CORONERS COURT
OF NEW SOUTH WALES

Inquest:	Inquest into the death of Tory Ganderton
Hearing dates:	2 to 6 March 2020
Date of findings:	25 March 2020
Place of findings:	Coroners Court of New South Wales at Lidcombe
Findings of:	Magistrate Derek Lee, Deputy State Coroner
Catchwords:	CORONIAL LAW – spinal muscular atrophy, Shoalhaven District Memorial Hospital, Newborn & Paediatric Emergency Transport Service, handover, end of life planning
File number:	2014/266567
Representation:	Mr G Moore, Counsel Assisting, instructed by Ms A Najjarin (Crown Solicitor's Office) Ms H Cooper (Legal Aid Commission of New South Wales) for Ms K Dowd Mr I Fraser for Dr T Greenacre and Dr M De Souza, instructed by Ms A Pale (HWL Ebsworth Lawyers) Mr M Lynch for Illawarra Shoalhaven Local Health District and Sydney Children's Hospital Network, instructed by Mr L Sara (Hicksons Lawyers)
Findings:	I find that Tory Ganderton died on 10 September 2014 at Kiama Heights NSW 2535. The cause of Tory's death was respiratory failure, with spinal muscular atrophy an antecedent cause. Tory died as a result of natural disease process, in circumstances where he suffered acute respiratory deterioration during an inter-hospital transfer.

Table of Contents

1. Introduction 1
2. Why was an inquest held? 1
3. Recognition of Tory's life 1
4. Background to the events of September 2014 3
5. The critical events of September 2014 4
6. What was the cause of Tory's death? 6
7. What issues did the inquest examine? 6
8. Was it necessary to transfer Tory in the early hours of 10 September 2014? 7
   Respiratory support 11
   Timing of the transfer 14
   Method of transfer 15
10. Was an appropriate handover conducted? 16
11. Were Tory's parents appropriately consulted in relation to his transfer? 17
12. The cause and effect of Tory's weight loss 19
13. End of life planning 21
14. Acknowledgments 26
15. Findings pursuant to section 81 of the *Coroners Act 2009* 26
16. Epilogue 27

1. Introduction

1.1 Tory Ganderton was diagnosed with a life-limiting illness at a young age, which necessitated frequent admissions to hospital. On 9 September 2014 during one such admission, when Tory was only three years and nine months old, arrangements were made to transfer Tory by road ambulance to another hospital for further care and management. After about an hour into the journey Tory experienced a sudden deterioration in his respiratory function requiring resuscitation measures to be initiated immediately whilst his mother was in the ambulance with him. Tragically, Tory could not be revived and died in the ambulance, which had stopped at the roadside, away from his father, siblings and other family.

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.

2.2 The coronial investigation into Tory's death was able to answer most of these questions. The inquest was primarily focused on the manner of Tory's death. That is, the sudden nature of Tory's deterioration, the traumatic circumstances in which it occurred, raised a number of questions. These questions related to the nature of Tory's condition, how it affected the decision to transfer Tory in the early hours of 10 September 2014, and what therapeutic measures were available to support Tory during the transfer.

2.3 In this context it should be recognised at the outset that the operation of the Act, and the coronial process in general, represents an intrusion by the State into what is usually one of the most traumatic events in the lives of family members who have lost a loved one. At such times, it is reasonably expected that families will want to grieve and attempt to cope with their enormous loss in private. That grieving and loss does not diminish significantly over time. Therefore, it should be acknowledged that the coronial process and an inquest by their very nature unfortunately compels a family to re-live distressing memories several years after the trauma experienced as a result of a death, and to do so in a public forum.

2.4 Inquests 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 made, usually, to government and non-government organisations, in order to seek 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.

3. Recognition of Tory'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 Tory's life in a brief, but hopefully meaningful, way.

3.3 Tory was the second child of Kayla Dowd and George Ganderton. He was born on 6 December 2010 and later diagnosed with Spinal Muscular Atrophy[1] (**SMA**) at around 12 months of age. Tory's brother, Justice, was born on 14 June 2009. Justice was subsequently diagnosed with Down syndrome, and it was suspected that he also suffered from SMA. However, Justice sadly passed away in 2011, before his second birthday, and before a diagnosis of SMA could be confirmed.

3.4 Tory's other siblings, Mikaylah and Billy-George, were born in December 2011 and September 2013, respectively. Neither Mikaylah or Billy-George suffer from SMA.

3.5 Tory's parents described him as cheeky, bubbly, intelligent and always happy. Tory had a particular love for The Wiggles, and adored his siblings. He would play games with Mikaylah by knocking down all her toys and had a special name for Billy-George, who he called, "Super Baby". Tory also had many pets and enjoyed spending time with them, in particular a pig that he named, "Peppa".

3.6 Despite having a life-limiting condition, Tory did not allow it to limit his enjoyment of spending time with his family and others, or limit how much joy he brought to them. Tory had a special chair which he loved and would often sit in it and pretend to run along with his siblings. Despite a hospital environment being a challenging one for a young child Tory never complained during his many admissions. Instead, Tory was known to make a cheeky comment and entertain the nurses with his irrepressible spirit.

3.7 Despite his own health conditions, Tory had a strength of will and determination that inspired his parents. Tory was also kind-hearted and caring, often showing concern for others. He frequently told his father, "*Don't be sad, be glad*", and regularly told his family how much he loved them.

3.8 It is heartbreaking to know how suddenly Tory was taken from his family, and how much he is, and will continue to be, enormously missed every day.

[1] Spinal muscular atrophy (**SMA**) is a group of neuromuscular disorders that results in the loss of motor neurons and progressive muscle wasting. As SMA manifests over a wide range of severity, the disease spectrum is divided into different Types, based on achievement of motor milestones. Tory was diagnosed with SMA Type 1 (also known as Werdnig-Hoffman Syndrome), regarded as the most severe Type of SMA, in which there is progressive degeneration of the anterior horn cells in the spinal cord, which causes progressive weakness and affects the muscles of respiration, resulting in respiratory failure and eventually death.

4. Background to the events of September 2014[2]

4.1 During the early period of Tory's life his family resided in the Nowra region. Sometime in 2011 or 2012 Tory's parents decided to relocate to Western Australia as George had family there. Following this interstate move, Tory's family subsequently returned to the Nowra region in early 2013. In early 2014, they again returned to Western Australia. Whilst living in Western Australia the family was based in a small rural town about two hours' drive from Perth.

4.2 Tory had a number of admissions to hospital in both New South Wales and Western Australia. In New South Wales, these hospital admissions took place at Shoalhaven District Memorial Hospital (**Shoalhaven Hospital**) in Nowra and were mainly due to recurrent bouts of pneumonia. Apart from his admission in September 2014, Tory had three admissions in May, July, October 2012, a further admission in March 2013, and another admission in July 2014.

4.3 In Western Australia, Tory was admitted to Princess Margaret Hospital in February 2014 for a sleep study. Relevantly, on admission it was noted that Tory weighed 13.1 kilograms. It is also significant that whilst in Western Australia Tory was given access to a cough assist machine[3] and the family was provided with Fortini, a high-energy, oral nutritional supplement.

4.4 As noted above, in June 2014 Tory's family returned to the Nowra region. On 2 July 2014 Tory saw Dr Mark de Souza, a consultant paediatrician in Nowra. It was noted that Tory had progressive weakness and that Tory was likely at eventual risk of respiratory failure. Following this consultation, arrangements were made for Tory to be referred to the Neuromuscular Multidisciplinary Clinic (**the Neuromuscular Clinic**) at the Sydney Children's Hospital in Randwick. Tory had previously been seen at the clinic before his family moved to Western Australia.

4.5 On 4 July 2014 Tory was seen by Dr Hugo Sampaio, a paediatric neurologist, at the Sydney Children's Hospital. On assessment, Dr Sampaio noted that because Tory's family had been living interstate for about 18 months there were a number of issues regarding Tory's condition which needed to be addressed. It was noted that Tory was then in need of a cough assist machine and arrangements were made for him to be provided with one, which would involve regular daily use.

4.6 It was also noted that Tory's weight had increased to 23 kilograms since February 2014 (placing him in the 97th centile on the growth chart). Although Tory was unwell on the day, Dr Sampaio noted that he was nevertheless bright and engaging and that he had made remarkable progress with his language. Dr Sampaio also noted that there had been a deterioration in Tory's muscle strength and that he was unable to maintain a seated posture, or achieve shoulder abduction or elbow flexion independently. Dr Sampaio made arrangements for Tory to be reviewed again in October 2014, and recommended to Kayla that she look into preschool options for Tory.

4.7 During his appointment on 4 July 2014 Tory was also seen by a number of other health professionals including a representative from the genetics department, a respiratory physician, an occupational therapist, and a dietician, Antonia Trollip.

---

[2] The factual background has been drawn from the helpful opening address of Counsel Assisting.
[3] A machine which assists breathing by clearing secretions from the lungs, helping to protect them from infection.

