STATE CORONER'S COURT
OF NEW SOUTH WALES

Inquest:	Inquest into the death of Jaxon McGrorey-Smith
Hearing dates:	29 to 31 October 2018
Date of findings:	14 November 20118
Place of findings:	NSW State Coroner's Court, Glebe
Findings of:	Magistrate Derek Lee, Deputy State Coroner
Catchwords:	CORONIAL LAW – neonatal hypoxic ischaemic encephalopathy, palliative care of infant, end-of-life care of infant, advanced care plan
File number:	2011/388722
Representation:	Dr H Bennett, instructed by Ms K Lockery (Crown Solicitor's Office), Counsel Assisting Mr M Lynch, instructed by Mr L Sara (Hicksons Lawyers) for NSW Health and Hunter New England Local Health District
Findings:	I find that Jaxon McGrorey-Smith died on 18 November 2011 at New Lambton NSW 2305. The cause of death was neonatal encephalopathy due to perinatal compromise. Jaxon died from natural causes.

Recommendations: ***To the NSW Minister for Health:***

1. I recommend that a copy of the reports of Professor Dominic Wilkinson dated 7 September 2018 and 27 October 2018 be forwarded to the NSW Minister for Health, together with a transcript of the oral evidence of Dr Peter Campbell, Associate Professor Nick Evans, and Professor Wilkinson, given on 30 October 2018, for the Minister's consideration regarding Recommendation 2.

2. I recommend to the NSW Minister for Health that, having regard to the material referred to in Recommendation 1, consideration be given to the following matters as they apply to any review of the NSW Health *End-of-Life Care and Decision-Making – Guidelines* (GL2005_057) (**the NSW Guidelines**):

    (a) Whether the NSW Guidelines ought to refer to palliative care professionals, and the role that such professionals might play in the end-of-life care and decision-making for infants and children; and

    (b) Whether the NSW Guidelines ought to refer to resuscitation plans and advance care plans in general, and for neonates less than 29 days old in particular.

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1. Introduction

1.1 Jaxon McGrorey-Smith was born to his parents Kirsty McGrorey and Lisa Smith on 20 October 2011. Within hours of his birth Jaxon began to experience clinical and electrical seizures and needed respiratory support. These features led medical staff caring for Jaxon to believe that he was suffering from a serious brain condition. This belief was later confirmed following scans of Jaxon's brain and, as a result, he was given an extremely poor prognosis.

1.2 In consultation with the treating team, Jaxon's parents made the difficult decision to withdraw intensive care and life-sustaining measures for Jaxon on 22 October 2011. Following this, Jaxon was provided with palliative care, which included comfort measures to manage pain and minimise suffering. Jaxon later died at home on 18 November 2011.

2. Why was an inquest held?

2.1 Under the *Coroners Act 2009* (**the Act**) a Coroner has the responsibility to investigate all reportable deaths. This investigation is conducted primarily so that a Coroner can answer questions that they are required to answer pursuant to the Act, namely: the identity of the person who died, when and where they died, and what was the cause and the manner of that person's death. All reportable deaths must be reported to a Coroner or to a police officer.

2.2 Jaxon's death was initially not reported. However, Jaxon's death was later regarded as being a reportable death because of the unusual circumstances in which it occurred.[1] That is, the length of time (27 days) between the withdrawal of life-sustaining measures and Jaxon's death, and issues which arose during this period regarding end-of-life care for an infant, were regarded as being a relatively unusual course of events so as to enliven the jurisdiction of the Coroner's Court.

2.3 In Jaxon's case the coronial investigation gathered sufficient evidence to answer the questions about his identity, and where and when he died, and the cause of his death. The inquest therefore examined the manner of Jaxon's death and, in particular, issues associated with decision-making and treatment provided to Jaxon as part of his end-of-life care.

2.4 It is with the benefit of hindsight, and with an opportunity for reflection, that an inquest is able to identify whether there have been any shortcomings, whether by an individual or an organisation, with respect to any matter connected with a person's death. It seeks to identify shortcomings, not for the purpose of assigning blame or fault but, rather, for the purpose of learning lessons from them.

2.5 In this regard, inquests look backwards in time, but have a forward-thinking, preventative focus. At the end of many inquests Coroners often exercise a power, provided for by section 82 of the Act, to make recommendations. These recommendations are usually made seeking to address systemic issues that are highlighted and examined during the course of an inquest. Recommendations in relation to any matter connected with a person's death may be made if a Coroner considers them to be necessary or desirable.

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[1] *Coroners Act 2009*, section 6(1)(c).

2.6 The coronial investigation into the death of a person is one that, by its very nature, occasions grief and trauma to that person’s family. The emotional toll that such an investigation, and any resulting inquest, places on the family of a deceased person is enormous. The recommendations made by Coroners are made with the hope that they will lead to some positive outcome by improving general public health and safety.

3. Recognition of Jaxon's life

3.1 Inquests and the coronial process are as much about life as they are about death. A coronial system exists because we, as a community, recognise the fragility of human life and value enormously the preciousness of it. Recognising the impact that a death of a person has, and continues to have, on the family and loved ones of that person can only serve to strengthen the resolve we share as a community to strive to reduce the risk of preventable deaths in the future.

3.2 Understanding the impact that the death of a person has had on their family only comes from knowing something of that person's life and how the loss of that life has affected those who loved that person the most. Therefore it is extremely important to recognise and acknowledge Jaxon's tragically all too brief, but important, life. It is hoped that these words do so in a meaningful and respectful way.

3.3 Jaxon lived for 30 days. Some parts of that period of time were incredibly painful and distressing for Jaxon's parents, Kirsty and Lisa, and for his family. Yet other parts of that same period were enormously special and uplifting. His parents and family celebrated weekly birthdays with him, and took great joy in the simple pleasure of cuddling him as often as they could.

3.4 The impact that Jaxon's life had on his parents and family defies measurement by hours, days and weeks. Instead, Jaxon's life can more appropriately be measured by the love his parents and family had, and continue to have, for him; by the deep connection that his parents and family had, and continue to have, with him; and by the way in which he brought his family together from afar and reminded them of the importance of presence.

3.5 From birth, Jaxon displayed his resilience, a sense of selflessness, and a cheeky personality. Whilst his younger brothers never had the chance to meet Jaxon, they remain constantly connected to him both in thought and in name. Jaxon's presence remains equally and constantly felt by his parents.

3.6 It is obviously most distressing to know that Jaxon's life was so tragically brief. It is difficult to understand the depth of the emotional journey that Jaxon and his parents experienced during their brief time together. However, what is clear is that whilst Jaxon is enormously missed he is, and will always be, lovingly remembered.

4. Events leading up to Jaxon's birth

4.1 Jaxon was conceived in January 2011 and his parents were initially advised that his expected due date was 12 October 2011. Following an ultrasound on 30 May 2011, this date was later revised to 15 October 2011. On 13 October 2011 Kirsty went to an antenatal clinic at John Hunter Hospital (**the Hospital**) for a review. The obstetrics and gynaecology (**OB&GYN**) consultant who performed the review advised Kirsty that she should be booked in for induction of labour the following week.

4.2 Kirsty returned to the Hospital on 18 October 2011 for induction of labour and was seen in the Antenatal Day Care Unit. Following examination it was found that the cervix was not favourable for labour. Cervidil was inserted to relax and dilate the cervix so that labour could begin. A cardiotocograph (**CTG**) monitor was also applied to monitor foetal heart rate. At about 4:45pm, it was noticed that the CTG was showing minimal reactivity and minimal accelerations[2] when Jaxon was moving. The CTG was reported as suspicious and escalated for repeat monitoring and review, and Kirsty was transferred to the delivery suite.

4.3 Dr Ayesha Akhter, Senior Resident Medical Officer, reviewed Kirsty at around 7:40pm. Dr Akhter had difficulty determining the foetal baseline heart rate and asked Dr Lauren Kite, an OB&GYN registrar, to review the CTG trace. Dr Kite was able to identify the baseline and found the trace to be normal. She made a notation for Kirsty to be admitted to the antenatal ward and Kirsty was later transferred there at about 10:25pm.

