equipment necessary to care for him.

SM was placed with the carer family on 28 April 2014 and it is clear from the very detailed records of Senses Australia that every attempt was made to assist all those involved in SM's care, while acknowledging he required more intense intervention than had originally been understood.[6]

[5] Ex 1, tab 16
[6] Ex 1, tab 16

The carer family believed SM settled into their household well, but were somewhat overwhelmed at the intensity of the intervention necessary to keep him functioning healthily. He frequently presented to the JHC Emergency Department (ED) due to his epilepsy and the respiratory issues he encountered due to his breathing difficulties. On occasion he would need to be transferred from JHC to PMH for intensive intervention. He was also under the care of a range of consultants at PMH which necessitated reviews and further interventions.

The initial care plan was considerably revised and a new care plan review was undertaken on 1 July 2014 involving SM's carers, the Department, Butler Primary School Ability Centre and Senses Australia. Following this review the need for permanent respite carers was identified and implemented.

It had become obvious the carer family were experiencing some tension with care of their own family due to the commitment necessary to properly care for SM and respite carers were arranged for SM. The arrangement was the respite family would take care of SM on a fortnightly basis for 48 hours on alternate weekends. It was intended this would be an ongoing arrangement, however, only occurred for one complete respite period in July 2014 prior to SM's deterioration. That respite placement appeared to go extremely well, with the respite carers identifying and implementing a number of improvements they believed would assist SM with his daily living.

It is clear Ms Perkins and Ms Comrie were involved in planning for SM and provided the carer family with 24 hour telephone or email support as required. There may have been some delay in the provision of material resources, however, needs were certainly met as soon as possible once raised. This included assistance with transport by way of taxis initially, and later a leased vehicle, provision of equipment as deemed necessary, and additional input due to the recognised need SM was requiring physical assistance every two hours due to his lack of mobility.

It is very clear from the records SM required very intensive intervention which would have been physically and emotionally exhausting. Nevertheless, his ability to express joy and appreciation appears to have rewarded those caring for him by his sense of delight when engaged and comfortable.[7]

SM's carer family became very concerned that although he appeared settled his seizure activity increased. It is also of note SM's weight significantly increased during the time he was with family carers. This confirmed the original advice from DRH their concern was SM's development was being hampered in an institutional environment, rather than that of a proper family.

[7] Ex 1, tab 16

Medical Events Once in Care in February 2013

During July 2013 SM had numerous appointments relating to his necessary medical care and two elective admissions to PMH for treatment related to his fragile bones and tendon contractions. The necessity of a hospital environment was not therapeutic to SM's tendency for respiratory tract infections, which then required treatment with oral antibiotics.

SM had a further elective admission in October 2013 for the removal of metal plates from both his hips which had been provided to assist with his hip deformity.

In November 2013 SM was admitted to PMH with an increase in his seizure frequency and changes to his anti-epilepsy medication were made. He was treated for constipation.

In February 2014 he was again admitted to PMH with aspiration pneumonia and given treatment for his bones as well as provided with iron due to an iron deficiency.

These interventions had all occurred while SM was at LLC.

On 28 April 2014 SM was placed with the carer family and in May 2014 required admission to JHC for increased seizures and likely aspiration pneumonia. He was transferred to PMH following a long seizure with choking.[8] He remained in PMH

[8] Ex 1, tab 3

until 9 May 2014 with increasing seizures, a lower respiratory tract infection and right sided ear infection. A new medication regime was implemented and formed part of the initial care plan for SM with his new placement.

SM had three separate admissions to hospital in June 2014, firstly to PMH with a lower respiratory tract infection and acute ear infection with perforation. He was released home. The next day SM presented to JHC with a recurrent respiratory tract infection and later PMH with increasing seizures.

Approximately a month later in late July 2014 SM was again admitted to JHC with a lower respiratory tract infection. Two days later he was again taken to JHC ED, although he was not admitted on that occasion. It was at about this time PMH arranged for a home suction machine to help clear SM's oral secretions. It was hoped this would reduce his propensity for respiratory tract infections.

Following not being admitted on 26 July 2014 SM was then admitted on 27 July 2014 with a lower respiratory tract infection initially treated with antibiotics, which were then ceased due to a viral influenza being isolated.[9]

SM was discharged on 31 July 2014, but it is recorded his carer family were concerned about returning SM to their home because their own children were unwell. The carer family as a unit were very distressed by this stage. The social workers

[9] Ex 2

attempted to obtain earlier respite with the respite carers, but were unable to arrange immediate transfer. It was the weekend for the respite carers to care for SM and provisions were put in place for that to occur after some issues around transport arrangements were resolved.