4.8 Ms Trollip had previously seen Tory in November 2012. At that time Tory had been referred to the Neuromuscular Clinic so that nutrition support could be provided as his oral intake fluctuated. Tory's weight at that time had decreased to 10.9 kilograms (from the 25-50th centile to the 10th centile). Ms Trollip provided Kayla with education regarding increasing calories in Tory's diet, and also recommended a nutritional supplement drink (Sustagen Kids Essential).

4.9 By the time of Ms Trollip's review in July 2014 it was noted that Tory had put on a significant amount of weight (23 kilograms) from when he was last seen in November 2012 (10.9 kilograms). Kayla reported that Tory was taking four 200ml bottles of Fortini per day in addition to his usual puree diet, whilst in Western Australia. MS Trollip registered Tory on the Home Enteral Nutrition program so that he could access Fortini in New South Wales. As Tory was considered to be overweight by July 2014, Ms Trollip recommended that Tory's intake of Fortini be reduced to one or two 200ml bottles per day, in addition to his pureed diet, in order to stabilise his weight. Tory was then scheduled to be reviewed again at the Neuromuscular Clinic in October 2014.

4.10 On 12 July 2014 Tory was admitted to Shoalhaven Hospital for two days following a period of unwellness. It was noted at the time that Tory's weight remained at 23 kilograms. Following his discharge, Tory was seen by his treating community paediatrician.

4.11 On 26 August 2014 Tory presented to his GP with a complaint of upper respiratory tract infection and symptoms that had been ongoing in the previous 2 to 3 weeks. On examination it was noted that Tory was well hydrated, appeared well, and was otherwise happy and playful.

5. The critical events of September 2014

5.1 On 7 September 2014 Tory was taken to the Shoalhaven Hospital emergency Department by his parents. On admission it was noted that Tory had a history of increasing lethargy and increased work of breathing over the previous week, associated with a persistent respiratory infection. Tory was subsequently diagnosed with pneumonia and dehydration. It was also noted that Tory's weight was 11.5 kilograms, a decrease of some 11.5 kilograms when he was last seen at Shoalhaven Hospital in July 2014. Tory was admitted under the care of Dr Toby Greenacre, consultant paediatrician. Although Dr Greenacre was not Tory's treating paediatrician, he had previously seen Tory during one of his earlier admissions to Shoalhaven Hospital in 2012.

5.2 Following his admission, Dr Greenacre made arrangements for Dr de Souza to attend the hospital in order to assess Tory on 8 September 2014, with a view to possibly transferring Tory to a tertiary hospital in Sydney. Concerns were raised about Tory's drastic weight loss, and the need to seek specialist input from clinicians at the Sydney Children's Hospital in relation to Tory's condition given this weight loss and his persistent infections which had led to pneumonia. At abut 3:00pm on 8 September 2014 a dietician conducted a nutritional assessment for Tory and noted that he was malnourished and had experienced severe loss of body weight. Arrangements were also made for Tory to be assessed by a physiotherapist.

5.3 Tory was reviewed again during morning ward rounds on 9 September 2014. It was noted that Tory's respiratory status was fluctuating in severity. Dr Greenacre contacted Sydney Children's

Hospital and requested a transfer for Tory, for assessment and treatment of his malnutrition and continuing care of his pneumonia, which was accepted.

5.4 At 3:40pm on 9 September 2014 a conference call was held involving a number of clinicians in both Nowra and Sydney order to discuss Tory's management. Dr Greenacre, Dr Eric Chung (paediatric registrar at Shoalhaven Hospital), Dr Linda Durojaiye (consultant emergency physician at Sydney Children's Hospital), Dr Fiona Mitchell (paediatric consultant from the Newborn and Paediatric Emergency Transport Service (**NETS**)) and a Dr Noel Friesen (paediatric fellow at Sydney Children's Hospital) all took part in the call. At some stage during the conference call, Dr Greenacre was called away to manage the transfer of another child with an acute condition from a regional hospital to Shoalhaven Hospital. Dr Greenacre was unable to return to the conference call before it concluded. However the call participants reached a consensus that Tory's transfer would not take place until the following morning, subject to Dr Greenacre's views.

5.5 Following the conference call, Dr Chung subsequently advised Dr Greenacre of the decision to defer Tory's transfer until the following day. Dr Greenacre subsequently instructed Dr Chung that the transfer should not be so deferred. It appears that this was based on concerns held by Dr Greenacre regarding a possible deterioration in Tory's respiratory status, and the ability of available nursing resources to respond to such a deterioration in circumstances where Dr Greenacre himself was not on site at the hospital overnight (and lived 15 minutes away).

5.6 At 4:55pm Dr Chung relayed Dr Greenacre's instructions during a second conference call. Arrangements were subsequently made for a NETS road ambulance to attend Shoalhaven Hospital in order to transfer Tory to Sydney. Due to resource and other limitations transfer by air (helicopter or fixed wing aircraft) was not available.

5.7 At around 11:30pm on 9 September 2014 the NETS transfer team, consisting of Dr Ahmed Mustafa and Registered Nurse (**RN**) Beckie Petulla (together with the ambulance driver), arrived at Shoalhaven Hospital. After conducting an initial assessment of Tory, Dr Mustafa arranged for another conference call at 12:25am on 10 September 2014. Dr Durojaiye participated in the call, along with Dr Jagdeep Grewal (a paediatric intensivist at Sydney Children's Hospital) and Dr Bilgrami (the admitting officer at Sydney Children's Hospital). The purpose of the call was to discuss Tory's management during transfer.

5.8 Whilst at Shoalhaven Hospital Tory had been receiving high flow humidified oxygen via nasal prongs, which was not available in the NETS ambulance. One of the possible options was for oxygen delivery to be provided by Continuous Positive Airway Pressure (**CPAP**) or Bilevel Positive Airway Pressure (**BiPAP**), both of which required use of a mask which had previously distressed Tory, and which he would not tolerate. Further, prior to conference call Dr Mustafa had trialled that use of the CPAP mask but discontinued it after Tory became distressed.

5.9 At 1:18am on 10 September 2014, after Tory had been stabilised, the NETS retrieval team departed Shoalhaven Hospital, with Tory and Kayla in the NETS ambulance. Shortly after departure it was noted that Tory's oxygen saturation was at 98 percent, and there was no increase in his respiratory effort. At around 1:45am, Tory's oxygen saturations suddenly dropped to 80 percent, and continued to desaturate. Oxygen flow was increased and suctioning was provided, but Tory's

condition continued to deteriorate, as he demonstrated prolonged bradycardia. A BiPAP mask was applied, but Tory became very sweaty and pale, started to hyperventilate, and showed reduced responsiveness.

5.10 Bag and mask ventilation was commenced and the ambulance pulled over to the side of the road along the Princes Highway at Kiama Bends. At 1:54am there was a changeover to an anaesthetic bag, and bag and mask ventilation continued, but Tory's heart rate continued to drop. At 1:55am cardiopulmonary resuscitation (**CPR**) was commenced, with chest compressions in conjunction with mask ventilation using anaesthetic bag. At 2:00am Tory was intubated and adrenaline was administered whilst CPR continued. However there was no return of cardiac output and a cardiac monitor showed heart rhythm to be asystole. Resuscitation measures continued for about 21 minutes, during which time a further NETS call was made in order to clarify the extent of resuscitation that would be provided. Tory remained in asystole with no return of spontaneous circulation. A decision was eventually made to cease resuscitation attempts, and Tory was subsequently pronounced deceased. The NETS ambulance later returned to Shoalhaven Hospital.

6. What was the cause of Tory's death?

6.1 Tory was later taken to the Department of Forensic Medicine where a post-mortem examination was performed by Dr Alex Olumbe, forensic pathologist, on 16 September 2014. Postmortem chest x-ray showed changes of bilateral bronchopneumonia. Generalised muscle wastage was also noted, together with moderate dehydration. It was further noted that Tory's weight and body mass index were extremely low for his age.

6.2 In the subsequent autopsy report dated 15 October 2014, Dr Olumbe opined that the cause of Tory's death was respiratory failure, with spinal muscular atrophy an antecedent cause.

7. What issues did the inquest examine?

7.1 Prior to the commencement of the inquest a list of issues was circulated amongst the sufficiently interested parties, identifying the scope of the inquest and the matters to be considered. That list identified the following issues:

(a) whether it was necessary to transport Tory in the early hours of 10 September 2014;

(b) whether the means of transfer was appropriate;

(c) whether an appropriate handover was conducted at Shoalhaven Hospital between the referring clinicians and retrieval clinicians;

(d) whether Tory's parents were properly consulted in relation to Tory's transfer;

(e) whether there should have been an end-of-life plan for Tory given his condition; and

(f) whether Tory's significant loss of weight prior to his admission to Shoalhaven Hospital in September 2014 contributed to his death and, if so, whether the cause of that weight loss can be identified.

7.2 In order to assist with consideration of some of these issues, opinion was sought from the following experts as part of the coronial investigation:

(a) Associate Professor Warwick Butt, consultant paediatric intensivist;

(b) Dr Richard Couper, senior paediatric gastroenterologist; and

(c) Dr Michael Harbord, paediatric neurologist.