4.4 The following morning, 19 October 2011, Kirsty was transferred to the delivery suite because of high blood pressure and suspicious foetal heart rate. Dr Mohamed Galal, an OB&GYN consultant, reviewed Kirsty shortly after 9:00am. On examination Dr Galal found that the CTG trace was normal and reassuring. Dr Galal ordered a syntocinon[3] infusion, which began at 9:50am, and continuous foetal heart rate monitoring.

4.5 Dr Rehena Ahmed, an OB&GYN registrar, reviewed Kirsty at 2:45pm. Initially it was noted that the CTG was abnormal. However, after about 30 minutes it was later noted that the CTG was normal. By 4:15pm, however, the CTG trace was again recorded as being suspicious. Dr Ruth-Ann Sterling, another OB&GYN registrar, reviewed the CTG at about 5:00pm and noted that it was reassuring at that time, although there had been long periods where it had been suspicious with variable decelerations.[4] Dr Sterling discussed Kirsty's management with Dr Mary Norris, the on-call OB&GYN consultant. Plans were made to increase the syntocinon as Kirsty's contractions were suboptimal and cervical dilation had not progressed past 3cm for over three hours. Plans were also made for Dr Sterling to review Kirsty at 8:00pm to ensure normal progress in labour.

4.6 At about 6:30pm Lisa alerted Michael Cook, a student midwife, to the fact that Jaxon's heart rate was dropping. Mr Cook in turn alerted Dr Sterling and Dr Bailey, an OB&GYN staff specialist. On review it was noted that Jaxon had experienced prolonged bradycardia[5] but that his heart rate was slowly returning to baseline.[6] A decision was made to turn down the syntocinon infusion and to turn it off if there were any further decelerations.

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[2] An abrupt increase in the baseline foetal heart rate, which is regarded as reassuring.

[3] Medication to induce labour.

[4] An abrupt decrease in the baseline foetal heart rate, of which there are different types with varying significance.

[5] Heart rate that is slower than normal.

[6] The average heart rate of the foetus within a 10-minute window.

4.7 Mr Cook reviewed Kirsty again at 7:00pm. He observed blood stained liquor and decreased the syntocinon infusion. It was noted that there had been nil accelerations since the last bradycardia episode but that there had been mild variable decelerations in the previous 20 minutes.

4.8 By 9:30pm, Mr Cook noted that the CTG was again reassuring. On examination, it was found that Kirsty was fully dilated. At 10:30pm she commenced pushing. Dr Ksenia Katyk, an OB&GYN, reviewed Kirsty at 11:30pm and noted that there were no signs of imminent delivery. Dr Katyk noted that the CTG had been variable throughout the day and formed the view that if it deteriorated, or did not improve, intervention would be necessary.[7]

5. Jaxon's birth

5.1 Dr Katyk reviewed Kirsty again at 12:00am. Due to the lack of progress, Jaxon's position, and Kirsty's fatigue, a decision was made that the best option would be to assist delivery by a trial of instrument delivery in the operating theatre. If this was unsuccessful, then it was decided to proceed to caesarean delivery. This plan was discussed with Dr Norris.

5.2 Kirsty was transferred to the operating theatre at about 12:45am on 20 October 2011. Dr Norris attended at about 1:10am to assist with the delivery. Initially an attempt was made to apply a forceps delivery[8] but this was unsuccessful as the second forceps blade could not be engaged. This procedure was abandoned and ventouse[9] assisted delivery was then trialled. An anterior ventouse cup was applied but there was no descent of the foetal head over two contractions and the cup was noted to come off easily with two pulls. This procedure was also abandoned. Dr Katyk and Dr Norris then performed a lower segment caesarean section and Jaxon was delivered at 1:53am. It was noted that there was meconium stained liquor present.

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[7] Exhibit 1, Tab 25 at [7].

[8] A type of assisted vaginal delivery where forceps are applied to help guide a baby out of the birth canal.

[9] A method to assist delivery using a vacuum device.

6. Jaxon's first hours of life

6.1 Jaxon weighed 3,260 grams at birth. He had APGAR[10] scores of 5 at one minute, 6 at five minutes, and 9 at ten minutes. Jaxon was admitted to the Neonatal Intensive Care Unit (**NICU**) a short time later. According to the NICU admission notes, he had experienced respiratory distress following birth, requiring intubation and supplemental oxygen for 30 seconds until he began to breathe spontaneously. It was also noted that Jaxon was admitted with meconium exposure, clinical and electrical seizures, metabolic acidosis[11] and risk of sepsis.[12]

6.2 Dr Javeed Travadi, one of the on-call neonatologists, reviewed Jaxon at around 10:15am. It was noted that Jaxon was showing evidence of electrical seizures on an aEEG[13] trace, and that he required continuous positive airway pressure to support his lungs. Plans were made for liver function and blood tests to be performed, for a formal full EEG[14] to be obtained, and to await the results of a head ultrasound scan.

6.3 At about 2:30pm Dr Travadi asked Dr Gopinath Subramanian, a paediatric neurologist, to review Jaxon due to uncertainty over the cause of Jaxon's seizures. Dr Subramaniam later examined Jaxon with Dr Christina Miteff, a paediatric neurology fellow. It was noted that Jaxon was a bit irritable on touch, and that he was displaying rhythmic jerking of his left upper limb. Dr Subramanian formed the impression that Jaxon may have hypoxic ischaemic encephalopathy (**HIE**) in view of his early seizures and head ultrasound, together with the possibility of brain infection. HIE is a serious complication affecting full-term infants where brain injury occurs when an infant's brain does not receive enough oxygen and blood. A lumbar puncture was requested in order to investigate the possibility of brain infection, and a MRI was ordered to investigate the possibility of a stroke for Jaxon's seizures.

6.4 Jaxon was given phenytoin[15] and commenced on acyclovir[16] to treat his seizures. A lumbar puncture was later performed at 5:30pm where it was found that cerebrospinal fluid was clear and nil organisms were detected. Jaxon was later commenced on a midazolam[17] infusion at 9:17pm due to his persistent seizures.

6.5 A cerebral MRI was performed at about 1:30pm on 21 October 2011. Evidence consistent with extensive bilateral infarcts[18] was found. It was eventually noted that the findings suggested that Jaxon had suffered "*a severe to profound hypoxic ischaemic insult*".[19]

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[10] A scale used to evaluate the health of a newborn infant using five criteria (**A**ppearance, **P**ulse, **G**rimace, **A**ctivity, **R**espiration) on a scale from zero to two, with overall scores ranging from zero to 10.

[11] A condition that occurs when the body produces excessive quantities of acid, or when the kidneys are not removing enough acid from the body.

[12] Exhibit 1, Tab 55, page 103.

[13] **Amplitude-integrated electroencephalography**: a method for continuous monitoring of brain activity commonly used in neonatal intensive care units.

[14] **Electroencephalogram**, a test used to find problems related to electrical activity of the brain.

[15] Anti-seizure medication.

[16] Antiviral medication.

[17] Medication used, amongst other things, for the treatment and control of seizures.

[18] Death of tissue, or brain cells, in the brain as a result of lack of oxygen and blood supply.

[19] Exhibit 1, Tab 55, page 22.

7. Initial discussions regarding Jaxon's prognosis and care

7.1 Dr Travadi reviewed Jaxon at 2:00pm and discussed the findings of the MRI with Kirsty and Lisa shortly afterwards. Dr Travadi explained that due to Jaxon's clinical picture and the MRI findings it was unlikely that Jaxon would have a "*normal outcome*".[20] Further, Dr Travadi explained that it was likely that Jaxon would have "*a moderate to severe neurodevelopmental delay which may include varying severity of cerebral palsy, epilepsy, hearing loss or blindness*" either in isolation or combination.[21]

7.2 Kirsty and Lisa were understandably distressed by this information and Lisa indicated that they were not ready to hear any more at that time. Respecting their wishes, Dr Travadi left Jaxon's parents with a member of the nursing staff and indicated that he would be happy to speak with them again when they felt ready to do so.