1 AUGUST 2014

Following SM's discharge to his carer parents on 31 July 2014, he represented to the JHC ED at 10.00 am on 1 August 2014 with increased seizure activity. His carer father noted he had approximately 20 seizures that morning, compared to his normal 2-3 seizures per day, and that the quality of those seizures was different. His carer father had contacted the long term care rehabilitation team at PMH with his observations and they had recommended that SM be transferred to the nearest facility by ambulance.[10]

Joondalup Health Campus

The St John Ambulance (SJA) Care Record indicated SM's carer father reported that SM usually had brief tonic/rigor seizures with lateral gaze. But on 1 August 2014 he had been more vocal than usual and his seizure gaze was different, in that his eyes were flickering, and they suspected those seizures were of short (less than 5 seconds) duration.[11]

The SJA paramedics reported SM appeared to be unsettled and warm to touch. They noted a mild increase in his work of

[10] Ex 1, tab 8
[11] Ex 1, tab 14

breathing, with no obvious strider or wheezes. There was an occasional wet non-productive cough and subtle accessory muscle use. His oxygen saturations were normal on room air and his respiratory rate 32-35 per minute. They did not note any urgent indication for bronchodilators or anticonvulsants. There was no change in SM's condition between home and JHC. He was cleared from the SJA records at 10.43 am 1 August 2014.

JHC ED triage indicated SM arrived at the ED at 10.09 am and was triaged at the same time. The history is recorded as;

> *"Respiratory - discharged from JHC yesterday post 3/7 stay for LRTI. Carers concerned this mane as he appears to be having seizure activity which is different from usual, under team at PMH, advised to present and admit for review."*[12]

SM was recorded as having a previous medical history of cerebral palsy, epilepsy and aspiration. Part of the medical assessment noted SM had increased from 21kg to 27kg in weight over the 14 weeks he had been with his family carers and on discussion with the PMH neurology team it was recommended his medication be increased.

SM was noted as having a very slightly elevated respiratory rate and a slightly elevated heart rate, just outside normal for children of his age. While his respiratory rate and heart rate remained slightly elevated, his oxygen saturations were normal. No seizure activity was noted in JHC ED following his

[12] Ex 1, tab 14

increased medication at the advice of PMH neurology. JHC considered SM to be clinically stable, but unwell enough to warrant his admission to a hospital under the care of a paediatric team and transfer to PMH was arranged because JHC paediatrics had no beds available and, although they were familiar with SM, he was under the long term care of PMH.[13]

While in the JHC ED SM's observations were taken at triage and then again at 10.30 am when he had been moved into the treatment area. He was again observed at 11.55 am, reviewed at 12.30 pm with observations at 1.00 pm and 2.20 pm, prior to his transfer while awaiting the ambulance.[14]

JHC policy is hourly observations in the ED for any child with signs of respiratory distress, however, this may be unpredictable due to the resources available at any one time. Once transferred to a ward the standard observations for children with elevated respiratory rates and heart rates would be hourly, as plotted on a Children's Early Warning Tool (CEWT) for 5-11 year olds. That would then have been monitored and altered depending upon his status. Clinical improvement would be followed with a reduction in observations.[15]

By the time SM left JHC he was considered to be clinically stable after six brief seizures had been noted on admission and his medication had been discussed with PMH. Admission to

[13] Ex 1, tab 14
[14] Ex 1, tab 14 & 20
[15] Ex 1, tab 14

PMH was to be under the blue general paediatric team as he was not known to PMH neurology. His transfer had been discussed with the relevant RMO. Prior to transfer an IV cannula was sited and a venous blood gas (VBG) performed which was normal.[16]

The SJA patient care record for SM's hospital transfer from JHC to PMH on 1 August 2014 shows the SJA crew as arriving at JHC at 3.42 pm. They were advised SM was experiencing increased seizure activity and had a seizure approximately 5 minutes before they arrived. They observed another seizure of less than 5 seconds during handover and were advised by SM's carer father he would need suctioning due to aspiration. They recorded another 3 second seizure during transport.[17]

Princess Margaret Hospital (PMH)

SM arrived at PMH ED at 4.40 pm on 1 August 2014. His recorded observations were normal, but for a mild increased heart rate with a normal blood pressure.

SM was seen by the paediatric RMO and noted as alert with diffuse crackles (upper airway) on chest auscultation.[18] SM remained in ED for a period of time before he was transferred to ward 5A (blue ward) where he was not formally admitted until approximately 9.30 pm by the evening medical registrar.

[16] Ex 1, tab 11
[17] Ex 1, tab 20
[18] Ex 1, tab 12

While waiting for admission no concerns were noted other than a bilateral wheeze with "creps".[19]

While in PMH ED SM's observations were taken at 4.40 pm, 5.25 pm and 6.20 pm. Using the CEWT a score of 2 was achieved at 6.20 pm indicating management by a nurse was appropriate. SM had a short seizure of 3 seconds at 6.55 pm just before he was transferred to blue ward. Following transfer his observations at 7.00 pm were said to be normal, followed by observations at 10.00 pm and 4.00 am on 2 August 2014.[20]

Dr Gervase Chaney was the consultant on call for the blue team and had been the paediatric consultant to last review SM at PMH in February 2014.