7.3 Each of the experts provided a number of reports which were included in the brief of evidence. Further, each expert also gave evidence during the inquest.

8. Was it necessary to transfer Tory in the early hours of 10 September 2014?

8.1 Dr Greenacre first saw Tory during a morning ward round with Dr Chung on 8 September 2014. Dr Greenacre noted that Tory's condition had gradually worsened over the previous few days, and that he was in worsening respiratory distress. After arranging for a consultation by Dr de Souza, Dr Greenacre made arrangements for Tory to be reviewed by a dietician, Megan White, to investigate the cause of his weight loss.

8.2 In evidence Dr de Souza explained that Tory's condition placed him at a risk of reduced quality and quantity of life. However Dr de Souza considered that, following his assessment of Tory on 8 September 2014, this risk was potentially reversible but that Shoalhaven Hospital lacked the facilities for this to occur. On this basis, Dr de Souza explained that Sydney Children's Hospital was best placed to offer care to Tory, hence the reason for the transfer.

8.3 After contacting Ms Trollip to obtain details regarding Tory's nutritional history and dietetic management, Ms White completed a nutritional assessment with Tory (and with Kayla and other family members present) at about 3:00pm on 8 September 2014. Ms White assessed Tory as malnourished, evidenced by severe loss of body weight (50 percent loss of body weight in the past month). It was also noted that there was "*possible further muscle wasting on a background of [SMA], associated with significant reduced nutritional intake of aural died and the quit oral nutritional supplements*".[4] Ms White discussed her assessment with Dr Chung, with recommendations made for Tory to continue with a recommended oral diet with a trial of oral liquid nutritional supplement, and gradual re-feeding as tolerated with close monitoring.

8.4 Dr Greenacre and Dr Chung later reviewed Tory again at about 5:10pm. It appears that following this Dr Greenacre first raised with Tory's parents the possibility of transferring Tory to Sydney Children's Hospital "*the following day for nutritional and respiratory management*".[5]

---

[4] Exhibit 1, page 63 at [18].
[5] Exhibit 1, Tab 12 at [22].

8.5 Dr Greenacre reviewed Tory again at 9:20am on 9 September 2014. He noted that Tory's respiratory condition was stable or slightly worse, but fluctuating in severity, and that Tory remained distressed by being in hospital and separated from his parents. Following this review Dr Greenacre called Dr Friesen and requested Tory's transfer to Sydney Children's Hospital, which was accepted. Dr Friesen agreed that Tory's condition would benefit from management at a tertiary children's hospital. According to Dr Friesen, "*it was thought that Sydney Children's Hospital could assist with a multidisciplinary team to address [Tory's] weight loss, consider a possible percutaneous endoscopic gastrostomy tube, and link him in with palliative care services*".[6] Dr Greenacre made these transfer arrangements "*in a semi-elective timeframe for assessment and treatment of [Tory's] malnutrition and continuing care of his pneumonia*".[7]

8.6 In evidence Dr Greenacre explained that he did not consider Tory to be a palliative care patient. He said that his assessment was that Tory presented as a young boy with a respiratory illness which he had recovered from since 2012. Although Dr Greenacre said that he "*felt unhappy*" with Tory's drastic weight loss, he considered that if that weight loss could be reversed then Tory's respiratory status might considerably improve.

8.7 In evidence Dr Couper explained that if Tory had been transferred to Sydney Children's Hospital the safest way to initiate re-feeding for Tory would have been via a nasogastric tube. Dr Couper further explained that another option was total parenteral which required a central line, but this was problematic because of Tory's pneumonia. The only other option was percutaneous endoscopic gastrostomy[8], which was also considered by Dr Couper to be unsafe because it required use of anaesthesia. Overall, Dr Couper expressed the view that, absent other intervening conditions which Tory demonstrated, the prospects of success at the Sydney Children's Hospital in addressing his nutritional issues would have been "*very good*".

8.8 In evidence Associate Professor Butt expressed the view that if Tory's nutritional issues were to be treated, and if Tory was to be assessed by a multidisciplinary team, then this necessitated a transfer to Sydney. Associate Professor Butt also indicated that, consistent with Dr Greenacre's assessment at the time, if Tory's malnutrition could be safely reversed, it was possible that his life could be prolonged. On this basis, the only way to perform such an assessment was at the Sydney Children's Hospital.

8.9 **Conclusions:** The view of Dr de Souza and the initial view of Dr Greenacre that Tory's transfer to Sydney was warranted on a semi-urgent basis were reasonable in the circumstances. It was considered that Tory's nutritional issues would be best managed at the Sydney Children's Hospital, and that further assessment and treatment could be provided by a multidisciplinary team. The combined expert evidence established that the clinical decision-making was sound in relation to these considerations.

---

[6] Exhibit 1, Tab 18 at [6].
[7] Exhibit 1, Tab 12 at [26].
[8] An endoscopic medical procedure where a tube is passed into the stomach, through the abdominal wall, to provide a means of feeding in circumstances of inadequate oral intake.

8.10 Following on from the initial decision on 8 and 9 September 2014 to transfer Tory to Sydney, events in the subsequent clinical course raised other issues relevant to the question of transfer. At about 1:00pm on 9 September Tory's condition deteriorated. His respiratory support was changed from low-flow non-humidified oxygen therapy (2 litres/minute) to high flow humidified oxygen therapy (6 litres/minute in 30% oxygen). This resulted in an improvement in Tory's condition. However the need to intensify Tory's respiratory support caused Dr Greenacre to determine that Tory required urgent transfer to Sydney Children's Hospital that day. This is because Dr Greenacre considered that Tory was likely to require intensive care at the Sydney Children's Hospital, which could not be provided at Shoalhaven Hospital. Dr Greenacre subsequently requested Dr Chung to contact NETS and arrange an urgent transfer to Sydney Children's Hospital.

8.11 During the conference call Dr Chung provided a history for Tory, noting that he had been provided with increased respiratory support and that nasogastric feeding had been initiated. On this basis Dr Durojaiye indicated that she would accept Tory's transfer to Sydney Children's Hospital. However, Dr Friesen informed the call participants that he had been advised that there were currently no beds available at Sydney Children's Hospital meaning that if Tory were transferred he would remain in the Sydney Children's Hospital emergency department until a bed became available. Dr Durojaiye therefore enquired with Dr Chung whether there was some urgency with Tory's transfer and whether it was thought, because of the unavailability of beds, it would be preferable for Tory to remain in Nowra until the following day. Dr Chung advised that Tory's transfer had originally been requested due to his level of deterioration during the morning ward round. However it was noted that Tory's condition had improved following the increase in oxygen therapy. On this basis, the call participants agreed with a plan to effect transfer the following morning, subject to Dr Greenacre's agreement, with Dr Chung to keep the Sydney Children's Hospital updated and that escalation could occur if necessary.

8.12 Dr Greenacre was subsequently advised, after prematurely leaving the NETS conference call, that Tory's transfer was to be delayed until 10 September 2014. In a statement provided to the inquest Dr Greenacre explained that he would not have agreed to this delay if he had not left the NETS conference call prematurely, on the basis that he was "*unwilling to continue [Tory's] care in Nowra overnight and had the support of nursing staff and hospital administration in this decision*".[9] As a result of being provided information regarding the delay in Tory's transfer, Dr Greenacre subsequently requested Dr Chung to contact NETS and arrange an urgent transfer for Tory, per his (Dr Greenacre's) original request.

8.13 During the subsequent conference call at 12:25am on 10 September 2014 following the arrival of the NETS retrieval team at Shoalhaven Hospital, Dr Mustafa noted: "*…It sounds like [Tory] has ongoing…gradual but ongoing deterioration… So I won't be surprised in the coming 24 hours he goes downhill even further*".[10] Further, when Dr Durojaiye raised the prospect of Tory being stable and safe and therefore whether he should remain at Shoalhaven Hospital, Dr Mustafa expressed the following: "*I think with the…With the staff resources here and his ongoing deterioration… My feeling is looking at that x-ray, looking at that white cell count, which is actually rising…[Tory is] only going to get worse and I won't be surprised if he's already got an infected pleural effusion in*

[9] Exhibit 1, Tab 12 at [43].
[10] Exhibit 1, page 1003.

that left side with temperatures spiking".[11] In response Dr Durojaiye considered that Tory needed admission to the ICU, noting "*because he's not going to get better. He's going to get worse*".[12]

8.14 In evidence, Dr Mustafa was asked what he meant by his reference to "*with the staff resources here*". He explained that it was clear to him (and the other members of the NETS team) that there was "*unanimous discomfort*" with Tory remaining at Shoalhaven Hospital due to his fragility, and the limited medical cover overnight. Further, Dr Mustafa explained that Tory's test results all suggested that he was on a "*downhill trend*". On this basis, and given the underlying anxiety expressed by nursing staff that he spoke to (including a nurse who appeared, in Dr Mustafa's view, to be a senior nurse), Dr Mustafa said that he supported the view that Tory required transfer to Sydney.

