Coroners Act, 1996
[Section 26(1)]

Western ***Australia***

RECORD OF INVESTIGATION INTO DEATH

Ref No: 26/15

I, Rosalinda Vincenza Clorinda Fogliani, State Coroner, having investigated the death of ***TP (name suppressed)*** *with an Inquest held* ***at Perth Coroner's Court, Court 51, CLC Building, 501 Hay Street*** *on* ***4 August 2015*** *find that the identity of the deceased person was* ***TP (name suppressed)*** *and that death occurred on 9 December 2011 at Sir Charles Gairdner Hospital from a cause of death that is consistent with seizure disorder (epilepsy) with associated vomit aspiration in the following circumstances -*

Counsel Appearing :

Sgt L. Housiaux assisted the State Coroner

Ms B. Allen (State Solicitors Office) appeared on behalf of the Department for Child Protection and Family Services and Child and Adolescent Health Services

Mr A. Power (instructed by WHL Legal Pty Ltd) appeared on behalf of Hale School.

SUPPRESSION ORDERS

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

Suppression of the name of any other person referred to who is or has been the subject of a Protection Order.

Table of Contents

INTRODUCTION 2
THE DECEASED 5
THE DECEASED'S MEDICAL HISTORY 7
History of the deceased's seizure disorder 8
The deceased's medication regime prior to her death 11
The deceased's medical diagnosis 13
DISCREPANCIES IN THE DOSAGES FOR THE DECEASED'S MEDICATION 13
SUPERVISION, TREATMENT AND CARE WHILST IN THE CARE OF THE DEPARTMENT FOR CHILD PROTECTION AND FAMILY SUPPORT 14
SUPERVISION, TREATMENT AND CARE AT THE HALE SCHOOL SONY CAMP 19
Selection of children for Hale School Sony Camp 20
Identification of children's medical needs 22
The deceased's first day at the Hale School Sony Camp 25
The deceased's second day at the Hale School Sony Camp 28
The night of 9 December 2011 29
CONCERNS EXPRESSED BY HALE SCHOOL SONY CAMP STAFF 35
CAUSE AND MANNER OF DEATH 40
COMMENTS REGARDING MEDICAL CLEARANCE 44
CONCLUSION 45

INTRODUCTION

The deceased child was 15 years old when she died at approximately 11.00pm on 9 December 2011 at Sir Charles Gairdner Hospital, having been conveyed there by ambulance after suffering a seizure earlier that evening at the Hale School Sony Foundation Holiday Camp for Kids. The camp catered for children with special needs.

Immediately before her death the deceased child was subject to a Protection Order pursuant to the *Children and Community Services Act* 2004. Consequently the Chief Executive Officer of the Department for Child Protection and Family Support had parental responsibility for the deceased.

Consistent with the non-publication order that I made pursuant to section 49 of the *Coroners Act* 1996 (the Coroners Act), the deceased child is to be referred to as TP, or "the deceased."

The deceased's death was a reportable death within the meaning of section 3 of the Coroners Act and it was reported to the coroner as required by section 17 of the Act.

Pursuant to section 19(1) of the Coroners Act I have jurisdiction to investigate the deceased's death. The holding of an inquest, as part of this investigation, is mandated by section 22(1)(a) of the Coroners Act because the deceased was immediately before death a "person held in care" within the meaning of section 3 of the Act, by reason of the Protection Order.

Pursuant to section 25(3) of the Coroners Act I must comment on the quality of the supervision, treatment and care of the deceased while in that care.

Section 25(5) prohibits me from framing a finding or comment in such a way as to appear to determine a question of civil liability or to suggest a person is guilty of any offence.

On 4 August 2015 I held an inquest into the death of the deceased at the Coroner's Court at Perth.

A number of witnesses gave evidence at the inquest and they are, in order of appearance, Senior Constable A. Nichol of the Coronial Investigation Unit who prepared the report into the deceased's death, the deceased's physician Dr J. Silberstein consultant paediatric neurologist, and Ms C Barnett, director of metropolitan services at the Department for Child Protection and Family Services.

The documentary evidence tendered at the inquest comprised four lever arch file volumes of material, numbered exhibits 1 to 4, and two further statements from clinicians numbered exhibits 5 and 6. Exhibits 1 to 4 contained the following documents:

- Exhibit 1 contained Tabs 1 to 47;
- Exhibit 2 contained Tabs 1 to 96;
- Exhibit 3 contained Tab 1, JM1 to JM38; and
- Exhibit 4 contained Tabs 2 to 5.