While SM was in PMH ED awaiting admission to a ward he was monitored and his signs of respiratory distress largely resolved, his breathing rate dropped and his oxygen saturation was normal. He was regarded as only having mild respiratory distress, rather than moderate. Both Dr Chaney[21] and Dr Porter[22] suggested his distress may have followed the hospital transfer itself and that once in the ED he returned to normal which indicated his distress may have been as the result of emotional upset rather than physical compromise.

On admission to blue ward the RMO planned that SM be continued on the higher level of medication as recommended

[19] Ex 3
[20] Ex 1, tab 12
[21] t 10.12.18, p63/64
[22] t 21.12.18, p35

by neurology, with the addition of as needed salbutamol for wheeze (not administered). This was confirmed with Dr Chaney. On arrival on the ward SM had been placed on 4 hourly observations on the nursing plan which were the normal paediatric observations unless specified otherwise by the prior admitting team. SM had not been reported as suffering any further seizures once on blue ward and he was not noted to have any respiratory distress or require supplemental oxygen. The 4 hourly observations were considered appropriate considering the lack of seizure activity for several hours following increased medication.[23]

It is common ground that once on blue ward SM was not on any form of continuous monitoring and was not attached to an oximeter. While these may be available in ED they were not used routinely on the blue ward when there is no indication they are necessary.[24] Continuous central monitoring was not regularly available in PMH blue ward in 2014 and it is unlikely SM would have been considered as a necessity for central monitoring, or even mobile monitoring, given his presentation. Had more monitoring been available then it is possible more children presenting in the way SM presented at that time would have been able to be more comprehensively monitored.[25]

SM was not observed to be producing excessive amounts of secretions and he was not observed as requiring suctioning at any time while on blue ward.[26]

[23] Ex 1, tab 11
[24] t 10.12.18, p52
[25] t 10.12.18, p53
[26] t 10.12.18, p37

Enrolled Nurse Lois Baxter (EN Baxter), an advanced skills enrolled nurse, was the EN rostered on night shift in PMH blue ward on 1 August 2014. She was provided with a handover of all patients on the ward by the evening shift coordinator between 9-9.30 pm and had been advised SM was on room air, four hourly observations, PEG feeds and clinically stable. Aside from the general handover EN Baxter was also given a handover at his bedside and advised he had only recently been formally admitted to the ward, although he had been present for some time.

It does not appear SM had any recorded observations[27] taken on blue ward until EN Baxter completed her first set of observations at 10.00 pm. The CEWT was used and monitored SM's respiratory rate, respiratory distress, oxygen saturations, temperature, heart rate, blood pressure, capillary refill time and level of consciousness. EN Baxter recorded no concerns for SM in any of those areas and his CEWT score was 0.[28]

In evidence EN Baxter stated that although the formal plan for SM's observations was 4 hourly, her clinical assessment also affected her discretion with respect to observations and, depending on a child's presentation, a full set of all nine criteria on the CEWT were not always taken. Her assessment of his presentation and the results of previous observations would inform her as to whether more frequent observations should be considered taking into account the need for

[27] Ex 1, tab 12
[28] Ex 1, tab 19, Ex 3

undisturbed sleep. From the recorded history and results at 10.00 pm EN Baxter had no concerns SM required any further or more frequent observations than the usual 4 hourly observations.[29]

However, EN Baxter did make a point of saying that children like SM, with seizures;

> "*From a nursing point of view on night shift in particular, we would have a big planner that we would all work off of but we worked in buddies and we had our certain children that we looked after. But children with seizures were checked on an hourly basis to make sure that they were okay.*"[30]

By way of clarification EN Baxter pointed out that although the observations were 4 hourly as guided by clinical assessment, in addition, as a matter of routine, children with a history of seizures, which she acknowledged SM had, would have been observed visually between routine observations as a matter of course. EN Baxter could not specifically remember doing more frequent observations, but was sure she would have done because she had known of him previously due to his long history in PMH.

EN Baxter did not think SM had been recorded as having any seizures while in PMH on this admission, but remained adamant SM would have been, at least, visualised hourly to ensure he had not suffered a seizure. EN Baxter agreed,

[29] t 10.12.18, p33
[30] t 10.12.18, p25

depending on the type of seizure, they may not always be observable, unless caught during the event.[31]

EN Baxter's next set of observations on the CEWT were at 4.00 am. Due to her observations SM was stable it was her clinical judgement a full CEWT was not required and she only performed the basic observations which it was anticipated would not wake him. These were temperature, pulse and respirations. She also observed him for signs of respiratory distress. On performing those observations at 4.00 am EN Baxter was satisfied there was no cause for concern with respect to SM and as a result did not complete a full (nine) CEWT.[32] EN Baxter also stated she did not believe waking SM unnecessarily was justified because he seemed to be sleeping well and she was concerned he had adequate rest.