8.15 On this basis, Dr Greenacre explained in evidence that the reason for Tory's transfer was the lack of nursing resources, not any life-threatening condition. More particularly, Dr Greenacre explained that there were inadequate numbers and expertise amongst nursing staff to care for Tory in the event of a possible sudden deterioration overnight. Dr Greenacre explained that the nurses on duty overnight were already required to provide nursing support for a 12-bed children's ward, along with a special care nursery. Further, Dr Greenacre explained that as he was not on site overnight (being located about 15 minutes away from the hospital) there would be a consequent delay in Tory's treatment if he deteriorated rapidly.

8.16 There is support for Dr Greenacre's view. Colleen Foy was the Nursing Unit Manager at Shoalhaven Hospital on 9 September 2014. After being told at around 4:00pm that Tory's transfer was to be delayed until the following day, RN Foy expressed concerns about Tory's worsening respiratory state and oxygen desaturations. She contacted Dr Greenacre and informed him that the paediatric nursing staff "*were not able to provide any extra nursing staff to 'special' Tory who required high dependency nursing care*". RN Foy also expressed concern to Dr Greenacre that Tory's condition would further deteriorate during the evening in circumstances where there would be only two nursing staff rostered for the night shift.

8.17 Dr Harbord considered that it was not necessary for Tory to be transferred in the early hours of 10 September 2014. This is because Dr Harbord noted that Tory had demonstrated clinical improvement when respiratory support was increased by the afternoon of 9 September 2014 compared to his condition in the morning. Further, Dr Harbord noted that there was no clinical evidence of a significant deterioration at the time when the NETS team arrived at Shoalhaven Hospital.

8.18 In evidence, Dr Harbord agreed that in making the decision to transfer Tory to Sydney, it was prudent to anticipate a possible deterioration in his condition in the 24 hours to follow. Notwithstanding, Dr Harbord considered that any subsequent deterioration given Tory's clinical condition at the time would be expected. However, later in his evidence, Dr Harbord agreed that the attending paediatrician was best placed to determine whether Tory's transfer was appropriate, and to liaise with the Sydney Children's Hospital regarding the manner of his transfer.

[11] Exhibit 1, page 1008.
[12] Exhibit 1, page 1008.

8.19 In evidence Associate Professor Butt was asked about the anxiety expressed by nursing staff at Shoalhaven Hospital in relation to being able to provide adequate care to Tory in the absence of a medical officer on site. Associate Professor Butt said that he considered that the nursing staff were "*good judges*" of the situation that they were confronted with on 9 September 2014.

8.20 **Conclusions:** By the time of the first NETS conference call at 3:40pm on 9 September 2014, Tory's condition had been stabilised following increased respiratory support in response to a deterioration earlier that day. Tory's condition remained relatively unchanged up until the time of his departure from Shoalhaven Hospital. Therefore, on the basis of Tory's relatively stable condition prior to departure transfer was not immediately indicated.

8.21 However, the evidence established that the most proximate assessment of Tory prior to his departure by Dr Mustafa indicated that Tory's condition was on a "downward trend", and likely to worsen. Indeed, it was considered by Dr Durojaiye that upon arrival at the Sydney Children's Hospital, Tory would require admission to the intensive care unit. It is evident from the various NETS conference calls that the participants gave careful and appropriate consideration to the various clinical issues at play in an obviously difficult and challenging situation. Further, the evidence established that in the event of Tory's condition acutely deteriorating overnight, the concerns expressed by nursing staff in being able to provide appropriate and timely response was well-founded. Having regard to each of these considerations, together with the concordant expert evidence, it was necessary for Tory to be transferred from Nowra to Sydney early in the morning on 10 September 2014.

9. Was the means of transfer appropriate?

9.1 In considering the issue of whether the means of Tory's transfer to Sydney was appropriate, there are three relevant matters: firstly, whether it was possible to provide Tory with appropriate respiratory support during the transfer; secondly, whether it was appropriate to transfer Tory shortly after midnight on10 September 2014; and thirdly, whether transfer via Road ambulance was appropriate in the circumstances.

Respiratory support

9.2 At 12:25am on 10 September 2014 Tory's condition was discussed again during a NETS conference call. Dr Mustafa indicated that he had trialled a CPAP mask for Tory but because he had become distressed the NETS team decided to step down again to oxygen delivery via nasal prongs, with a maximum delivery rate of four litres per minute, which Tory had previously been on. Dr Mustafa noted that as a result Tory had been stable, with oxygen saturations at 98 to 99 percent, and no increase in his work of breathing. Dr Mustafa also indicated, following an enquiry from Dr Durojaiye, that it would be possible to escalate respiratory support for Tory from four litres of oxygen via nasal prongs to CPAP in the event of acute deterioration during transfer.

9.3 Further, Dr Durojaiye gave consideration to whether Tory should remain at Shoalhaven Hospital, if his condition was stable. However Dr Mustafa indicated that Tory's chest x-ray and rising white cell count indicated that his condition was deteriorating, and likely to worsen. On that basis, Dr

Mustafa expressed concern about Tory remaining at Shoalhaven Hospital, given the absence of sufficient staff resources to manage him. Therefore, Dr Durojaiye considered that upon arrival at the Sydney Children's Hospital, Tory would require admission to the intensive care unit. She therefore made arrangements for Dr Grewal to join the conference call.

9.4 In essence there were three options in relation to respiratory support for Tory during the transfer to Sydney:

(a) intubation and placing Tory on a ventilator;

(b) sedating Tory and using either CPAP or BiPAP; or

(c) nasal prong oxygen delivery.

9.5 The following evidence is relevant to consideration of the first option of intubation:

(a) Dr Mustafa described intubation as the most extreme method of support. He said that intubation introduced a significant risk in the sense that it was uncertain whether systemically Tory would be able to cope. That is, Dr Mustafa explained that intubation could lead to a situation where, because of his SMA, Tory could become deconditioned and weaker, and consequently become entirely dependent on a ventilator.

(b) Dr Durojaiye similarly explained that this option would be one of last resort. Further she said that it would not be considered for any child with Tory's condition as intubation had "*huge ramifications*" for long-term care and prognosis in a child with SMA. That is, there was a risk that Tory would become ventilation dependent, develop further muscle weakness, and be unable to be extubated. On this basis (and because Tory was not so acutely unwell where intubation would be considered as an urgent procedure) Dr Durojaiye explained that she did not feel that it was appropriate to embark on this treatment given the implications.

(c) Dr Grewal agreed with the above considerations and additionally explained that intubation in a child who was already compromised from a respiratory point of view could potentially precipitate cardiac arrest.

9.6 Turning next to the second option of sedation and positive airway pressure:

(a) Dr Mustafa explained that it is not uncommon for children to not tolerate positive airway pressure to varying degrees. On this basis, he explained that it is common practice to use sedation to assist this process. However, in Tory's case Dr Mustafa considered that because of Tory's fragility and underlying muscle weakness, there was a risk that sedation could take away his respiratory drive.

(b) Dr Durojaiye similarly referred to the fact that Tory had not tolerated CPAP and so this option could not easily be achieved whilst Tory was still awake, and without sedation. However whilst sedation might be considered in another patient, because of Tory's decreased respiratory reserve and complex history, the concern was that sedation would further deprive Tory of

respiratory drive resulting in possible decompensation leading to intubation (with its inherent risks as already noted above). As Dr Durojaiye explained in evidence she expressed fears that this would "*start a downward spiral*".

9.7 Finally, the following evidence is relevant to the third option of nasal prong oxygen delivery:

(a) Dr Mustafa considered that nasal prongs was realistically the only option for Tory. He explained that Tory was trialled on positive airway pressure for about 10 minutes with his own strawberry scented mask (which was applied to a ventilator). However, Tory clearly was distressed by this, and was constantly crying, which led Dr Mustafa to conclude that positive airway pressure was not viable. Therefore, Dr Mustafa trialled Tory on low-flow nasal prong oxygen for about 30 minutes. This resulted in Tory settling down gradually with his work of breathing returning to baseline and sufficient oxygenation. Dr Mustafa explained that this gave him confidence to proceed with the transfer on this basis.

(b) Dr Durojaiye similarly agreed that nasal prong oxygen was the only option. She said that Tory had already tolerated it prior to transfer, albeit at a higher flow and in humidified form. On the basis that Tory had been trialled on it for about 30 minutes by the NETS team Dr Durojaiye considered that this course was appropriate.

9.8 Apart from the three options available to provide respiratory support to Tory during transfer, there was also a separate fourth option which involved not proceeding with the transfer, and Tory remaining at Shoalhaven Hospital. Dr Mustafa acknowledged the availability of this fourth option, and explained that this issue was discussed with Dr Durojaiye. However, it was felt that Tory's trajectory was trending downwards. That is, whilst Tory was stable at the time, it could be envisaged that he was likely to deteriorate in the subsequent 24 to 48 hours, thereby increasing the need to transfer him due to his instability.