7.3 With the consent of Kirsty and Lisa, Dr Travadi later met with Kirsty's mother, Margaret McGrorey, Lisa's mother, Jennifer Smith, and Mel Logan, a friend of Kirsty and Lisa at about 3:00pm. Dr Travadi repeated the prognosis for Jaxon based on the clinical situation and the results of the MRI. Dr Travadi also discussed options regarding resuscitation and ventilation in the event that Jaxon stopped breathing due to a major seizure. However, in this context, Dr Travadi explained that "*any decision regarding this would need to be discussed with and made by Lisa and Kirsty*".[22]

7.4 Dr Subramanian and Dr Miteff later reviewed Jaxon at 3:30pm. Dr Subramanian noted that the MRI findings showed changes indicative of hypoxic ischaemia and that, with such severe changes being present on the second day of life, this was usually indicative of a very poor prognosis.[23]

7.5 Jann Barton, a social worker, spoke with Kirsty, Lisa and Margaret at about 5:00pm. Ms Barton noted that Jaxon's family were understandably very distressed and that they declined social work involvement at the time. Margaret told Ms Barton that she was a social worker herself and that Jaxon's parents had a good support network, including a friend who was also a social worker.[24] Ms Barton respected their wishes and informed Jaxon's family that assistance from the social work team was available over the weekend if they needed it.

7.6 During the evening of 21 October 2011 Jaxon continued on aEEG bedside monitoring. It was noted that he experienced several clinical seizures and numerous electrical seizures. It was also noted that Jaxon experienced an episode of apnoea[25], which required intubation at 6:50pm, and other episodes of apnoea which required use of intermittent positive pressure ventilation for 60 to 90 seconds after which Jaxon started breathing again.

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[20] Exhibit 1, Tab 55, page 46.

[21] Exhibit 1, Tab 55, page 46.

[22] Exhibit 1, Tab 55, pages 47-48.

[23] Exhibit 1, Tab 30 at [14].

[24] Exhibit 1, Tab 55, page 49.

[25] The temporary cessation of breathing.

8. Discussions regarding the withdrawal of life-sustaining treatment and palliative care for Jaxon

8.1 Dr Ian Wright, senior staff specialist neonatologist, reviewed Jaxon on the morning of 22 October 2011. He noted that the aEEG tracing showed an abnormal pattern and that Jaxon continued to experience short seizures. Dr Wright later met with Jaxon's parents, grandmothers, and Mel at about 10:40am to discuss Jaxon's care. The progress notes, written by NICU Nurse Unit Manager (**NUM**) Natalie Butchard, records that Dr Wright explained that the likelihood of severe disability for Jaxon remained high. Jaxon's parents indicated that they would like for the ventilator to be removed to be able to spend time with Jaxon, and for him not to be in any pain or have any clinical seizures whilst they were cuddling him.

8.2 Dr Wright went on to explain the intensive care measures that Jaxon was being provided with and what withdrawal of these measures would mean. Dr Wright explained that it was not possible to say how long Jaxon could survive without these measures, and that the period could range from hours, to days, to weeks.[26] The possibility of home palliative care and organ donation was also discussed. Below NUM Butchard's notes, Dr Wright wrote the following: "*Await confirmation of timing but looks like [Jaxon's parents] want to cease intensive care. They understand that it could be a prolonged death*".[27] Dr Wright also noted that arrangements would be made for photos to be taken and that organ donation would be discussed with the transplant team.

9. Withdrawal of life-sustaining treatment and commencement of palliative care of Jaxon

9.1 At 12:00pm Jaxon was moved to the parents' room, known as the Butterfly Room, and the Brainz monitor[28] was removed. The Peripheral Intravenous Catheter (**PIVC**) in Jaxon's arm was removed at 12:20pm, resulting in the ceasing of midazolam. A few minutes later, the endotracheal tube was also removed.[29] Jaxon continued to breathe on his own. Shortly before 3:00pm the progress notes record that one of the doctors came to speak with Jaxon's parents about any questions that they might have, but Jaxon's parents did not wish to speak with the doctor at that time.[30]

9.2 During the afternoon of 22 October 2011, NUM Butchard asked Dr Larissa Korostenski, neonatologist, to speak with Mel. During the conversation Mel expressed concern that the wishes of Jaxon's parents had not been met. Specifically, Mel referred to the earlier discussion with Dr Wright and that he had said that the intravenous midazolam for Jaxon would continue and that it would be unethical not to do so.

9.3 As Dr Korostesnki had not been present at that meeting, she called Dr Wright to discuss the issue raised by Mel. According to notes made by Dr Korostesnki, Dr Wright said that he told Jaxon's parents that all treatment, including midazolam, would stop once intensive care was withdrawn. Further, Dr Wright indicated that there was no point treating Jaxon's seizures with anticonvulsant medication as it would only prolong his suffering. Dr Wright went on to explain that the only indication for further treatment would be if Jaxon was in discomfort and in such case, opiates would be given.[31] Dr Korostenski later returned to report her discussion with Dr Wright to Mel.

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[26] Exhibit 1, Tab 55, page 55.
[27] Exhibit 1, Tab 55, page 55.
[28] Technology that provides for continuous bedside cerebral functioning monitoring.
[29] Exhibit 1, Tab 55, page 57.
[30] Exhibit 1, Tab 55, page 57.
[31] Exhibit 1, Tab 55, page 59.

9.4 At 4:30pm a progress note entry was made by one of the nursing staff recording that Mel had reported that Jaxon was in respiratory distress, that his status was changing rapidly, and that she demanded that morphine be given to Jaxon "*right now*".[32] Dr Korostenski subsequently went to Jaxon's bedside to assess him. She wound that Jaxon was sleeping peacefully, was pink in colour, and appeared comfortable.[33] Dr Korostenski did not observe Jaxon to have any signs of respiratory distress as reported by Mel.[34]

9.5 Dr Wright next met with Jaxon's parents at 5:00pm on 22 October 2011. Margaret, Mel, Dr Korostenski and one of the nursing staff, Registered Nurse (**RN**) Victoria Hunter were also present. Before the meeting began, Dr Wright obtained the consent from all present to record the discussion. Dr Wright addressed the issue raised by Mel regarding withdrawal of midazolam and explained that he had previously informed Jaxon's parents that all medication would be withdrawn and that Jaxon would only be treated for symptomatic distress. Jaxon's family agreed to this. Dr Wright went on to explain that Jaxon would be observed for such distress at any time and that if it was observed, oral morphine via a nasogastric tube would be appropriate treatment.[35]

9.6 Dr Wright also explained that Jaxon was not receiving any food or fluid at the time and that he would not be fed via a tube as this was an invasive procedure and likely to prolong Jaxon's demise. However Dr Wright explained that that appropriate relief would be provided to Jaxon if he was observed to be in distress from hunger or any other cause.[36]

9.7 During the meeting the following exchange occurred:[37]

> ***Lisa:*** *So if [Jaxon] goes into any distress, we're going to have the supports there.*
>
> ***Dr Wright:*** *Absolutely. That's what we're here for.*
>
> ***Lisa:*** *That's all we need to know. That's all we need to know.*

9.8 Later in the meeting, Dr Wright said this:

> "*So palliation we are not doing intensive care, we are still doing care…People don't realise that this happens so we do have some experience of what happens in this situation which is why I tried to tell you that it may be something quick in terms of minutes, when it wasn't, it may be something that takes hours, and it can sometimes take days or even weeks for the baby to pass away*".[38]

9.9 At 5:30pm, Jaxon's parents took him from the NICU to the maternity ward. RN Hunter told them that they could bring Jaxon back to the NICU at any time, especially if he was in distress or discomfort, and that they could call for the NICU staff to attend to assess him. RN Hunter later returned to see Jaxon's parents at 6:05pm and told them to contact the NICU if they felt Jaxon was not comfortable

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[32] Exhibit 1, Tab 55, page 60.
[33] Exhibit 1, Tab 55, page 60.
[34] Exhibit 1, Tab 25 at [12].
[35] Exhibit 1, Tab 55, page 61.
[36] Exhibit 1, Tab 55, page 62.
[37] Exhibit 1, Tab 34, page 2.
[38] Exhibit 1, Tab 34, page 5.

in any way. RN Hunter again reiterated that the NICU would provide comfort measures and pain management for Jaxon at the slightest hint of discomfort.[39]

9.10 On the morning of 24 October 2011 Margaret contacted a social worker, Ms Marilyn Fletcher, and made arrangements for her to meet with Jaxon's parents, asking Ms Fletcher to "*advocate on their behalf*".[40] During the meeting Ms Fletcher noted that both Kirsty and Lisa were understandably teary and that they were keen to have a meeting to review the MRI scan, which had already been arranged.