EN Baxter was adamant that when she did her observations at 10.00 pm she had completed pressure area care (PAC) by ensuring his position was changed. She placed him on his left side at 10.00 pm on 1 August 2014 and supported him with pillows to prevent him from rolling out of position.

[31] t 12.12.18, p34-35
[32] t 10.12.18, p36

EN Baxter stated that at her 2 August 2014 4.00 am review of SM she again performed PAC and turned SM onto his right side and ensured he was appropriately supported.

> "*these children that have many different health issues, depending, you know, whether they have any sort of contractions and things like that, you know, with the cerebral palsy and things, is depending on how you may actually position them. But from memory I kind of did like an A-frame sort of pillow that he was supported. You know, one pillow was sort of coming down behind his back. Normal practice would be that you would put one between their legs as well, but I don't remember exactly…whether I put that pillow there. But there would have been then the pillow that was sort of under his arm as he was propped to the right…sort of trying to - in a more sort of sitting position…on his bottom basically…we tend to nurse them side to side if possible. But depending on what their condition is as well as to how you position them.*"[33]

EN Baxter explained the 6 hours between observations and use of the CEWT as an attempt to adjust SM onto the normal 4 hourly observations routinely undertaken in the ward. On the criteria observed at 4.00 am EN Baxter was satisfied there had been no deterioration in SM's condition since the full observations undertaken at 10.00 pm the previous evening.

EN Baxter appeared to be a competent paediatric nurse and advised the court that at no point was she concerned about SM's condition that night.[34]

[33] t 10.12.18, p39
[34] t 10.12.18, p42

With respect to SM's repositioning EN Baxter informed the court the normal policy for children prone to pressure injury will be repositioning at 2 hourly intervals, however, there was some flexibility based on clinical assessment. It was her clinical assessment SM did not need to be repositioned every 2 hours overnight when he was sleeping well and needed his rest. She did not observe any red areas on SM when she was turning him which would have warranted more frequent repositioning.[35]

Location of SM

It is unclear whether SM continued to be visually observed hourly, however, the next event recorded with respect to SM was his discovery by a nurse, not EN Baxter, face down and unresponsive at 6.20 am. A medical emergency was called and then a code blue.

The nursing note states "*patient found at 6.20 face down and unresponsive. Unable to detect a HR. Code Blue called and ICU now in attendance. CPR commenced immediately on finding patient and calling code. Patient was turned at 4.00 and IV bung flushed. Nappy checked and dry. Nil issues at time transfer to ICU at 7.10.*"[36]

Once the code blue was instituted the resuscitation trolley was collected and cardio pulmonary resuscitation (CPR) commenced. Resuscitation resulted in a brief pulse followed

[35] Ex 1, tab 19
[36] Ex 3

by pulseless electrical activity (PEA). Further resuscitation resulted in an established cardiac output and SM was transferred to the Paediatric Intensive Care Unit (PICU). Both the blue ward consultant on call, Dr Chaney, and the PICU consultant on call, Dr Croston, were called and reviewed SM once he had been resuscitated. It was noted SM had fixed dilated pupils, was demonstrating gasping respirations and sympathetic surging. It was apparent the prognosis for SM was not good.

Arrangements were put in place to call SM's carers, his respite carers, SM's social worker with Senses Australia and the Department.

SM's carers were on respite that weekend and his respite carers remained with SM from the time of their arrival at the hospital on 2 August 2014 until he passed away later that day.

SM was left on life support while the Department attempted to locate his biological mother to attend at PMH. Sadly, it was not possible to contact SM's biological mother and later that day SM was withdrawn from life support and died in the evening.[37]

It was clear SM had a sudden and unexpected cardiac arrest on blue ward during his overnight admission sometime after 4.00 am. There had been prior evidence of increased seizure activity which appeared to have been brought under control,

[37] Ex 3

and evidence of a prior viral lower respiratory tract infection. The fact SM was non-mobile and had been positioned on his side, supported by pillows, would imply that seizure activity had caused him to roll from the pillows and present face down. This may have precipitated a respiratory arrest, however, it was not possible to say whether the arrest had precipitated the seizure or the seizure the facedown position and then arrest.[38]

POST MORTEM REPORT

The post mortem examination of SM was undertaken on 6 August 2014 by Dr Jodi White, Forensic Pathologist, at PathWest Laboratory of Medicine WA.[39]

On initial examination Dr White recorded the deceased was a 7 year old boy with heavily congested lungs with evident aspiration, plus mucoid material in the airways. There were no evident injuries. His brain appeared small for his age. Dr White requested further medical information relating to the deceased's known physical and intellectual disabilities. She noted he had postural changes and physical appearance in keeping with cerebral palsy.