9.9 During the conference call Dr Durojaiye turned her mind to whether Tory should remain at Shoalhaven Hospital. In evidence she explained that this was because nine hours after the initial conference call Tory's condition had not deteriorated significantly. Further, the transfer would involve a long road trip out of hours in circumstances where there was a possibility that Tory would deteriorate during the night, and he was to be received in an emergency department which, she explained, is ordinarily a chaotic environment (particularly for a patient with a need for high level care such as Tory). As a receiving clinician, Dr Durojaiye considered that these were not ideal transport conditions. However she explained that it was not her role to make any judgement about a referring hospital's capacity to care for a patient. In this regard, Dr Durojaiye explained that the basis for a referring hospital requesting a transfer is because insufficient local resources are available. Therefore, because the request for transfer had been made on two occasions by Dr Greenacre, Tory's transfer was accepted. Dr Mitchell similarly indicated that if Dr Greenacre had conveyed his wish for Tory to be transferred (as he did) she would not overrule such a request.

9.10 In evidence, Associate Professor Butt agreed that the three options in relation to respiratory support were the only ones available to the NETS retrieval team. He expressed the view that in the circumstances it was reasonable to not intubate Tory. Associate Professor Butt explained that this method of transfer involved the greatest risk of mortality. Associate Professor Butt further

expressed the view that in September 2014 Tory was admitted to Shoalhaven Hospital in almost a terminal condition, with malnutrition and chronic respiratory problems. On this basis, he considered that had Tory remained at Shoalhaven Hospital it was most likely that he would become a palliative care patient. Further, Associate Professor Butt considered that there was no reason to suspect even if humidified oxygen had been available in the NETS ambulance that this would have altered the clinical course.

9.11 In this regard it is important to note that Associate Professor Butt explained that newer equipment and technology now exists in New South Wales (in the form of high flow nasal catheters that deliver humidified oxygen), compared to the situation in September 2014, to allow patients with similar requirements to Tory's to be transferred more safely.

9.12 **Conclusions:** The NETS retrieval team was confronted with a challenging situation with respect to the available options to provide respiratory support to Tory during transfer. The evidence established that each option was given appropriate consideration. The evidence also established that the options involving intubation and sedation carried too great a risk to Tory in the sense that, because of his inherent fragility, his respiratory drive could be depleted to the point where he became ventilator dependent.

9.13 Therefore, having also considered that having Tory remain at Shoalhaven Hospital was not a viable option given the possibility of acute deterioration with limited nursing support, the only remaining option in terms of respiratory support was nasal prong oxygen delivery. Whilst this option also carried its own associated risks, the evidence established two relevant considerations: firstly, the NETS retrieval team was equipped to escalate respiratory support in the event of acute deterioration during transfer; and secondly, the expert evidence established that even if respiratory support of the kind that was available at Shoalhaven Hospital was actually available during transfer, this would not have altered the clinical course. Having regard to each of these matters, the respiratory support provided to Tory during transfer was appropriate in the circumstances.

9.14 One final matter should be noted. In evidence Bradley Scotcher, the Director of Nursing and Midwifery Services for Shoalhaven Hospital explained that in July 2014 the use of high flow oxygen was a new therapy and, to his understanding, some members of the nursing staff had expressed anxiety in circumstances where a patient showed signs of deterioration at night with no medical officer present. However Mr Scotcher explained that oxygen is now a well-recognised and more widely used therapy and that since 2014 nursing education within the Ward's at Shoalhaven Hospital has been increased with the appointment of a full-time clinical nurse educator.

Timing of the transfer

9.15 In evidence Dr Mustafa was asked whether or not the timing of transfer (daytime versus night time) impacted at all on the prospects of a successful transfer. He explained that in his role as a retrieval clinician he is routinely tasked to retrieve patients at any time of the day or night. Whilst acknowledging that "*everything is better during the day time*" Dr Mustafa explained that it was not his role to determine whether a daytime transfer is preferable over a night time one.

Notwithstanding, Dr Mustafa explained that at night, in cold weather respiratory illnesses such as asthma can often "*flare up*", and increasing symptomatology is often present during the night. However Dr Mustafa explained that in general the greater consideration, rather than the time of transfer, is whether or not it is appropriate to transfer a patient at all.

9.16 In evidence, Dr Mitchell explained that whilst Dr Mustafa was available to depart Sydney by around 7:00pm on 9 September 2014 there was no available registered nurse to complete the retrieval team due to "*knock on events*" from the previous day. This meant that RN Petulla was not available to commence her shift until 9:00pm. Dr Mitchell explained that within five minutes of RN Petulla's arrival the NETS road ambulance departed Sydney for Nowra.

9.17 It should be noted that in evidence Kayla said that she was told on 9 September 2014 that it was "*not safe*" to transfer Tory during the night, particularly because it was raining at the time and because a helicopter would be unable to reach him in the event of a sudden deterioration.

9.18 **Conclusions:** Although Tory's transfer in the early hours of the morning on 10 September 2014 was not ideal, the overriding consideration was whether it was appropriate to transfer him at all. The appropriateness of this decision has already been discussed above in circumstances where, put briefly, transfer at the time was warranted given the unavailability of a suitable level of care during the night. Further, whilst the eventual time of departure was attributable to the unavailability of a NETS retrieval team to depart Sydney earlier on 9 September 2014, this was an unforeseeable circumstance and one that was incapable of being remedied.

Method of transfer

9.19 In evidence Dr Durojaiye said that she considered the possibility of a transfer by air on the basis that she wanted to mitigate any risk associated with transfer. She said that the increased duration of road transfer with a fragile patient such as Tory added to the inherent risks. On this basis, Dr Durojaiye considered that air transfer was the preferable option. However when enquiries were made regarding the possibility of air transfer the result was that no other method of transfer (apart from road ambulance) was available.

9.20 In this regard, Dr Mitchell explained that NETS has a variety of ways to effect patient transfer: namely helicopters, fixed wing aircraft, and road ambulances. When a request for an air transfer is made to the NSW Ambulance Aeromedical Control Centre (**ACC**) (which is responsible for tasking and coordinating air retrieval services), an indication is given as to a preference for helicopter or fixed wing aircraft. Following this request, the ACC performs an assessment having regard to various factors such as the availability of assets, staff availability, weather conditions and other relevant matters. A decision is then made as to what asset is provided.

9.21 In Tory's case, Dr Mitchell requested a helicopter for the transfer, primarily on the basis that a fixed wing aircraft was unsuitable given the lack of proximity of Shoalhaven Hospital to an airport. Dr Mitchell explained that whilst there is a perception that a helicopter is a relatively rapid form of transfer, this is not necessarily the case. This is because additional time is required to prepare a helicopter for take-off, to load necessary equipment, and in circumstances where a helicopter is unable to land at the site of the referring hospital, a road ambulance would still be required. In

contrast Dr Mitchell explained that NETS uses its own road ambulances which are already loaded with equipment and able to depart its facility immediately upon being tasked. Ultimately, due to availability of assets, it was not possible to deploy a helicopter for Tory's transfer.

9.22 In evidence, Dr Mustafa was asked whether, having regard to the possibility of air transfer versus road transfer, there is a preferred method of transfer for a patient. He explained that whilst there are complex logistical and clinical questions that factor into any such decision-making process, decisions of this kind are made by the relevant consultant depending on the assets available and the clinical condition of a patient. Nevertheless, Dr Mustafa explained that regardless of the method of transfer the services delivered to a patient remain the same. Indeed, Dr Mustafa explained that certain clinical measures may be more challenging within a helicopter environment because, for example, the associated noise and vibrations potentially make it more difficult to use a stethoscope in order to assess a patient.

9.23 **Conclusions:** Each of the possible methods of transferring Tory presented their own challenges. Whilst a helicopter was requested as the method for transfer, this issue was ultimately decided by the availability of assets at the time. Given the factors relevant to Tory's particular transfer (such as location) it is not possible to reach any conclusion about whether one method of transfer would likely have been significantly timelier than another. Further, given the evidence regarding the availability of equivalent services being able to be delivered, regardless of the method of transfer, it cannot be concluded that the method of transfer adversely contributed to the eventual outcome.

10. Was an appropriate handover conducted?

10.1 There is some degree of inconsistency in the documentary evidence regarding the handover at Shoalhaven Hospital upon the arrival of the NETS retrieval team. On the one hand Dr Mustafa and RN Petulla said that they arrived at the hospital at 11:13pm and received a handover from a nurse in the paediatric ward.

10.2 On the other hand, Dr Chung states that the NETS retrieval team arrived at 11:30pm, and that he provided them with a handover before leaving the hospital and going home. Dr Chung further states that whilst waiting for the NETS retrieval team to arrive he had written a discharge letter which he handed over to the NETS retrieval team, along with copies of Tory's chest x-ray imaging. In evidence, Dr Chung adhered to his statement and said that he recalled meeting the NETS team upon their arrival. However he explained that he did not perform a formal handover in the sense of providing all of Tory's relevant details. Rather, that was left to nursing staff. Instead, Dr Chung said that he provided the NETS retrieval team with a "*brief introduction*" to Tory's condition.