As the deceased died on the second night of her attendance at the Hale School Sony Camp, the inquest focussed upon her medical needs, the provision of information concerning her medical needs to staff members at the Hale School Sony Camp and the management of her medical needs at the camp.

At the conclusion of the inquest on 4 August 2015 I found that the care that the deceased child received at the Hale

School Sony Camp was appropriate and proper.[1] However, given the acuity of participating children, I sought further submissions from Hale School on the desirability, in future, of obtaining a medical clearance from a child's treating medical practitioner.

On 25 August 2015 I received comprehensive submissions from Hale School on that point. These are addressed later in this finding.

THE DECEASED

The deceased was born on 11 March 1996. She had three siblings and two half siblings. She was a very sociable and affectionate child.

The deceased had been born with an intellectual disability (global developmental delay) that put her mental age at a significantly lower level than her chronological age. Throughout her life she had also suffered from epileptic seizures for which she required medication and medical review on a regular basis.

At various stages, the deceased and all of her siblings were taken into care, initially under the *Child Welfare Act* 1947 and later, they remained in care under the *Children and Community Services Act* 2004.

[1] T 38

The deceased had been taken into care shortly before she attained the age of two years in late 1997. She remained in care for the rest of her life.[2]

From an early stage the Department for Child Protection and Family Support (the Department) made efforts to secure a single carer for the deceased and her siblings, so that they could remain together. In July 1999 a long-term placement was secured for the deceased and her siblings. This appeared to be largely successful for many years and positive changes in the children were noted. However, some concerns for the childrens' welfare emerged in 2007. These were responded to promptly by the Department. Following monitoring, in-home parenting support and review the Department terminated the placement in 2007.[3]

The deceased and her siblings were placed with a respite carer for a short period. In mid-2008, when the deceased was 12 years old, she was moved into a specialist placement without her siblings, with a Life Without Barriers carer who was a qualified nurse (the Carer), with whom she remained for the rest of her life.[4]

The deceased thrived in this placement with her Carer. She was loved, cared for and nurtured. Her contact with family was appropriately maintained, her social needs were

[2] Exhibit 1, Tab 31
[3] Exhibit 2, Tab 96
[4] Exhibit 2, Tab 96

addressed, her schooling was regular and suitable and her medical needs were assiduously attended to by her Carer.

THE DECEASED'S MEDICAL HISTORY

The deceased had been diagnosed with seizure disorder (epilepsy) prior to her death.

An examination of the deceased's medical history reflected a long and regular contact with her clinicians (particularly her neurologist) for the purpose of treating her seizure disorder. She had multiple admissions to hospital. Her medications were reviewed and adjusted over time. Shortly before her death, some further adjustments to her dosages were planned.

At the inquest I heard evidence concerning the dosages of the deceased's medications; this became relevant because the dosages provided by the deceased's Carer to staff members at the Hale School Sony Camp were different to the ones that her neurologist understood her to be taking at the time of her death. Whilst in the circumstances of this investigation, the differences were not material, it did raise the issue of whether the medication regime for children attending the Hale School Sony Camp ought to be provided by or reviewed by their treating doctors. This aspect is dealt with later in my finding.

History of the deceased's seizure disorder

From 2001 until the time of her death the deceased was a patient of the neurology clinic at Princess Margaret Hospital for Children (PMH) under the care of consultant paediatric neurologist Dr Jonathon Silberstein.

The deceased was first admitted to PMH under his care when she presented to the Emergency Department (ED) on 22 May 2001. At that point, Dr Silberstein had already treated two of the deceased's older siblings for hereditary neuropathy with predisposition to pressure palsy. One of those brothers also had epileptic seizures and these were managed by Dr Silberstein with medication.

The deceased was reported to have had three seizures on 22 May 2001, prompting her presentation to the ED. She was accompanied by her foster carer who also reported that the deceased had had a number of other seizures in early and mid-May 2001.

The deceased was admitted and treated on the ward at PMH with anti-epileptic medication. She was treated primarily with sodium valproate (brand name Epilim). In addition, clobazam (brand name Frisium) a rapidly acting anti-epileptic, was administered as a temporary measure while the sodium valproate took effect. She was discharged after

two days, with follow-up as an outpatient, including a planned electro-encephalogram (EEG).