9.11 This meeting later took place with Dr Wright at 12:30pm. Apart from Jaxon's parents, Jaxon's maternal grandmothers, Clinical Nurse Consultant (**CNC**) Suzanne Wooderson, RN Hunter and Ms Fletcher were also present. During the meeting, Jaxon's parents were shown representative images from the MRI and it was explained to them what to expect as Jaxon came closer to death. Dr Wright reiterated Jaxon's current palliative care plans and told Jaxon's parents again that he would be given opiates if they were required. There was also discussion about various palliative options, including home palliative care, depending on Kirsty's discharge status.

9.12 At about 2:30pm Jaxon was transferred to a family room with his parents. RN Hunter later visited Kirsty and Lisa at about 2:55pm and reminded them that they could call, or bring Jaxon to, the NICU at any time if they had any concerns.

9.13 Ms Fletcher met with Lisa and Kirsty on the morning of 25 October 2011. They indicated that they had some questions for CNC Wooderson and Ms Fletcher said that she would pass this on. Later that morning Ms Fletcher called Margaret who said that she was happy with the support and care received since the meeting on Monday. Margaret went on to express concern that Kirsty was expecting that Jaxon would pass on quickly and was unprepared for the process to take longer. Ms Fletcher told Margaret that CNC Wooderson planned to speak with Jaxon's parents about what to expect over the coming days. Ms Fletcher later met with Kirsty and Lisa that afternoon. Jaxon's parents expressed their wish for any nursing observations of Jaxon to be performed with minimal intrusion, and that they did not want detailed feedback about things such as Jaxon's heartrate unless they asked. Ms Fletcher confirmed that it was important for Jaxon's parents to state their wishes so that the wishes could be respected and so they could feel supported.

9.14 Dr Wright, CNC Wooderson and Ms Fletcher visited Jaxon's parents during the afternoon of 26 October 2011. They asked that Jaxon not be examined, and Jaxon's heart or respiratory rate not be taken, unless necessary or requested by them. Ms Fletcher later returned to meet with Jaxon's parents separately, at their request, for a lengthy visit. During this visit, Kirsty and Lisa again stated that the reason for their initial decision to withdraw care was due to concerns for Jaxon's quality of life, and that this reason remained unchanged. Ms Fletcher recorded in the progress notes: "*Parents agreed that their core belief that this decision in Jaxon's best interest is still firm, despite the emotional journey being so distressing*".[41]

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[39] Exhibit 1, Tab 55, page 63.
[40] Exhibit 1, Tab 55, page 69.
[41] Exhibit 1, Tab 55, page 74.

10. Commencement of morphine for Jaxon

10.1 On the morning of 27 October 2011, Jaxon's parents rang the NICU asking for a nurse. Two nurses from the NICU went to the maternity ward where Kirsty and Lisa expressed concern about whether Jaxon was becoming distressed because he had cried out a few times during the previous night and was grimacing at times. At the time it was noted that Jaxon was not grimacing but that he was occasionally crying as though hungry. The nurses discussed with Kirsty and Lisa that Jaxon could be given morphine if distressed and suggested a review by medical staff, which Jaxon's parents were happy with. Dr Wright recorded in the progress notes later that morning that it was appropriate to start Jaxon on opiates for relief. At around 11:00pm Lisa called the NICU and asked one of the nurses to see Jaxon as he was crying. When the nurse arrived Jaxon had settled.

10.2 Early the next morning, 28 October 2011, Lisa called the NICU again for a nurse to review Jaxon. At this time it was noted that Jaxon appeared paler than he had the previous evening and that he had been crying intermittently, but more often. The nurses discussed providing Jaxon with some morphine and he was given a dose (0.4mg) via nasogastric tube at 6:00am. Jaxon continued to receive morphine on 29, 30 and 31 October 2011. On 1 November 2011, following consultation with Dr Wright and CNC Wooderson, Jaxon's morphine dose was changed to 0.8mg twice daily with agreement from Jaxon's parents.

10.3 Over the next couple of days, Kirsty and Lisa took Jaxon out of the hospital for periods of time, usually returning for his scheduled dose of morphine. On 3 November 2011, Dr Wright, CNC Wooderson and Ms Fletcher met with Jaxon's parents. They discussed Jaxon's morphine administration and options for Jaxon's palliative care to continue in hospital, or at home. Both Dr Wright and CNC Wooderson offered to remain on call at all times, should Jaxon's parents require them.[42]

10.4 On the morning of 8 November 2011 Dr Wright and CNC Wooderson met with Kirsty and Lisa again. They discussed increasing Jaxon's dose of morphine by 50%. Jaxon's parents later agreed that they were happy for this to occur and the first increased dose (1.2mg) was given to Jaxon that evening.

10.5 Over the next few days Jaxon was noted to be unsettled on occasions. It was also noted that Jaxon appeared to be experiencing some distress associated with his right eye. Dr Wright reviewed Jaxon on the morning of 15 November 2011. Jaxon's parents discussed increasing his morphine dose as its effect appeared to be decreasing and Dr Wright agreed that this was reasonable. Accordingly, Jaxon's dose was increased to 1.5mg.

10.6 On 16 November 2011 Jaxon's parents expressed a concern that the increase in morphine had little effect. Jaxon appeared to be in pain and unsettled and was making a small cry at times.[43] Dr Wright spoke with Jaxon's parents on the phone in 17 November 2011 and they reported that Jaxon appeared to be in increasing distress with his eye cleaning. They requested that the morphine be increased and Dr Wright agreed, increasing the dose to 2mg. Jaxon's parents later decided to take him home to spend the night. CNC Wooderson later visited them there in the evening and noted that Jaxon appeared very frail.

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[42] Exhibit 1, Tab 55, page 85; Tab 33 at [36].

[43] Exhibit 1, Tab 55, page 99.

11. Jaxon's death

11.1 CNC Wooderson returned the following morning to review Jaxon at home. Jaxon's parents reported that he had not had a good night and that he had vomited during the night but settled again after they comforted him. Jaxon's parents described him having a "*rattling chest*". CNC Wooderson noted that Jaxon appeared "*blueish and pale*" and made arrangements to visit again in the evening.[44]

11.2 CNC Wooderson later visited at around 7:00pm. Lisa and Kirsty reported that Jaxon had had a bad day and CNC Wooderson encouraged them to call her if they needed her. At 11:00pm Lisa called CNC Wooderson and told her that Jaxon had passed away at about 9:30pm. A registrar from the NICU went to examine Jaxon and he was formally declared life extinct at 12:15am on 19 November 2011.

12. What was the cause and manner of Jaxon's death?

12.1 A death certificate[45] was subsequently issued which recorded the cause of Jaxon's death as being neonatal encephalopathy due to perinatal compromise.

12.2 **Conclusion:** The clinical findings following Jaxon's birth and the results of the cerebral MRI performed on 21 October 2011 are entirely consistent with the death certificate that was issued following Jaxon's death. Therefore, the cause of Jaxon's death was neonatal encephalopathy due to perinatal compromise. Given the well documented clinical findings, results of investigations and contemporaneous notes, it is evident that Jaxon died of natural causes.

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[44] Exhibit 1, Tab 55, page 100.

[45] Exhibit 1, Tab 2.