10.3 Whilst it has not been possible to precisely identify the participants in any handover, the evidence establishes that clearly a handover took place. Further, the evidence also establishes that the NETS retrieval team were provided with an appropriate history for Tory. Finally, the NETS retrieval team also had access to other information regarding Tory's history (including from the NETS conference calls) separate to any information provided in any in-person handover. In this regard, Dr Harbord noted: "*There did appear to be an appropriate handover of Tory's information from the staff at the*

Shoalhaven Hospital to the NETS team. The transcripts of the teleconferences showed that the retrieval service were aware of the issues with Tory's condition".[13]

10.4 Since September 2014 New South Wales Health has introduced the *New South Wales Paediatric Service Capability Framework Guideline*. This Guideline ensures that a senior paediatrician is now identified and rostered within each Local Health District to provide advice and support for local hospital staff. This role includes supporting clinicians at the referring hospital during handover to a retrieval team such as NETS.

10.5 **Conclusions:** The evidence established that a handover clearly took place upon the arrival of the NETS retrieval team at Shoalhaven Hospital. It is most likely that a member of the nursing staff provided this handover to the retrieval team. Having regard to this matter, together with information that was available to the retrieval team prior to their arrival, it could not be said that the retrieval team were deprived of information relevant to Tory's care. Since September 2014, further measures have been introduced by New South Wales Health to ensure that a robust handover process is undertaken involving paediatric patients requiring transfer.

10.6 It should also be noted that in evidence Mr Scotcher explained that in 2014 the practice of handover of a patient to a NETS retrieval team would either involve a face-to-face handover by nursing staff, or a handover by the relevant consultant over the phone. Mr Scotcher went on to explain that since 2014 new documented procedures have been put in place at Shoalhaven Hospital to now ensure that a senior medical officer is always present for a face-to-face handover with a NETS retrieval team.

11. Were Tory's parents appropriately consulted in relation to his transfer?

11.1 In evidence, Kayla said that during the course of Tory's admission in September 2014 she had several conversations with Dr Greenacre. Kayla explained that Dr Greenacre informed her that the reason for Tory's transfer was so that the nasogastric tube (for the purposes of feeding) could be inserted. In her evidence, Kayla said that she queried this decision with Dr Greenacre because her observations were that whilst Tory was initially lethargic upon admission, he had returned to his normal self in the following two days. Indeed, Kayla said that Tory's condition had improved to the point where he was requesting food.

11.2 Dr de Souza said that he could not recall whether he had any conversation with Tory's parents about the purpose of Tory's transfer to Sydney. However, Dr de Souza explained that if Kayla had been present at the time that he assessed Tory it was unlikely that he would not have said anything to her. Notwithstanding, Dr de Souza said in evidence that if such a conversation had taken place it would not have involved discussion about the risks to Tory associated with the transfer. This is because, Dr de Souza explained, at the time he assessed Tory the risks of transfer were not high.

11.3 In evidence it was suggested to Dr de Souza that if any paediatrician was to discuss with Tory's parents what would occur in the event of a sudden deterioration in Tory's health, he was best placed to do so given his previous involvement with Tory and his family. Dr de Souza indicated that

[13] Exhibit 1, page 162.4.

such a discussion was open to any of the clinicians involved in Tory's care. When asked whether, because of his relationship with Tory and his family, he considered that he should take a leading role in such a discussion, Dr de Souza indicated that at the time he assessed Tory there was no evidence that he was in rapid decline and therefore there was no need to have such a discussion with Tory's family. Dr de Souza sought to further explain that it was not his role to make management decisions at that time.

11.4 Dr Greenacre was asked whether he discussed the purpose of Tory's transfer with Tory's parents. Dr Greenacre said that he could not recall having such a conversation. However he said that it was not his usual practice to not make decisions which were not conveyed to the parents of a patient. On this basis, Dr Greenacre considered that he would have had such a discussion. Dr Greenacre also said that he had no recollection of discussing any risks associated with Tory's transfer, on the basis that he did not personally feel that there were any such risks. Notwithstanding his inability to recall whether any conversation took place, Dr Greenacre positively denied in evidence that he informed Kayla of the following (on Kayla's account): that Tory would only be transferred by helicopter and that he would not survive a road transfer, and that Tory was fine, only had a "*bit of pneumonia*" and was improving. Dr Greenacre also said that whilst it was possible that he assured Kayla that there was no chance of losing Tory, it would not have been his usual practice to do so.

11.5 It should be noted that Dr Greenacre last reviewed Tory at about 6:30pm on 9 September 2014. At this point, Tory was noted to be stable and still awaiting the arrival of the NETS retrieval team for transfer. As Dr Greenacre's shift concluded before the arrival of the team he did not participate in any handover (although he explained that he would have been prepared to return to the hospital to perform a handover if requested by NETS). The effect of this was that Dr Greenacre was unaware of the limitations associated with the respiratory support available Tory during transfer, and the associated consequences in relation to any potential resuscitation plan.

11.6 Dr Chung said that he could not recall any conversation with Tory's parents regarding Tory's transfer. However he acknowledged that Kayla was the main person that he spoke to. Although he could not recall specific details of any such conversation, Dr Chung said that the question of the method of Tory's transfer would have been a matter for NETS.

11.7 Lisa Zordan, a social worker at Shoalhaven Hospital, met with Tory's parents on the afternoon of 8 September 2014. Ms Zordan made an entry made in Tory's progress notes with a timestamp of 2:40pm which noted: "*Discussed the possibility of Tory being transferred to Sydney and Kayla stated that she wouldn't be able to go until after Wednesday, though they would arrange for either George or another family member to go*".[14]

11.8 In evidence Dr Mustafa explained that the discussion with a patient's parents about the reason for the transfer of a patient is not a matter for a NETS retrieval team. This is because a retrieval team has not had any opportunity to develop rapport with a patient's family. Dr Mustafa explained that under normal circumstances a retrieval team would be seeing a patient's family for the first time and that it would be assumed that consent from a patient's parents would have been obtained. In

[14] Exhibit 1, page 56.

this context Dr Mustafa said that it would not be routine practice to ask a patient's parents if they were aware of the reason for a patient's transfer.

11.9 **Conclusions:** Unfortunately, any discussion that might have taken place between Tory's parents and the clinicians involved in his care as to the reason for Tory's transfer is not documented in any of the clinical progress notes (apart from Ms Zordan's progress note entry). There is therefore some difficulty identifying the content of any discussion that may have taken place with any degree of precision. However, what is clear from the oral evidence, and also from Ms Zordan's progress note entry, is that at least by about 2:40pm on 8 September 2014 Tory's parents were aware that a transfer to Sydney was a distinct possibility.

11.10 It is accepted that there are certain difficulties with aspects of Kayla's recollection of factual matters. For example, her recollection of certain events (whether an NGT was inserted during Tory's resuscitation, the timing of the family's interstate relocations) is inconsistent with contemporaneous documentary records. Of course, this is not meant to be critical of Kayla's evidence in any way. Rather, it is common experience that with the passage of time human memory is imperfect.

11.11 Having regard to Dr Mustafa's evidence, it is accepted that the responsibility for conveying the reason for Tory's transfer to his parents rested with the clinicians at Shoalhaven Hospital, and not the NETS retrieval team. Although both Dr Greenacre and Dr Chung had no specific recollection of any conversation with Tory's parents regarding the reason for Tory's transfer, it is most likely (in absence of any evidence to the contrary) that Dr Greenacre followed his usual practice and explained the need for Tory to be transferred to Sydney by 9 September 2014.

11.12 However, it cannot be said with any certainty that Tory's parents were advised that by the evening of 9 September 2014 the need to transfer Tory in the event of an acute deterioration, in circumstances where an inadequate level of nursing and medical was available, had taken primacy over other reasons for transfer, namely investigation of nutritional issues and the need for specialist multidisciplinary input. Certainly, given that Dr Greenacre had concluded his shift by the time the NETS retrieval team arrived it is most likely that Tory's parents were not advised of the limitations associated with respiratory support for Tory during transfer, and how this might affect the limits of any potential resuscitation measures. This ultimately had the regrettable and highly traumatic consequence of Kayla having to confront these issues in the midst of an obviously already distressing situation whilst resuscitation was being performed on Tory by the roadside.

12. The cause and effect of Tory's weight loss

12.1 In a statement made on 11 September 2014, Kayla explained that Tory had been losing weight upon the family's most recent return from Western Australia until the time of Tory's admission to Shoalhaven Hospital in September 2014. In response to this, Kayla explained that she provided Tory with additional liquid nutritional supplement in the form of Sustagen. However, on the available evidence it is unclear whether Kayla had the means and opportunity to access the Fortini supplement that had been provided to Tory in Western Australia. Ultimately, Kayla expressed the

following view: "*I believe [Tory] lost this weight because of the fight he put up to battle his sickness*".[15]

12.2 There is evidence that supports Kayla's view:

(a) In evidence, Dr Sampaio indicated that it is not unusual for SMA patients to have phases associated with rapid weight loss unless supported by nutrition, and that these phases become cyclical in nature. This is because neuromuscular weakness impacts upon a patient's ability to swallow and therefore maintain nutrition. Inadequate nutrition then has a consequent effect on muscle strength thereby resulting at times in rapid progression of weight loss.