The deceased was re-admitted to PMH under Dr Silberstein's care on 21 June 2001 and 12 July 2001, following further clusters of seizures. After the first re-admission, her medications were reviewed and she was re-started on clobazam and commenced on lamotrigine (brand name Lamictal), an anti-convulsant.

An EEG was able to be successfully performed on 27 June 2001. This demonstrated a diffuse excess of slow frequencies in the background. No epileptiform activity was seen. Accordingly at this stage it was not possible to identify a predisposition to epilepsy, nor what type of epilepsy it was or whether it was one that could affect the whole brain or different parts of the brain.[5]

The deceased was seen at an outpatient appointment on 29 November 2001 and seizures were reported to be occurring every three weeks. Her lamotrigine dose was increased.

When seen on 2 April 2002 the deceased was reported to be having seizures every two weeks, and when seen on 7 August 2002, her seizures were reported to be occurring weekly. Her medications were continually reviewed and

[5] T 16; Exhibit 1, Tab 26

eventually she was able to experience improvement in seizure control throughout 2003 and 2004 through a combination of lamotrigine at 150mg per day and sodium valproate at 600mg per day.[6]

However, seizure control deteriorated again in 2005 and the deceased was readmitted to PMH for two days on 17 July 2005 after a cluster of seven seizures whilst in respite care. She was administered a dose of clobazam to treat that cluster. The dosages of her regular medications were reviewed on that occasion, and again in December 2005.

The deceased was readmitted to hospital on 26 August 2006 for six days after another cluster of seizures whilst in respite care. It transpired that her foster carer at the time had decided to reduce the dosage of lamotrigine because she believed it was causing the deceased abdominal pain. During this admission her clinician determined that the deceased needed to be restarted on lamotrigine, and her other medications were reviewed and dosages adjusted. Another EEG was performed and whilst it revealed a mild excess of slower frequencies and irregularity consistent with the deceased's intellectual disability, no epileptiform activity was seen.[7]

On 21 January 2008 the deceased was conveyed to PMH by ambulance after another cluster of seizures, resulting in

[6] T 17; Exhibit 1, Tab 26
[7] T 18; Exhibit 1, Tab 26

further review of her medications and on this occasion, an assessment of her behavioural problems. It was around this period that the deceased's care arrangements were altered.

Later in 2008, the deceased was placed with her Life Without Barriers Carer, a qualified nurse who remained a constant and nurturing presence for the remainder of the deceased's life. Dr Silberstein observed the positive effect of this placement. He noted that there were no other young children in the house and that the deceased's behaviour "*seemed to improve with this placement, in which she received love, care and one on one attention from a very patient lady with sound behaviour management strategies.*" He formed a high opinion of the Carer's capacities and of her care for the deceased.[8]

Over the next period and particularly during 2010, the deceased's seizure control and behaviour both improved. However, towards the end of 2010 the deceased's seizure frequency increased again and her clinicians adjusted and reviewed her medication dosages as required.

The deceased's medication regime prior to her death

Dr Silberstein last saw the deceased on 5 July 2011. At that time she was taking clobazam 5mg at night, topiramate (an anti-convulsant) 50mg in the morning and 100mg at

[8] T 19 and 29; Exhibit 1, Tab 26

night, sodium valproate 200mg in the morning and 400mg at night and lamotrigine 50mg in the morning and 100mg at night. Dr Silberstein decided to discontinue her regular dose of clobazam and replace it with oxcarbazepine (brand name Trileptal).

On 1 November 2011 the deceased missed her outpatient appointment at the neurology clinic due to illness. On 25 November 2011 Dr Silberstein contacted the deceased's Carer by telephone to discuss her progress with her new medication (oxcarbazepine). The Carer reported that she had not persisted with the oxcarbazepine as the deceased appeared worse on it. This was the last contact that Dr Silberstein had in connection with the deceased's health care. As at this date, the deceased was continuing with topiramate 50mg in the morning and 100mg at night, sodium valproate 400mg twice a day and lamotrigine 50mg in the morning and 100mg at night. The only change from July 2011 was that the morning dosage of sodium valproate had doubled from 200mg to 400mg, and the oxcarbazepine was ceased. Dr Silberstein supported the deceased's Carer's discontinuance of the oxcarbazepine, considering her to be a reliable observer. The plan at that stage was for Dr Silberstein to see the deceased again, in order to review her management and come up with a different strategy, in light of that discontinuance.[9]

[9] T 20 – 21; Exhibit 1, Tab 26

There was no opportunity for this to occur because tragically, the deceased died two weeks later.