Following further investigations Dr White confirmed the evidence of acute bronchopneumonia with underlying chronic inflammatory changes in the airway. Microbiology isolated abundant growth of *Streptococcus agelactiae* and *Staphylococcus aureus (MRSA)* in tissues from the lung and

[38] Ex 1, tab 11
[39] Ex 1, tab 4.2

spleen and *Parainfluenza* RNA within the lung and tracheal samples.

Neuropathology confirmed microencephaly with abnormal gyri with a reduction in the white matter and the size of the brain stem. Toxicology showed prescribed medication in keeping with SM's known medical care.

Dr White reviewed SM's known medical history noting his significant history of spastic quadreparesis and cerebral palsy with associated severe disabilities due to hypoxic-ischaemic encephalopathy from birth, asthma, and chronic difficulty in managing seizures, with osteoporosis and recurrent pneumonia.

At the conclusion of all her investigations Dr White was of the opinion SM died due to "*complications following cardio respiratory arrest in association with a seizure in a young boy with bronchopneumonia suffering cerebral palsy and chronic seizure disorder.*" [40]

This cause of death is consistent with Dr Chaney's view SM died as the result of a generalised tonic clonic seizure which dislodged him from the safe sleeping position in which he had been placed by EN Baxter. It is impossible to determine whether the seizure alone caused the cardiorespiratory arrest, or whether there was an element of the change of position into his facedown position when located, which also contributed to

[40] Ex 1, tab 4.1

the outcome. Certainly aspiration as the result of either the seizure or the cardiorespiratory arrest would have exacerbated his bronchopneumonia and further compromised his ability to breathe effectively.[41]

In addition to evidence from Dr Chaney the court heard evidence from Dr Paul Porter on 21 December 2018. Dr Porter is a consultant paediatric emergency physician with practices at both JHC and PMH. He was asked to review the medical care of SM for the Office of the State Coroner (OSC).

Dr Porter outlined that SM was still experiencing some seizure activity while in PMH ED and was still unwell from his parainfluenza pneumonia on transfer to blue ward. There a four hourly observation nursing plan was instituted, but SM was not monitored electronically, nor was there any documentation as to his care between formal observations. Dr Porter was concerned not enough attention was focused on SM's recently changed presentations, especially the uncontrolled multiple seizures of different types in conjunction with his respiratory distress due to his recent infection. In view of those factors Dr Porter believed more frequent or continuous observations were warranted in order to detect any respiratory difficulties for SM, prior to arrest. This could have improved the outcome for SM. Dr Porter believed SM's recent, changing presentations were predictable for a clinical deterioration, although not necessarily his survival.

[41] t 10.12.18, p53

In evidence, Dr Porter confirmed his view a child in SM's situation should have had more frequent monitoring in the hope earlier intervention may have changed the outcome when he was known to be unwell.[42] Continuous monitoring would have alarmed with either an acute or chronic deterioration in his condition and allowed prompt intervention. It may not have changed the outcome.[43]

Dr Chaney agreed continuous monitoring would have alerted staff to any acute deterioration, as well as a chronic deterioration, which may have alerted staff to SM's difficulties before he was located unresponsive at 6.20 am.[44]

Dr Porter thought the mechanism of death for SM more likely followed an aspiration event, but could not determine whether that related to a seizure, though it seemed likely. Regardless his airway became obstructed, his oxygen levels fell and he had a cardio respiratory arrest.[45]

CONCLUSION AS TO THE DEATH OF THE DECEASED

I am satisfied on the whole of the evidence SM was a 7 year old male child born with profound intellectual and physical disabilities in the form of cerebral palsy, epilepsy, microencephaly, osteoporosis, and asthma. His family of origin and where he was initially cared for, aside from DRH,

[42] t 21.12.18, p77
[43] t 21.12.18, p91, 96
[44] t 10.12.18, p54
[45] t 10.12.18, 94-95

was a remote community where, with the best will in the world, it was impossible to care for his needs satisfactorily.

SM's biological father had very little to do with his upbringing and his mother had a number of other children for whom she had to care. There is no record of there being any concern with the care SM's biological mother provided to him in the limited capacity she was able to do so in the environment in which she found herself. Inevitably this was not going to be successful and resulted in SM's biological mother taking him to DRH frequently, then needing to leave him there for long periods of time.