(b) Ms White explained that following her assessment of Tory on 8 September 2014 she gave consideration to whether there were "*possible causative medical factors resulting in such a severe weight change and malnutrition*".[16] On this basis, Ms White considered that such factors included the effects of SMA such as ongoing muscle loss, negative effects on respiratory function and swallowing.

(c) Dr Couper similarly expressed the view "*that there would have been considerable problems with [Tory's] intake because of his neuromuscular difficulties*".[17] In evidence, Dr Couper expanded on this view by explaining that because of Tory's neuromuscular weakness there was an associated risk of choking or gagging whilst feeding.

(d) During the course of the NETS conference call at 3:40pm on 9 September 2014 Dr Greenacre informed the call participants: "*[Tory is] cachectic and it's pretty clear that [Tory's parents] haven't been able to feed him. They haven't been able to feed him because I think he [sic] probably knows he aspirates and so…I think that's why he's had a lot of weight loss*".[18]

(e) In his evidence, Associate Professor Butt raised for consideration the possibility that Tory's weight loss might also have been attributable to not only malnutrition, but also to dehydration and profound infection associated with his existing condition, or a combination of these factors.

12.3 As to the effect of Tory's drastic weight loss, and associated malnutrition, it has already been discussed above that this was a pressing concern for both the clinicians in Nowra and in Sydney. As to the possible contribution of this weight loss and malnutrition to Tory's death, the expert evidence is clear. Dr Couper expressed this opinion: *"[Tory's] nutritional status undoubtedly contributed to his death from usual causes for spinal muscular atrophy. There is a corpus of paediatric literature which suggests that muscular strength affects the outcome of major respiratory diseases… Additionally, children who are malnourished have reduced ability to clear infections, they probably have reduced immunity because their white cells function less efficiently.*

[15] Exhibit , Tab 10 at [20].
[16] Exhibit 1, Tab 14 at [44].
[17] Exhibit 1, page 162.75.
[18] Exhibit 1, page 983.

You also need to cough to clear secretions and the more malnourished and weaker you are, the less likely this is to be achieved".[19]

12.4 **Conclusions:** Whilst it has not been possible to resolve any possible issues in relation to the opportunity and means for Tory's family to access Fortini supplements in New South Wales, the available evidence established that Tory's neuromuscular weakness from SMA had a direct effect on the nature and quality of his oral intake. Further, it is clear from the available expert evidence that Tory's weight loss and malnourished state directly contributed to his subsequent death.

13. End of life planning

13.1 The question of whether end of life planning should have been initiated for Tory prior to September 2014 is dependent on a number of factors, but principally whether Tory had SMA Type 1 or SMA Type 2. There appears to be no dispute on the evidence as to the following:

(a) The distinction between SMA Types 1 and 2 is based on achievement of motor milestones. Relevantly SMA Type 1 is dependent on a patient being able to sit with support only, whereas SMA Type 2 is dependent on a patient being unable to sit independently when placed.

(b) End of life care planning is a priority for patients with a diagnosis of SMA Type 1 because the median lifespan is considered to be 8 to 10 months.[20]

(c) There is substantially less urgency for end of life care planning for patients with a diagnosis of SMA Type 2 (although this is likely to depend on the rate of deterioration in their clinical condition) as the lifespan expectancy is considered to be 70 percent alive at age 25 years.[21]

13.2 Dr Harbord expressed the view that Tory did have SMA Type 1 and that it was therefore "*highly unlikely that he would survive beyond four years of age*".[22] Dr Harbord noted that Tory was never able to sit independently. Dr Harbord drew attention to the following matters in support of his view:

(a) Following a review by Dr Michelle Farrar, paediatric neurologist, at the Sydney Children's Hospital on 22 November 2012, it was noted that "*Tory's best motor function was sitting between his parents legs or propped on a mattress. This was maintained for approximately two months. His mother, Kayla, has noted a deterioration in his strength, such that he is no longer able to sit with support and he has a variability in holding his head up*".[23]

(b) In a discharge summary prepared by Dr Sampaio 18 January 2013 (following Tory's admission to Sydney Children's Hospital for multidisciplinary review and trial of night time CPAP) the following was noted: "*[Tory] is not able to sit independently, and frequently drops his head although he has been observed to lift it back himself sometimes*".[24]

---

[19] Exhibit 1, page 162.75.
[20] Exhibit 1, Tab 18A at [11].
[21] Exhibit 1, Tab 18A at [11].
[22] Exhibit 1, page 162.5.
[23] Exhibit 1, page 162.26.
[24] Exhibit 1, page 162.28.

(c) When Tory attended the Neuromuscular Clinic on 4 July 2014, Dr Sampaio recorded the following in a letter to Dr de Souza: "*There has been a deterioration in muscle strength…[Tory] is unable to maintain a seated posture, or achieve shoulder abduction or elbow flexion independently*".[25] Following occupational therapy review it was also reported that Tory had difficulty lifting and rotating his arm to effectively bring food to his mouth for feeding.

13.3 Dr Sampaio sought to explain that the typing of SMA is "*not always clear cut*" and that SMA Types 1, 2 and 3 are not different diseases "*but rather points on a spectrum of severity of the same disease*" where the distinctions are not always clear.[26] In Tory's particular case, Dr Sampaio explained that his classification of Tory having SMA Type 2 was based on a review of Tory when he was about 15 months of age during which it was noted that Tory "*was able to maintain a seated posture when placed, albeit with a rounded back, 'slumped forward'*".[27] Dr Sampaio also referred to the fact that in about May 2013 it was noted that Tory demonstrated the ability to sit independently for a period of approximately two months. On this basis, Dr Sampaio referred to the fact that the observations made by Dr Farrar (referred to above) were based on parental recollection and not direct observation. Instead, Dr Sampaio explained that this finding indicated that Tory "*had lost a previously attained motor milestone which is entirely expected as SMA is a degenerative disease*".[28]

13.4 It should be noted that in her evidence, Kayla explained that up until the age of about 10 or 11 months Tory was able to sit up unaided, use a "jolly jumper", feed himself and began crawling. It was only following this period of time that Tory began to deteriorate so that by the middle of 2014 he was no longer able to sit up unaided. It should also be noted that in evidence, Dr Harbord agreed that Kayla was best placed to identify whether Tory could sit unaided (provided that a distinction could accurately be drawn between any type of sitting and actually sitting unsupported), and that if it was assumed that he could do so then this indicated that his diagnosis was not SMA Type 1.

13.5 On the basis of the opinion expressed above, Dr Harbord considered that an end of life plan should have been in place for Tory well before his admission to Shoalhaven Hospital in September 2014. In particular, Dr Harbord noted that following Dr Greenacre's review of Tory in July 2012 he wrote a letter in which he stated, "*I think Tory's parents are keen for him to have relatively conservative treatment but don't wish him to have any heroic treatment such as assisted ventilation or external cardiac massage*". On this basis, Dr Harbord considered it surprising that no written plan for Tory's resuscitation requirements was formulated when he returned to Nowra 2014.

13.6 However, in evidence Dr Harbord conceded that in patients with SMA Type 1 the inherent risk is acute deterioration, such as with respiratory illness. On that basis, Dr Harbord agreed that if Tory was well in July 2014 it was reasonable to plan for his future requirements until such time as an intervening illness or events forced a change in the clinical picture.

[25] Exhibit 1, page 162.30.
[26] Exhibit 1, Tab 18A at [5].
[27] Exhibit 1, Tab 18A at [6].
[28] Exhibit 1, Tab 18A at [7].

13.7 Notwithstanding the above, Dr Harbord said in evidence that some end of life planning should have been initiated for Tory by July 2014. Dr Harbord explained that it was necessary to introduce the idea or concept of end of life planning (which could have been done simply with one sentence) so that Tory's parents were made aware of the need to keep this issue at the forefront in the event of acute respiratory deterioration in Tory. Dr Harbord explained that this would put Tory's parents "*in the picture for the longer term outlook*" for Tory. In evidence, Dr Harbord rejected the suggestion that in circumstances where Tory's demise was not imminent, there were certain considerations involved in the timing and manner of initiation of any end of life discussion. Rather, Dr Harbord considered that because Tory had progressive weakness it was better to raise the idea of end of life planning without the distraction and distress that would be associated with an acute deterioration of his condition.

13.8 Dr Sampaio explained that in his view the standard practice for a patient with a life limiting illness such as Tory's "*would be to manage all pending medical concerns which may lead to an enhanced quality of life and then over a series of appointments, and consideration of multidisciplinary input, develop an appropriate end of life care plan with the family, unless clinical circumstances force a more precipitous timeline*".[29] Dr Sampaio indicated that this model is very closely followed in the Neuromuscular Clinic. Dr Sampaio expressed the view that it was not appropriate to prepare an end of life plan for Tory by July 2014 because:

(a) the clinical priority at that time was for Tory to re-engage with local support services;

(b) Tory's clinical state was stable with no indication that he was entering a rapidly progressive phase of his illness; and

(c) Tory's family had recently relocated from interstate (and Tory had not been seen for nearly 18 months) and so it would have been standard practice for end of life care planning to occur with wide consultation over a series of appointments.