The deceased's medical diagnosis

At the inquest Dr Silberstein gave evidence about the deceased's medical diagnosis. In Dr Silbertein's opinion, the deceased had epilepsy refractory to treatment. That is, she continued to have seizures despite being on treatment, so her seizures were not 100% controlled.[10]

DISCREPANCIES IN THE DOSAGES FOR THE DECEASED'S MEDICATION

At the inquest, Dr Silberstein's attention was drawn to the deceased's Care Plan Summary that had been produced in anticipation of her attendance at the Hale School Sony Camp in December 2011. Dr Silberstein was not involved in the production of this Care Plan Summary. However, he was questioned in connection with it because the stipulated dosage of one of the deceased's medications was lower than what he understood the deceased to be taking on the last occasion that he spoke with her Carer. Dr Silberstein understood that the deceased was taking 400mg of sodium valproate (Epilim) twice a day, whereas the Care Plan Summary, derived from the Carer's instructions, provided for 200mg of Epilim in the morning and 400mg of Epilim at

[10] T 21

dinnertime. At an earlier stage Dr Silberstein had reduced the dosage of Epilim to what appeared on the Care Plan Summary, but that was when he had started the deceased on oxcarbazepine. Later the oxcarbazepine was discontinued and the dosage of the Epilim was increased to 400mg twice a day. At the inquest, Dr Silberstein's evidence was that the lower dosage of Epilim would not have made a significant difference to the deceased's treatment. In his experience her dosages indicated that her epilepsy was not easy to control; from his perspective her medication was the most effective that had been found over the years up until that point.[11]

I accept Dr Silberstein's opinion and am satisfied that the lower dosage of Epilim stipulated on the deceased's Care Plan Summary did not have a role in the deceased's death.

SUPERVISION, TREATMENT AND CARE WHILST IN THE CARE OF THE DEPARTMENT FOR CHILD PROTECTION AND FAMILY SUPPORT

Pursuant to section 25(3) of the Coroners Act, I must comment on the quality of the supervision, treatment and care of the deceased while in the care of the Chief Executive Officer of the Department.

[11] T 27 - 28

Ms Cheryl Barnett, executive director of metropolitan services for the Department prepared a report on the Department's involvement with the deceased and she gave evidence at the inquest. Reports from the Department of Health's Child and Adolescent Health Service and the Western Australian Disability Services Commission were also received into evidence. Together, the evidence reflected that the deceased was regularly and appropriately reviewed for her medical and social needs.[12]

The evidence disclosed that the deceased's parents were assessed as being unable to provide the deceased and her siblings with a safe and nurturing environment. The deceased and two of her siblings were apprehended in December 1997 under the *Child Welfare Act* 1947. Her remaining sibling was similarly apprehended in December 1999. Following a number of assessments and interim orders, on 5 March 2009 the deceased was made the subject of a Protection Order until the age of 18 years under the *Children and Community Services Act* 2004. Similar orders were made in respect of her siblings. In the deceased's case, her Protection Order would have expired in March 2014.[13]

In arranging for the deceased's care the Department took account of her identified high needs particularly the constant monitoring and supervision that she required due

[12] T 31 – 37; Exhibit 1, Tabs 22 and 25
[13] Exhibit 1, Tabs 29 and 31; Exhibit 2, Tab 96

to her level of intellectual disability. She also required assistance with her self-care.

The deceased's Carer under the Department's arrangement with Life Without Barriers was a qualified nurse. She was committed to the deceased's wellbeing and she was described as being passionate about advocating for her rights. The deceased was observed by the Department's officers to be well cared for and cheerful. A strong and affectionate bond was formed between the deceased and her Carer, the latter having expressed her wish to care for the deceased beyond the age of 18 years, after the cessation of her Protection Order. In his report to the deceased's family doctor dated 11 May 2010, Dr Silberstein commented that the deceased seemed to be thriving in her placement with the Carer. She had first come into Dr Silberstein's care nine years previously.[14] Accordingly, he was well placed to have commented upon her demonstrable improvement.