13. What issues did the inquest examine?

13.1 Prior to the inquest a list of issues was circulated to Jaxon’s parents and the Hunter New England Local Health District (**HNELHD**), within which the Hospital operated. This list identified that the following issues were to be examined at inquest:

(a) In relation to the end-of-life care decision-making:

    (i) Were Jaxon’s parents provided with adequate time and opportunity for discussion and reflection?

    (ii) Were Jaxon’s parents provided with the opportunity to review their decisions, once made?

(b) Did the cessation of intensive care, including the cessation of anti-convulsant medication, food and fluids, amount to appropriate palliative care?

(c) Were the NSW Health Guidelines regarding end-of-life care and decision-making appropriately followed? Ought the Guidelines be reviewed and updated following any findings from this inquest?

13.2 In order to consider the above issues, opinion was sought from the following experts:

(a) Dr Peter Campbell, a consultant neonatologist;

(b) Associate Professor Nick Evans, a Senior Staff Specialist neonatologist and Clinical Associate Professor in neonatal medicine; and

(c) Professor Dominic Wilkinson, a consultant neonatologist and Professor of Medical Ethics.

13.3 Each of the experts prepared reports which were tendered as part of the brief of evidence. Each expert also gave evidence, in conclave, during the inquest.

13.4 Each of the issues is examined in detail below.

14. Were Jaxon's parents provided with adequate time and opportunity for discussion and reflection?

14.1 Dr Campbell noted that the withdrawal of intensive care had been explained several times to Jaxon's parents.[46] In evidence during the inquest, Dr Campbell expressed the view that Jaxon's parents had been provided with adequate time and opportunity for discussion and reflection following these explanations.

14.2 Associate Professor Evans offered the opinion that Dr Travadi and Dr Wright appropriately discussed with Jaxon's parents the implications of the MRI findings on Jaxon's prognosis, and raised the issue of moving to palliative care.[47] Associate Professor Evans said this was consistent with the way in which he, and most other neonatologists, would have managed the situation.

14.3 Professor Wilkinson noted that there were three clearly documented conversations with Jaxon's parents and family on 21 and 22 October 2011. He opined that the information provided to Jaxon's parents regarding Jaxon's prognosis and the withdrawal of treatment was adequate for them to make an informed decision about Jaxon's care.[48] Further, Professor Wilkinson noted that on each occasion, Jaxon's parents had an opportunity overnight to reflect on the information that they had been provided with and to make decisions about Jaxon. Whilst noting that some families will take longer than others to make decisions when confronted with the same situation, Professor Wilkinson ultimately felt that sufficient time had been afforded to Jaxon's parents for them to make decisions about moving to palliative care.

14.4 In evidence, Professor Wilkinson explained that the decision which Jaxon's parents were required to make were most serious ones, but ones which were also carried with them some degree of urgency. Associate Professor Evans agreed that in such a situation whilst parents are faced with, what he described as, the "*worst decision*", an infinite period of time cannot be taken for a decision to be made. Associate Professor Evans agreed with Professor Wilkinson as to the element of urgency in the decision-making process, and explained that the longer it takes to make a decision, the greater the likelihood of a prolonged death. Notwithstanding the combined gravity of the decision and the pressure of time, Associate Professor Evans opined that the timeframe afforded to Jaxon's parents was well within a standard of care.

14.5 **Conclusion:** Dr Travadi first spoke with Jaxon's parents at about 2:00pm on 21 October 2011 to discuss the nature of the MRI findings and Jaxon's prognosis. When Lisa indicated that they were not ready to discuss the issue further, discussion was appropriately deferred. The contemporaneous records establish that social work support was offered to Jaxon's parents and family later that afternoon at around 5:00pm. Further discussion took place the following day, 22 October 2011, at about 10:40am between Dr Wright and Jaxon's parents and family. A decision was later made to withdraw intensive care, which occurred at around 12:00pm when Jaxon was moved to the butterfly room.

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[46] Exhibit 1, Tab 52, page 2.
[47] Exhibit 1, Tab 53 at [50].
[48] Exhibit 1, Tab 54 at [23].

14.6 The contemporaneous records, together with the combined expert opinion, establish that the implications of Jaxon’s MRI were appropriately explained to his parents. There is no doubt that the seriousness of Jaxon’s condition meant that the decision which his parents had to make was a most difficult and distressing one. The evidence establishes that any decision-making about Jaxon’s ongoing care was appropriately deferred, respecting the wishes of his parents, and after they had been given adequate time and opportunity for discussion and reflection.

15. Were Jaxon's parents provided with the opportunity to review their decisions, once made?

15.1 In his first report, Dr Campbell opined that "*in protracted cases of neurological demise*", such as in Jaxon's case, the withholding of fluids was a decision which could have been reviewed.[49] Later in the report, Dr Campbell expressed the view that whilst the medical team involved in Jaxon's care followed palliative care guidelines, "*the management of Jaxon should have been reviewed and food, fluids and medication could have been reconsidered*".

15.2 The opinions expressed by Dr Campbell in his first report were explored further with him in evidence. He explained that he personally did not have experience in being involved in the palliative care of an infant who had survived for more than a week following the withdrawal of life-sustaining care. Dr Campbell went on to explain that from the contemporaneous records he saw that there were multiple discussions between the treating team and Jaxon's parents regarding administration of morphine, and provision of hydration and nutrition. From this, Dr Campbell agreed that Jaxon's parents were given opportunities to discuss his care, and that the treating team responded appropriately to these discussions.

15.3 Professor Wilkinson referred to a Canadian study from a single large neonatal unit which indicated that the median time between withdrawal of artificial nutrition and hydration and death was 16 days, with a range from 2 to 37 days.[50] Professor Wilkinson therefore noted that the period of 27 days between the decision to withdraw intensive care and Jaxon's death was consistent with published literature, and also with his own experience of palliative care of infants with HIE.

15.4 Professor Wilkinson expressed the view that given the relatively long period of 27 days there was ample opportunity for decisions about Jaxon's palliative care to be revisited.[51] Professor Wilkinson was of the view that regular contact between Dr Wright and Jaxon's parents was documented in the progress notes and that such contact would have provided opportunities for concerns to be raised and for decisions to be reconsidered, if needed.

15.5 In evidence Professor Wilkinson explained that there would have been two factors warranting a change in treatment for Jaxon:

(a) if he demonstrated some neurological improvement; or

(b) if his parents no longer considered the withdrawal of intensive care to be in Jaxon's best interests.

15.6 Professor Wilkinson expressed the view that from the contemporaneous records there was no evidence of either of the above two factors being present. Therefore he concluded that there was no basis to revise the decision regarding the withdrawal of intensive care, although he noted that there was ample opportunity to do so.

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[49] Exhibit 1, Tab 52, page 2.

[50] J. Hellman, C. Williams, L. Ives-Bain, P. Shah (2013) "Withdrawal of artificial nutrition and hydration in the neonatal intensive care unit: parental perspectives", *Arch Dis Child Fetal Neonatal Ed 98*.

[51] Exhibit 1, Tab 54 at [36].

15.7 Associate Professor Evans was of a similar view. He opined that the discussion of end of life decisions and the process of moving to palliative care were within a standard of care.[52] Further, in relation to the specific issue of management of Jaxon's medications during his palliative care, Associate Professor Evans noted that the contemporaneous documentation showed that the medical and nursing staff listened to Kirsty's and Lisa's fears and responded to their concerns with appropriate counselling.[53] In evidence Associate Professor Evans repeated that, in his opinion, there were appropriate opportunities to review decisions. He explained that such opportunities should have been directed from a change in Jaxon's circumstances, or a change in his condition. However, Associate Professor Evans explained that the medical records did not suggest that there had been any change in Jaxon's prognosis.