In negotiation with DRH, PMH, DSC and the Department it was apparent SM needed a different environment. Following letters from DRH to the Department an Order was obtained from the Broome Children's Court of Western Australia for SM to be declared a child in need of protection until he was 18 years of age. This was done with SM's biological mother's full cooperation. She consented to the Order. It was made in Broome on 5 February 2013 when SM was 6 ½ years of age.[46]

The situation then arose of the Department, in conjunction with DSC, needing to find appropriate carers for SM. This was done with the help of Senses Australia who used recently registered carers with experience in dealing with children with disabilities.

[46] Ex 1, tab 3

There is no doubt SM's high care needs made him a very difficult proposition for any organisation or carer family to accommodate. SM spent periods of time at LLC before carers became available to care for him. They had small children of their own and while it may have been envisaged SM would be a difficult proposition in those circumstances, there is no doubt SM benefited from the family environment. This was reflected in his weight increasing from 21-27kg in the 14 weeks he was cared for by his carer family, with the assistance of Senses Australia, their social worker contacts and the Department.

It is apparent from the Senses Australia care management plans there were difficulties noted when caring for SM which all attempted to address, however, there is inevitably some delay when needing to rely on a chain of action for limited resources. This put carers in a stressful situation as it did those attempting to support them.

Much equipment and resources were provided to those caring for SM, but possibly not in a timely enough fashion in reality. Pragmatically it is difficult to see how it could have been done more rapidly, which would have seen longer and quicker respite periods which I am sure would have been beneficial for all concerned.

I am satisfied SM was cared for as well as was possible in a family environment, with all the difficulties that placed on

those in that environment. It is clear SM's carers developed carer fatigue quite significantly, quite quickly.

Respite carers were accessed, however, prior to his death on 2 August 2014 it had only been possible for his respite carers to ameliorate the situation for his family carers over one weekend.

I am further satisfied that SM's respite carers were dedicated and intuitive in providing for SM in the short time he was in their care.

While I am satisfied SM was cared for in all the circumstances reasonably well, it is also clear his health began to deteriorate from his disability perspective. His carers noted increased seizures and these became a problem, especially when attempting to care for him with their own small children. In hindsight, it is possible a consequence of his improved growth in a family environment may have contributed to his necessary medications being outpaced by his growth.[47]

Towards the end of July 2014 SM became increasingly unwell with his respiratory issues. This necessitated his admission to JHC at the end of July and it is clear his carer family were also unwell. The additional concerns with SM appears to have caused difficulty for all of those involved in caring for SM.

[47] t 21.12.18, p90

SM was discharged home from JHC to his carer family on a Friday, due for respite care the following day.

SM's carer father noted increased seizure activity for SM, not just the tonic clonic variety with which most people were familiar, but additional brief blank periods only observable if one was actually with SM and watching him. He returned SM to JHC where he was noted to suffer short blank seizures while in the ED.

The fact PMH's long term care team were looking after SM influenced the JHC RMO's decision to contact PMH for advice in caring for SM. Neurology was contacted, despite their lack of direct knowledge of SM, and advised increased medication to assist with his seizures.[48] SM was provided with additional medication which appeared to be effective, but it was suggested it would be appropriate to transfer him to PMH due to the lack of available paediatric facilities for SM at JHC.

Once in PMH ED it was reported SM had some minor seizures, however, he appeared to settle and by the time he was transferred to blue ward, where there was a consultant on call, who was also the last consultant to have reviewed SM on behalf of PMH, Dr Chaney, he was considered to be relatively stable.

While SM had frequent observations taken while in the ED, this did not occur on blue ward, partly because he appeared to be stabilising with the additional medication, needed sleep,

[48] Ex 1, tab 13

and also because continuous monitoring was not readily available on the ward.

The plan was he be monitored 4 hourly and while there is some tension between Dr Chaney and Dr Porter, as to the predictability of further serious seizure activity, the practical situation in PMH at that time did not support SM's more frequent monitoring.[49]

EN Baxter was satisfied that at her 10.00 pm complete observation check of SM, he was normal in all areas and appeared to settle and sleep well. She did not believe it was necessary to wake him for more frequent observations and left his next observations until 4.00 am to allow him to sleep as part of his recovery. EN Baxter positioned him on his left side at 10.00 pm with adequate support to prevent him from rolling and he maintained that position until her more restricted observations at 4.00 am. The observations she took at 4.00 am on 2 August 2014 reassured her SM was not in trouble physiologically. She repositioned him on his right side, again supporting him on his side to prevent him rolling.