13.9 Notwithstanding his opinion regarding the more accurate diagnosis being SMA Type 1 for Tory, Dr Harbord considered that, irrespective of the diagnosis of Type 1 or Type 2, an end of life plan should have been prepared in the latter half of 2014. In evidence, Dr Sampaio agreed that in relation to the issue of end of life planning it made no material difference whether Tory's diagnosis was SMA Type 1 or severe SMA Type 2. However, Dr Sampaio sought to emphasise that irrespective of a patient's SMA Type, the urgency of an end of life plan is dependent upon a clinician's impression of the patient in front of them.

13.10 Dr Harbord agreed with Dr Sampaio that provision of a palliative care plan may be constructed over several months, but repeated the view that discussion regarding the need for such a plan should have been initiated in July 2014. The purpose in doing so was to raise awareness with Tory's parents that he may not necessarily survive future episodes of acute respiratory illness due to the progression in his generalised weakness. However, Dr Harbord considered that embarking on such a discussion was even more important when Tory was admitted to Shoalhaven Hospital in September 2014, particularly given Tory's drastic weight loss.

---

[29] Exhibit 1, Tab 18A at [26].

13.11 Associate Professor Butt expressed the view that decisions regarding end of life care in children with SMA should be made for the occurrence of life-threatening events, and by staff who are familiar with the patient and their family. Further, Associate Professor Butt noted that in Tory's case the issue should have been discussed and a clear end-of-life plan made by Sydney Children's Hospital but that this did not occur "*presumably because of the discontinuous nature of care Tory received due to family geography and the fact that Tory was well when seen in clinic in July*".[30]

13.12 In evidence, Associate Professor Butt was asked when he considered that end of life planning should have been undertaken, if at all, when Tory presented to Shoalhaven Hospital in September 2014. Associate Professor Butt expressed the view that Tory's presentation in September 2014 was materially different to that of July 2014, and that those best placed to undertake such a task were the clinicians at Sydney Children's Hospital through the Neuromuscular Clinic. On this basis Associate Professor Butt considered that end of life planning should not have been contemplated at Shoalhaven Hospital. Rather, Associate Professor Butt considered that there was no immediate need to discuss end of life planning prior to Tory's transfer, and that this type of discussion would only have been appropriate if Tory required intubation.

13.13 **Conclusions:** The evidence established that the general issue of Tory's SMA Type 1 or Type 2 diagnosis was ultimately not materially relevant to the question of end of life planning. Rather, the determining factor as to the timing of initiating end of life planning for Tory was the clinical course of his condition, and whether sudden or expected deterioration indicated that end of life planning needed to be accelerated. In this sense, it could not reasonably be said that in July 2014 this type of planning was clearly indicated. This is because July 2014 represented the first opportunity in 18 months that Tory had been reviewed at the Neuromuscular Clinic in circumstances where there was evidence of weight gain and improvement in language skill, to the extent that consideration was being given to preschool arrangements.

13.14 However, for clarity, it should be noted that the available evidence establishes that a diagnosis of SMA Type 2 for Tory was most likely correct. This is for two reasons. Firstly, the diagnosis was made by Dr Sampaio, who had the opportunity to assess and treat Tory directly. Secondly, Dr Sampaio's observations of Tory's motor function that allowed for a diagnosis of SMA Type 2 to be made is broadly consistent with Kayla's evidence regarding her own, obviously daily, observations of Tory's motor function and, in particular, his ability to sit unsupported. Thirdly, the evidence given by Kayla is also consistent with Dr Sampaio's explanation regarding the attainment and loss of motor milestones given the degenerative nature of SMA.

[30] Exhibit 1, page 162.126.

13.15 The evidence also established that substantive end of life planning was not indicated in July 2014 or, on Associate Professor Butt's evidence, in September 2014 prior to Tory's departure from Shoalhaven Hospital. However, consistent with the views of both Dr Sampaio and Dr Harbord, it was possible to develop an end of life plan for Tory over a period of months. This meant that it was therefore open in July 2014 for discussion of end of life planning to be initiated. That said, Tory's clinical condition at the time and the need for him to reengage with support services following his lengthy absence interstate, meant that initiation of such discussion was not necessarily indicated.

13.16 One final matter should be noted. The New South Wales Health Policy Directive, *Using Resuscitation Plans in End of Life Decisions (PD2014_030)* (**the Resuscitation Policy Directive**), provides that a resuscitation plan "*is a medically authorised order to use or withhold resuscitation measures and which documents other aspects of treatment relevant at end of life*".[31] It further notes that "*decisions to withhold CPR and other resuscitation measures seek to avoid unwanted, excessively burdensome or insufficiently beneficial interventions for patients at the end of life. At some point in the course of life-limiting illness, a shift in the focus of care away from aggressive intervention and towards a palliative approach is often the agreed outcome*".[32] The Resuscitation Policy Directive identifies that discussion of a resuscitation plan should be undertaken where a patient's recovery is uncertain, if a treating clinician does not consider it to be surprising if a patient were to die in 6 to 12 months, if a patient clinically deteriorates, or such deterioration is anticipated, so as to require activation of a rapid response system; or if a patient's condition is considered high-risk.

13.17 The Resuscitation Policy Directive was not in operation as at 10 September 2014. As explained by Dr Mary McCaskill, the Acting Director of Clinical Governance for Sydney Children's Hospital Network, prior to the introduction of the Resuscitation Policy Directive it was often difficult to identify within a patient's progress notes any directions in relation to intervention for patients at the end of life. Indeed, Mr Scotcher indicated that in 2014 there was no template available at Shoalhaven Hospital (or elsewhere) to document a specific end of life care plan. This meant that in the absence of a resuscitation plan as provided for by Resuscitation Policy Directive the only way to identify any such plan or directions would be to manually review a patient file, which would not be without difficulty. However, Dr McCaskill sought to emphasise that the institution of a resuscitation plan for a patient will be a matter of clinical judgement. Dr McCaskill went on to express the view that the responsibility of raising the issue of a resuscitation plan with a patient's family rested with either the patient's admitting consultant or specialist treating physician, rather than a NETS physician.

13.18 Dr Mustafa acknowledged that it would be important to identify the boundaries surrounding escalation of care for a deteriorating patient and that patient's ceiling of care. He indicated that one of the first questions that would be asked by a retrieval team on handover is the order surrounding end of life care and whether there was a "natural death order" in place, and that any orders would be documented. However, consistent with the view expressed by Dr McCaskill, Dr Mustafa explained that a retrieval team would not initiate such a discussion with a patient's parents as it would be arguably inappropriate to do so given that a retrieval team would be seeing

[31] Exhibit 1, page 137.16.
[32] Exhibit 1, page 137.23.

a patient's parents for the first time. To this extent, Dr Mustafa said that he had an expectation that the boundaries of care for a child with a life limiting illness would be clearly documented prior to departure.

13.19 **Conclusions:** It is undoubtedly the case that the absence of any resuscitation plan for Tory placed Kayla in an extremely challenging and traumatic situation during Tory's transfer to Sydney. The improvements that have been made since 2014, both specifically at Shoalhaven Hospital and more broadly across NSW Health, indicate that the initiation and implementation of resuscitation plans will assist in planning end of life care for patients.

14. Acknowledgments

14.1 Before turning to the findings that I am required to make, I would like to acknowledge, and express my gratitude to Mr Greg Moore, Counsel Assisting, and his instructing solicitor, Ms Ann-Marie Najjarin of the NSW Crown Solicitor's Office. They have both provided invaluable assistance and shown exceptional dedication and professionalism in preparing for the inquest, and during the inquest itself. I am also extremely grateful for the sensitivity and empathy that they have shown throughout the course of this particularly distressing matter.

14.2 I also thank the legal representatives for the various parties for their assistance, and for the sensitivity and compassion that they too demonstrated during the inquest.

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

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

Identity
The person who died was Tory Ganderton.

Date of death
Tory died on 10 September 2014.

Place of death
Tory died at Kiama Heights NSW 2535.

Cause of death
The cause of Tory's death was respiratory failure, with spinal muscular atrophy an antecedent cause.

Manner of death
Tory died as a result of natural disease process, in circumstances where he suffered acute respiratory deterioration during an inter-hospital transfer.

16. Epilogue

16.1 At the conclusion of the evidence in the inquest Tory's parents honoured those gathered in the Court by sharing some deeply loving, yet painful, memories of Tory. One matter stands out amongst their many wonderful memories of Tory: the expression by Kayla and George of how fortunate they are as parents to have had time with a special child such as Tory, even though it was only all too brief.

16.2 On behalf of the Coroner's Court of New South Wales, I offer my deepest sympathies, and most sincere and respectful condolences, to Kayla, George, Tory's siblings, and Tory's family for their most tragic and unbearable loss.

16.3 I close this inquest.

Magistrate Derek Lee
Deputy State Coroner
25 March 2020
Coroners Court of NSW