15.8 **Conclusion:** The contemporaneous records reveal that the treating team were in frequent contact with Jaxon's parents to provide information about his ongoing care, discuss any questions that they might have, and respond to any concerns that they held. For example, at about 3:00pm on 22 October 2011, around two hours after the withdrawal of intensive care, a doctor offered to speak with Jaxon's parents about any questions they might have. Then, on 24 October 2011 the treating team spoke to Jaxon's parents and family about what to expect as the withdrawal of life-sustaining treatment continued. Similarly, on 3 November 2011 both Dr Wright and CNC Wooderson informed Jaxon's parents that they would make themselves constantly available, beyond their usual hours of duty, to address any concerns that Lisa and Kirsty might have. This demonstrates that Jaxon's parents were supported at the critical time when decisions were made regarding Jaxon's care, and remained supported during the period that followed if any decision required review or revision.

15.9 Clinically there was no change in Jaxon's prognosis or circumstances which suggested that the decision to withdraw intensive care ought to be reviewed. Further, there is no evidence to suggest that Jaxon's parents had come to a different view regarding such a decision. Indeed, the evidence establishes that during a meeting with Dr Wright on 26 October 2011, Jaxon's parents remained of the view that the decision was in Jaxon's best interests, notwithstanding the emotional toll associated with such a decision, and its implications. Even though there is no basis to conclude that a review of the decision to withdraw life-sustaining treatment was required, the evidence establishes that there were many opportunities for such a review to occur if one was in fact warranted.

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[52] Exhibit 1, Tab 53 at [51].

[53] Exhibit 1, Tab 53 at [55].

16. Did the cessation of intensive care, including the cessation of anti-convulsant medication, food and fluids, amount to appropriate palliative care?

16.1 The NSW Health *End-of-Life Care and Decision-Making – Guidelines* (GL2005_057), published on 22 March 2005 (**the NSW Guidelines**), sets out as part of its principles, the following:

> ***Appropriate withholding and withdrawal of life-sustaining treatment***
> *Appropriate end-of-life care should intend to provide the best possible treatment for an individual at that time. It recognises that if the goals of care shift to primarily accommodate comfort and dignity, then withholding or withdrawal of life-sustaining medical interventions may be permissible in the best interests of the dying patient.*[54]

16.2 The Glossary to the Guidelines defines life-sustaining treatment as follows:

> ***Life-sustaining treatment***
> *Life sustaining treatment is any medical intervention, technology, procedure or medication that is administered to forestall the moment of death, whether or not the treatment is intended to affect life-threatening diseases or biological processes. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation or certain medications (including antibiotics).*[55]

16.3 Section 7.4 of the NSW Guidelines goes on to provide:

> ***7.4 Artificial hydration and nutrition***
>
> *Use of artificial hydration and nutrition is an intervention with its own possible burdens and discomforts, for example, those related to having tubes in situ or regularly replaced. Withdrawal of artificial hydration and nutrition, like the withdrawal of other medical interventions, can be seen as a treatment limitation decision that may be made in accordance with these guidelines. It is recognised that the provision of artificial hydration and nutrition may be a particularly sensitive matter for some in the community who believe that it must be continued, unless specifically refused by the patient. The offering of food and fluids by ordinary, non-medical means should be part of the care of dying patients as appropriate to their clinical condition or wishes.*[56]

16.4 Dr Campbell expressed the view that the initial withdrawal of medication, hydration and nutrition was appropriate, but noted that in Jaxon's case the withdrawal of hydration and nutrition up until 18 November 2011 seemed to be "*at the extreme limit of palliative care guidelines*".[57]

16.5 In evidence, however, Dr Campbell agreed that the cessation of medication, food and fluids in Jaxon's case constituted appropriate palliative care. Associate Professor Evans and Professor Wilkinson expressed an identical view. Professor Wilkinson in evidence went on to explain that the commencement of palliative does not simply mean the cessation of treatment. He explained that it is

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[54] Exhibit 1, Tab 48, Annexure B, page 2.
[55] Exhibit 1, Tab 48, Annexure B, page 16.
[56] Exhibit 1, Tab 48, Annexure B, page 13.
[57] Exhibit 1, Tab 52, page 3.

a holistic approach to the care of an infant, and also involves providing holistic support to the infant's parents.

16.6 Professor Wilkinson explained that palliative care for infants involves three elements:[58]

(a) Providing interventions and treatments to alleviate an infant's symptoms of distress or discomfort;

(b) Withholding or stopping medical treatments (including life-prolonging treatments) that are not in the infant's best interests; and

(c) Providing holistic support for the infant's family to help them make the most of the time remaining with the infant.

16.7 Professor Wilkinson noted that withdrawing clinically assisted feeding, that is providing artificial food or fluids via an intravenous catheter or enteral feeding tube, is an option for palliative care management. Further, Professor Wilkinson noted that withholding of artificial feeding as part of palliative care is a potential ethical option and supported by professional guidance from the United Kingdom, United States, and Canada. Professor Wilkinson explained that "*in infants with profound neurological compromise, continued life may not be regarded as a benefit to the infant, and accordingly life prolonging treatment (including clinically assisted artificial nutrition and hydration) may be withheld*".[59]

16.8 Associate Professor Evans noted that the issue of feeding and hydration is a difficult and ethically challenging area in end-of-life care. He explained that whilst a balance needs to be found between the need to provide comfort during palliative care, and the goal to not unnecessarily prolong life, withholding life-sustaining treatment (such as nutrition and fluids) is an integral part of palliative care.[60] Associate Professor Evans explained it in this way:

> "*However, if considered rationally, fluids and nutrition are life sustaining interventions just as artificial ventilation or antibiotics may be life sustaining. Once a decision to move to palliative care has been made, the goal is to allow end of life by withholding life sustaining interventions but in a way that minimises suffering*".[61]

16.9 Associate Professor Evans noted that following the decision to withdraw life-sustaining treatment at around midday on 22 October 2011, some degree of misunderstanding was expressed later that afternoon by Mel, in the interest of Jaxon's parents, about whether withdrawal of midazolam would also occur. According to the contemporaneous records, Dr Wright explained to Jaxon's parents that this would occur. In doing so, Dr Wright explained that there was no point in treating Jaxon's seizures with anticonvulsant medication as it would only prolong his suffering. In this regard Professor Wilkinson said that he was aware of no evidence that treatment of seizures with anticonvulsants would prolong the suffering of an infant with severe brain injury.[62] However, Professor Wilkinson explained that it is not possible to say what effect continuing anticonvulsants would have had on

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[58] Exhibit 1, Tab 54 at [24].

[59] Exhibit 1, Tab 54 at [27].

[60] Exhibit 1, Tab 53 at [60].

[61] Exhibit 1, Tab 53 at [65].

[62] Exhibit 1, Tab 54 at [33].

Jaxon. However, he opined that even if they had been continued it would have been unlikely to change his outcome.[63]

16.10 Associate Professor Evans explained in evidence that, generally, the use of anticonvulsant medication is not routinely continued in cases of infants with HIE because the period of any seizure activity is usually limited to the first three to five days of life. Associate Professor Evans explained that in Jaxon's case the first indication of a clinical seizure was not until 15 November 2011. At that time Dr Wright recorded the following in a progress note after reviewing Jaxon: "*Episodes of stereotypical movements of limbs and mouth – probable seizures. No colour change. Appeared distressed by this*".

16.11 In this context, Associate Professor Evans explained that there is a difficult line between comfort care and the use of sedating drugs, such as midazolam, which may hasten death.[64] He went on to explain that it is usual in palliative care situations to not give such drugs "*prophylactically*", but to instead withhold them and only use them if an infant is displaying distress. However, in such cases of distress, the appropriate drugs to use would be an opiate, usually morphine. This is because midazolam has no pain relief properties. With this in mind, Associate Professor Evans expressed the opinion that when there were concerns that Jaxon was showing signs of distress on 27 October 2011, morphine was appropriately commenced on 28 October 2011, with the dose subsequently appropriately escalated according to Jaxon's response.[65] Having regard to these factors, Associate Professor Evans concluded that the management of Jaxon's medication was with in a standard of care.[66]

16.12 **Conclusion:** The end-of-life care provided to Jaxon was consistent with the principles set out in the NSW Guidelines. Whilst the withdrawal of artificial nutrition and hydration is a confronting and ethically challenging area, it is appropriately regarded as life-sustaining intervention and therefore may be withheld as part of palliative care. In Jaxon's case this was done in an appropriate manner and in a way to minimise any suffering.