In the event SM had minor seizures between those observations, but recovered by the time of the observations, it would not be possible to tell without continuous monitoring. However, Dr Porter agreed the evidence would support the fact generally that those observations at 4.00 am would indicate SM was reasonably stable, however, without more detailed

[49] t 21.12.18, p113-116

observations or continuous oximetry it was impossible to be certain.[50]

Nevertheless, it is clear EN Baxter, who I accept as an experienced and conscientious paediatric nurse, did not see any clinical signs she should be concerned for SM's welfare, either at the time of her recorded checks or at the time of any hourly visualisations.[51]

I am satisfied on the whole of the evidence the more likely explanation for SM's collapse following 4.00 am and his discovery at 6.20 am, face down and unresponsive, was a sudden acute event, probably in the form of a seizure, which resulted in aspiration, and his movement to face down on the bed. That is, the evidence would generally support this was an acute event on a background of chronic respiratory difficulties and increased seizure activity.

Once in a face down position as the result of a seizure with aspiration and the resultant restricted exchange of oxygen then cardiorespiratory arrest was inevitable, if not immediately fatal. Had SM been on continuous monitoring at that time the fact he was in respiratory distress would have caused an alarm to sound before he was discovered at 6.20 am. It is still not possible to predict whether that would have improved his prognosis and saved his life in view of the fact SM was already

[50] t 21.12.18, p92
[51] t 21.12.18, p114

compromised and would have been further compromised by any period of oxygen deprivation.[52]

We will never know whether continuous monitoring would have improved the outcome for SM, although I suspect that had he survived he would have been even more severely compromised than he was initially.

MANNER AND CAUSE OF DEATH

I am satisfied, on the balance of probabilities, SM died as the result of complications of a generalised seizure when in an already compromised respiratory state due to recovering from a respiratory illness days beforehand. It is possible his seizures had increased as he outgrew his medication dosages, however, an increase in seizure frequency with age was not unexpected in SM's circumstances.

I believe that as part of his seizure SM, both moved from his protected side position to face down and aspirated.[53] That caused him further respiratory depression and he suffered a cardio respiratory arrest which caused serious hypoxic brain injury. Although he was resuscitated to the extent he was able to be placed on life support he was brain dead. He was maintained on life support while attempts were made to locate his biological family, however, that did not occur and a decision was made that life support be removed. Very shortly

[52] t 10.12.18, p54
[53] t 21.12.19, p96

thereafter he died in the presence of a number of people who had cared for him during the previous 14 weeks.

I find SM was a 7 year old boy who suffered from cerebral palsy and chronic seizure disorder. He died as a result of complications following a cardiorespiratory arrest in association with a seizure and his bronchopneumonia.

I find death occurred by way of Natural Causes.

SUPERVISION, TREATMENT AND CARE OF SM

There are two issues which have arisen with respect to SM's supervision, treatment and care. The one which is the major concern of this court hearing is the supervision, treatment and care of SM as the subject of a care and protection order administered by the CEO of the Department (s.25(3))

The other has arisen as a subsidiary issue related to medical treatment, in the narrow sense, and this court's jurisdiction to comment upon matters related to public health (s.25(2)).

Supervision, Treatment and Care of SM as a Child Held in Care

SM's disabilities were significant. He required assistance for all aspects related to his daily functioning and was completely unable to protect himself from any type of adverse event due to his limited mobility. He responded to positive input; he suffered in a hospital environment no matter how caring those who cared for him may be. This was demonstrated by his improvement in a family environment as opposed to his times

at DRH and LLC. Unfortunately, he also increased in his seizure activity as he grew. It is not clear if this related to an increase in body size or a natural progression of his naturally occurring serious medical issues.

It was totally impractical for SM's biological family to care for him in their environment with remoteness from medical or even functional input to SM's care. His mother's decision, and that of the Department, to take him into care was entirely appropriate and done with SM's best interests, and those of his biological family, at heart. That decision having been made there was always going to be an issue as to his optimal care. There was clearly a tension between best medical and best therapeutic input. I believe the decision to place SM in a family was one which took into consideration all aspects of the best supervision, treatment and care for SM.

I am of the view, in all the circumstances, everybody caring for SM tried their best to ensure his care was as appropriate as could be provided for his physical and emotional wellbeing, despite necessitating that, on occasion, his physical care may not have been optimal. For it to be optimal one could argue he should have always been on continuous monitoring for seizure activity. I do not believe that continuous monitoring of SM, which may have saved his life physically, would have been beneficial to SM psychologically.

I am concerned SM's carers did not believe they fully understood the level of care SM required, however, I am

satisfied that as best they could, Senses Australia and the Department had tried to apprise them of the level of care he required. While SM received the medical level of care necessary while in DRH and LLC, his paediatric consultants were not of the view those environments were beneficial to him psychologically.

I note SM's social worker, the Senses Australia manager and the respite carers were with SM continuously from when he was revived, until he was withdrawn from life support and died. His family carers were in and out of hospital while also attempting to care for their own children.

It is clear SM was in a much better position with respect to care than he would have been had he remained in the Kimberley. Further he had the opportunity to benefit from a family environment prior to his very tragic demise.