16.13 Further, it was also appropriate to cease use of midazolam once life-sustaining treatment for Jaxon was withdrawn on 22 October 2011. This is because any distress that Jaxon was displaying was appropriately managed with morphine for pain relief, rather than midazolam for which no clinical indication was demonstrated on the contemporaneous records.

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[63] Exhibit 1, Tab 54 at [33].
[64] Exhibit 1, Tab 53 at [53].
[65] Exhibit 1, Tab 53 at [54].
[66] Exhibit 1, Tab 53 at [55].

17. Were the NSW Health Guidelines regarding end-of-life care and decision-making appropriately followed?

17.1 Professor Wilkinson expressed the opinion that the Guidelines were appropriately followed in Jaxon's case. Much of this has already been discussed above. In particular, Professor Wilkinson noted that Jaxon was provided with analgesia in accordance the section 7.3 of the Guidelines.[67] That section provides:

> ***7.3 Appropriate use of analgesia and sedation***
> *Analgesia and sedation should be provided by whatever route is necessary for relief, in proportion with clinical need, and with the primary goal of relieving pain or other unwanted symptoms. Such administration will not be unlawful provided the intention of the medical practitioner is the relief of symptoms, even if the medical practitioner is aware that the administration of the drug might also hasten death.*[68]

17.2 Professor Wilkinson considered the doses of morphine given to Jaxon to be well within range of doses commonly used in paediatric palliative care. Further, Professor Wilkinson noted that the morphine was started at a low dose and only increased appropriately in response to Jaxon's symptoms.[69]

17.3 Associate Professor Evans expressed the view, as already noted above, that the withholding of artificial hydration and nutrition, and the use of morphine in Jaxon's case was consistent with NSW Guidelines. Both Dr Campbell[70] and Associate Professor Evans[71] agreed that the treating team and Jaxon's parents were aligned in their wishes for Jaxon's end-of-life care, and that the NSW Guidelines were appropriately followed.

17.4 **Conclusion:** The withholding of artificial nutrition and hydration, and the use of analgesia in the form of morphine, in Jaxon's case was consistent with the relevant principles set out in the NSW Guidelines. The NSW Guideline recognises that treatment to prolong life may be withheld where a patient's prognosis is so severe that prolonging life is of no benefit and not in the patient's best interests. These principles applied to Jaxon's case and were appropriately followed. Further, the doses of morphine provided to Jaxon were regularly reviewed and the escalation in dosage was appropriately commensurate with the symptoms that were reported. In this sense, analgesia was provided in accordance with clinical need.

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[67] Exhibit 1, Tab 54 at [39].
[68] Exhibit 1, Tab 48, Annexure B, page 13.
[69] Exhibit 1, Tab 54 at [35].
[70] Exhibit 1, Tab 52, page 3.
[71] Exhibit 1, Tab 53 at [72].

18. Should the NSW Health Guidelines be reviewed and updated?

18.1 Professor Wilkinson suggested that there were two aspects of the NSW Guidelines which warranted further consideration:

(a) The absence of any reference to palliative care professionals within the NSW Guidelines, and advice which might be provided by such professionals to families of infants and children receiving palliative care at home; and

(b) The absence of any reference in the NSW Guidelines to resuscitation plans or advanced care plans.

18A. Specialised palliative care

18.2 Professor Wilkinson explained that, in his experience, "*there is increasing recognition of the benefit of specialised palliative care input for children and newborn infants with life limiting illnesses*".[72] Professor Wilkinson went on to note that in Jaxon's case he and his parents may have benefited from the expertise of specialised palliative care in symptom management, parallel planning, and family support. In identifying this potential area of improvement, Professor Wilkinson referred to the United Kingdom National Institute for Health and Care Excellence Guideline, *End of life care for infants, children and young people with life-limiting conditions: planning and management* (**the NICE Guideline**).

18.3 Section 1.5 of the NICE Guideline provides that children and young people with life-limiting conditions should be cared for by a defined multidisciplinary team.[73] Depending on the needs of the child or young person, the multidisciplinary team may include members of a specialist palliative care team.[74] The NICE Guideline notes that this team should include at a minimum a paediatric palliative care consultant, a nurse with expertise in paediatric palliative care, a pharmacist with expertise in specialist paediatric palliative care, and experts in child and family support who have experience in end of life care.[75] Further, Section 1.5.9 of the NICE Guidelines provides that "*for children and young people who are approaching the end of life and are being cared for at home, services should provide (when needed): advice form a consultant in paediatric palliative care (for example by telephone) at any time (day or night)*".[76]

18.4 In evidence, Professor Wilkinson explained that in his experience there were three benefits to the use of specialised palliative care input for children with life-limiting conditions:

(a) Families having access to palliative care professionals for advice in circumstances where the final phase of end-of-life care often occurs in the home;

(b) Palliative care professionals provide assistance with parallel planning in circumstances where there is importance in having the flexibility to revise care if the child's or infant's situation changes; and

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[72] Exhibit 1, Tab 54 at [40].
[73] Exhibit 1 Tab 54A, page 31.
[74] Exhibit 1 Tab 54A, page 31.
[75] Exhibit 1 Tab 54A, pages 31-32.
[76] Exhibit 1 Tab 54A, page 32.

(c) Palliative care professionals have expertise in supporting families, and can provide specialised counselling and support over protracted periods.

18.5 Associate Professor Evans said in evidence that he agreed with Professor Wilkinson but emphasised that one of the hallmarks of end-of-life care was the need for flexibility. Associate Professor Evans expressed some reservation about the possibility that any guideline might create rigidity when, instead, flexibility is needed. Associate Professor Evans went on to note that the addition of a simple paragraph to a guideline (acknowledging the area of improvement identified by Professor Wilkinson) would probably offer little practical change. Associate Professor Evans explained that, in his experience, much of palliative care remains hospital-focused and that there is limited access to specialised palliative care services in remote and regional areas. In this context, Associate Professor Evans instead urged for the development of palliative care as a state-wide service, rather than predominantly as an in-hospital service.

18.6 In response, Professor Wilkinson agreed that what matters most to families are not guidelines but, rather, the ability to access specialised palliative care services, professionals, and advice. However, he emphasised that reference to palliative care input within the NSW Guidelines would highlight the usefulness and availability of such services. Further, Professor Wilkinson expressed the view that such a reference would potentially become a tool for the state-wide delivery of such services.

18B. Advanced Care Plans

18.7 Professor Wilkinson noted that he did not find a recorded resuscitation plan for Jaxon and that one may have been helpful. Professor Wilkinson explained that "*it would be valuable to have available a consistent form of documentation to assist with planning and communicating palliative care plans for newborn infants who are being managed outside neonatal units*".[77]

18.8 Section 1.2.5 of the NICE Guidelines deals with Advanced Care Planning.[78] It provides that an Advanced Care Plan should be developed and recorded at an appropriate time. It should include items such as:

(a) a statement about who has responsibility for giving consent;

(b) an agreed approach to communicating with and providing information to the child or young person and their parents or carers;

(c) a record of significant discussions with the child or young person and their parents or carers;

(d) agreed treatment plans and objectives; and

(e) a record of any discussion and decisions that have taken place on matters such as management of life-threatening events, including plans for resuscitation and support.

18.9 The NICE Guidelines also provide that the Advanced Care Plan should be regularly reviewed with members of the multidisciplinary team caring for the child or young person, and in discussion with

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[77] Exhibit 1, Tab 54 at [41].
[78] Exhibit 1 Tab 54A, pages 10-12.

the child or young person and their parents or carers. Finally, the Guidelines provide that the Advanced Care Plan should be shared with professionals involved in the care of the child or young person, and should be updated when needed if, for example, the care setting changes or if the child or young person and their parents or carers move home.

18.10 The NSW Health Policy Directive, *Using Resuscitation Plans in End of Life Decisions (PD2014_030)* (**the Resuscitation Policy Directive**), describes standards and principles relating to the use of resuscitation plans by NSW public health organisations in the process of planning quality end-of-life care. A resuscitation plan (formerly known as "No CPR Orders") is made with reference to pre-planning by patients (such as an Advanced Care Plan) and is a medically authorised order to use or withhold resuscitation measures and document other time critical clinical decisions related to end of life.[79] However, the Resuscitation Policy Directive only applies to patients 29 days and older.

18.11 Professor Wilkinson explained that a resuscitation plan may not always be helpful or necessary when newborn infants are managed within a neonatal unit, where the clinical team are all likely to be familiar with the patient. However, Professor Wilkinson explained that where a newborn infant is managed outside the environment of a neonatal unit, such as at home or when being transferred to other hospitals, a resuscitation plan "*can be important to record and communicate interventions that should or should not be provided*".[80]

18.12 In evidence, Associate Professor Evans explained that resuscitation plans had largely been developed in the context of medical care for adults, where such care can often be provided across different wards in a hospital setting. In these situations, directives such as resuscitation plans become imperative in order to ensure that different personnel who might be involved in a patient's care clearly understand a patient's wishes. Associate Professor Evans went on to explain that in his experience the standard paediatric resuscitation plan[81] provided for by the Resuscitation Policy Directive is still utilised in clinical practice for neonates less than 29 days old. Associate Professor Evans explained that he had not noticed any shortcomings, beyond the title of the document, and that much of it is applicable in the clinical context.

18.13 Professor Wilkinson explained in evidence that in his experience the development of advanced care plans have become more complicated and richer over time. He explained that initial versions of such documents were too simplistic and did not provide for the need for flexibility. Professor Wilkinson also noted that more recent advanced care plans seek to be more holistic: setting out priorities for the care of a patient, timetables for revision of care, the views of persons involved in a patient's care, and the reasons why certain conclusions have been reached.

18C. Response from NSW Health

18.14 Before the commencement of the inquest the Crown Solicitor's Office wrote to NSW Health to advise that the inquest intended to explore issues relating to palliative care. A copy of Professor Wilkinson's first report dated 7 September 2018 was provided with an indication that the two aspects of the Guidelines referred to by Professor Wilkinson above might, at the conclusion of the inquest, form the

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[79] Exhibit 1 Tab 48, Annexure G, page 13.
[80] Exhibit 1 Tab 54B at [11].
[81] Exhibit 1 Tab 48, Annexure G, page 19.

basis of recommendations made pursuant to section 82 of the Act. In this context, NSW Health was invited to provide any submission in relation to any possible recommendations.

18.15 In response NSW Health sent an email to the Crown Solicitor's Office on 26 October 2018. That email explained that the Guidelines are currently under review and that "*NSW Health is soon to release a new End of Life and Palliate [sic] Care Framework*". The email also advised that Professor Wilkinson's suggested improvements had been provided "*to the relevant Branch at the Ministry for comment*" and would be provided to "*the team reviewing the Guidelines so they can be considered as part of the review*".[82]

18.16 At the conclusion of the inquest a further response was provided by NSW Health. That response noted that "*NSW Health is currently developing an End of Life and Palliative Care Framework which will guide the future direction of state-wide policy and strategy that relates to end of life and palliative care*"[83] and that it is anticipated that the Palliative Care Framework (**the Framework**) will be released by the end of 2018. It was further noted in the response that following release of the Framework, NSW Health will "*develop a high level implementation plan*" and that as part of this implementation "*policy guidelines would be reviewed and updated to ensure consistency with the Framework's overarching principles and priorities*".[84]

18.17 Counsel for NSW Health submitted that what is envisaged by the Framework is not examining separate and individual issues such as specialised palliative care input and resuscitation plans. Rather, it was submitted, the process of review as part of implementation of the Framework would hopefully ensure that policy guidelines such as the NSW Guidelines were richer in the way advocated for by Professor Wilkinson. In this context, it was submitted that any recommendation made in his regard would be "*unhelpful*", although it was not explained why this was the case. It was speculated that any recommendation might impede or delay implementation of the framework.

18.18 **Conclusion:** The expert evidence adduced during the inquest highlighted the value of input from specialised palliative care professionals and use of advanced care plans in end-of-life care. Given that the last phase of Jaxon's end-of-life care often took place at home, it is most likely that his parents would have benefitted from access to palliative care advice, and assistance with parallel planning and family support.

18.19 Further, in Jaxon's case there was a degree of misunderstanding associated with the ceasing of midazolam for Jaxon at the time of withdrawal of life-sustaining treatment. It would therefore appear, on the basis of the experience of Jaxon and his parents, that there is value in ensuring that there is consistency in understanding and communication between treating teams and families regarding a patient's treatment. Further, given that the Resuscitation Policy Directive specifically excludes neonates less than 29 days old, there would also be value in ensuring consistency of documentation across end-of-life care planning.

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[82] Exhibit 2.
[83] Exhibit 4.
[84] Exhibit 4.

18.20 The initial response provided by NSW Health, prior to the inquest, demonstrated a willingness to consider Professor Wilkinson's suggested improvements as part of the review of the NSW Guidelines. It is therefore unclear why the submission made at the conclusion of the inquest was that any potential recommendation made in this regard would be considered to be unhelpful. To the contrary, the confirmation given by NSW Health on 26 October 2018 was that Professor Wilkinson's suggested improvements would be considered as part of a review of the NSW Guidelines. It would therefore appear to be desirable to make the following recommendations.

18.21 **Recommendation 1:** I recommend that a copy of the reports of Professor Dominic Wilkinson dated 7 September 2018 and 27 October 2018 be forwarded to the NSW Minister for Health, together with a transcript of the oral evidence of Dr Peter Campbell, Associate Professor Nick Evans, and Professor Wilkinson, given on 30 October 2018, for the Minister's consideration regarding Recommendation 2.

18.22 **Recommendation 2:** I recommend to the NSW Minister for Health that, having regard to the material referred to in Recommendation 1, consideration be given to the following matters as they apply to any review of the NSW Health *End-of-Life Care and Decision-Making – Guidelines* (GL2005_057) (**the NSW Guidelines**): (a) Whether the NSW Guidelines ought to refer to palliative care professionals, and the role that such professionals might play in the end-of-life care and decision-making for infants and children; and (b) Whether the NSW Guidelines ought to refer to resuscitation plans and advance care plans in general, and for neonates less than 29 days old in particular.

19. Findings pursuant to section 81 of the *Coroners Act 2009*

19.1 Before turning to the findings that I am required to make, I would like to acknowledge, and express my gratitude to, Dr Hayley Bennett, Counsel Assisting, and her instructing solicitor, Ms Kate Lockery of the Crown Solicitor's Office. Their assistance during both the preparation for inquest, and during the inquest itself, has been invaluable. I would also like to thank them both for the sensitivity and empathy that they have shown in what has been a particularly distressing matter. I also thank Detective Senior Constable Alexandra Pacey for her efforts during the investigation into Jaxon's death and for compiling the initial brief of evidence.

19.2 The findings I make under section 81(1) of the Act are:

Identity
The person who died was Jaxon McGrorey-Smith.

Date of death
Jaxon died on 18 November 2011.

Place of death
Jaxon died at New Lambton NSW 2305.

Cause of death
The cause of Jaxon's death was neonatal encephalopathy due to perinatal compromise.

Manner of death
Jaxon died from natural causes.

20. Epilogue

20.1 The brevity of Jaxon's life is not commensurate with the enormity of the loss felt by his parents and family, their deeply felt love for him, and the joy he brought to them all. As Jaxon's parents explained at the end of the inquest, Jaxon's life cannot be measured in weeks, but rather in the gifts in installed in all of his family.

20.2 On behalf of the Coroner's Court, and the counsel assisting team, I offer my deepest and most respectful condolences to Jaxon's parents, Kirsty and Lisa; Jaxon's brothers, Cooper and Rylan; and the rest of Jaxon's family for their tragic loss.

20.3 I close this inquest.

Magistrate Derek Lee
Deputy State Coroner
14 November 2018
NSW State Coroner's Court, Glebe