Medical Care as a Specific Issue

The fact SM was in the care of the CEO of the Department mandated an inquest. The issue of his medical care while in a public hospital arose during discussion of SM's medical care while 'in care'. It is not an issue about which I am critical, but it did attract comment from a number of doctors involved in SM's ongoing care and it would be remiss not to review the evidence as it became relevant to the mechanism of death.

The issue of the option for continuous monitoring of SM's oxygen needs, taking into account his very recent respiratory illness and reported increased seizure activity of different

types, formed the basis for the differences in emphasis as to the predictability, as opposed to the expected occurrence, of a further seizure for SM.[54]

I think the final analysis related to the fact there was a difference in relevant information exchange when considering the continuity of care for SM on 1 August 2014.[55] SM had seizures of seconds duration in JHC ED,[56] during the hospital to hospital ambulance transfer and PMH ED, prior to transfer to blue ward before admission.

Nevertheless, I am satisfied EN Baxter performed a full CEWT at 10.00 pm and used her clinical judgement when confirming the admission plan SM be placed on four hourly observations on the nursing plan. In addition, due to her knowledge of SM's tendency to seizure activity she performed visual observation at about hourly intervals as standard procedure, although not documented. There were no directions from medical officers the nursing staff should do otherwise.

This was in accordance with both Dr Kameron's report of the practice in JHC ED when transferring a child with signs of respiratory distress to the paediatric ward[57] and Dr Chaney's expectation at PMH.[58] The difference being the emphasis on respiratory distress by PMH, when SM was there for increased seizure activity.[59]

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[54] t 21.12.18, p113-114
[55] t 21.12.18, p88
[56] Ex 1, tab 13
[57] Ex 1, tab 14
[58] Ex 1, tab 12
[59] t 21.12.18, p115 & 10.12.18, p63

Dr Porter's view was that it was predictable, not expected, that SM could suffer a significant seizure which would affect his respiration and so should have been on continuous oximetry, at least.[60] He had no knowledge of the availability or otherwise of continuous monitoring in PMH blue ward in 2014. It was available in JHC inpatient paediatrics.[61] It is also available in the new Perth Children's Hospital (PCH) as outlined by Dr Chaney[62] and referred to by Dr Porter as an understanding that it was a good idea.[63]

Dr Chaney advised the court that in 2014 in PMH blue ward children were not routinely put on continuous monitoring because it was not readily available, as it is now in PCH. It was available in ED, but SM had been transitioned to blue ward as a more therapeutic way of dealing with him and the need for continuous monitoring did not seem to be as significant as it had earlier when he was experiencing frequent seizures and before he had appeared to settle with extra medication.[64] However, in view of the suspected mechanism of death for SM it is debatable whether continuous monitoring would have improved his prognosis. He may have been located earlier, but there is no guarantee he would have survived such further insult to his already compromised health.

I have taken the view SM's increased weight while in a family environment is indicative of the fact his medical consultants

[60] t 21.12.18, p96
[61] t 21.12.18, p117
[62] t 10.12.18, p67
[63] t 21.12.18, p116
[64] t 10.12.18, p45-50

were correct in their view SM was happier in that environment. It possibly masked his need for increased medication levels due to his growth. Six kilograms in 14 weeks is significant when considering a body size of 21-27kg.[65] I note SM was due for paediatric review later in the month in which he died.

I fully accept both Dr Porter and Dr Kameron's view[66] that continuous monitoring or more frequent observations while in PMH blue ward may have alerted nurses to a problem for SM more rapidly than was the case with the timing between 4-6.20 am. If I am correct and it was a generalised seizure which dislodged him from his supported position and caused him to aspirate and be face down in his bedding, continuous monitoring would have alerted staff to that situation at the time it had occurred. However, that was a serious seizure for a child already so compromised. It is my view it is likely SM may not have survived such further insult to his physiology, and that although his situation may have been detected earlier, it would have made little difference to the outcome.

I am relieved the situation in PCH is such that there is much more likelihood of a child in SM's position being on more frequent observations, if not continuous monitoring. As Dr Chaney said, in hindsight, he would agree that the possibility of SM sustaining a further seizure was predictable, even though he may not have expected it. As such he believed it possible that in similar circumstances he would now plan for

[65] t 10.12.18, p47 & t 21.12.18, p89
[66] Ex 1, tab 14

a child such as SM to have continuous monitoring, whether that would have improved his prognosis or not.

In view of the improved facilities at PCH I do not intend to make any recommendations with respect to this matter other than all clinicians involved take on board the weighting of the benefits of continuous monitoring in future cases. I am sure they do not need any input from me to consider those issues.

Overall, I am of the view SM's supervision, treatment and care were appropriate while in the care of the Department. This was a difficult and challenging situation with an unfortunately tragic outcome.

E F Vicker
Deputy State Coroner
14 May 2019