Life Without Barriers had developed an epilepsy management plan for the deceased for distribution to all persons or services assuming care responsibilities for the deceased. The deceased received therapeutic services including occupational therapy, physiotherapy and speech therapy from appropriately qualified clinicians for a number of years, to assist with her development and general wellbeing. The deceased and her Carer were also provided

[14] T32-34; Exhibit 2, Tab 96, attachment 2

with the services of a clinical psychologist to assist with some of her more challenging behaviours.[15]

I am satisfied that whilst held in care, the deceased's care plans were reviewed and the quality of her care was assessed against the criteria set out in those plans. The deceased's last Care Plan dated 22 September 2011 was developed in consultation with her Carer. It reflects that the deceased required a skilled carer to manage her epilepsy and intellectual disability, that the Carer arranged and attended all of the deceased's medical and dental appointments, that appropriate family contact was ongoing, and that the chosen school was meeting the deceased's needs. The assessment reflected positively on the supervision, treatment and care provided by the deceased's Carer.[16]

The deceased's last Quarterly Care Report dated 5 December 2011 reflects that the deceased was observed to be happy and sociable, that she interacted well with her Carer and that there was good communication and bonding between them. The deceased's neurologist was reviewing her every three months. It is clear from this report that her epilepsy was ongoing and, consistent with Dr Silberstein's view, it was refractory to treatment. She was prescribed medications to alleviate her symptoms. Further, her

[15] T 34 – 35; Exhibit 2, Tab 96
[16] Exhibit 2, Tab 96, attachment 5

medication was being reviewed regularly and altered as required.[17]

The deceased had been regularly attending the same special needs school for a number of years and an individual education plan had been prepared for her. Her special needs were taken into account and a range of teaching methods were employed to enhance her opportunities for development. In the school environment the deceased was also observed to be sociable, she enjoyed the company of school friends and she participated in a broad range of learning and recreational activities, with appropriate supervision. Her developmental assessment attested to her continual improvement in her educational goals.[18]

Ms Barnett's evidence was that the Department's observations confirmed the deceased's progress and the optimal care she was receiving. In the Department's view, the placement with her Carer was assessed to have enhanced the quality of the deceased's life. This was supported by the review undertaken by the Western Australian Acting State Manager of Life Without Barriers.[19]

I am satisfied that the Department's supervision, treatment and care of the deceased, including the selection and

[17] Exhibit 2, Tab 96, attachment 6
[18] Exhibit 2, Tab 96, attachments 6 to 8
[19] T 37; Exhibit 1, Tab 27

monitoring of her placement, was proper and appropriate to her needs.

Given the deceased's progress it was entirely appropriate for the deceased's Carer to have given her permission for the deceased to attend the Hale School Sony Camp in December 2011.[20]

SUPERVISION, TREATMENT AND CARE AT THE HALE SCHOOL SONY CAMP

Whilst the deceased remained in the care of the Department at all times, when she attended the Hale School Sony Camp, the allocated staff members assumed responsibility for her day to day care.

On 8 December 2011 the deceased arrived at Hale School, accompanied by her Carer, to take part in the Hale School Sony Camp. She had previously participated in this type of camp and she was looking forward to this occasion.

Participation involved a four day live-in camp, held on the Hale School grounds in the boarding house, for up to 24 special needs children. It aimed to provide for an enjoyable and social experience for the children and respite for their families. The Year 12 students at Hale School and

[20] Exhibit 2, Tabs 32-34, 37, 39-40.

St Mary's Anglican Girl's School volunteered to act as companions to the children.[21]

The student companions benefited from the opportunity to care for a child with special needs over a four day period. They learnt about the challenges and demands involved in caring for a child with special needs. Not only did the student companions have an enriching experience, but the children were treated to a weekend full of activities and interactions they would not normally have the opportunity to experience.[22]

Selection of children for Hale School Sony Camp

Ms Jill Maskiell organised the Hale School Sony Camp that the deceased attended. Ms Maskiell had been the Hale School health education teacher, and since 2005 she was also student service learning coordinator. She had been associated with the Hale School Sony Camp since their first inaugural camp in 2003. The camps originated in New South Wales and Ms Maskiell was instrumental in setting up the camp structure for Hale School. Sony Foundation Australia supports children's holiday camps and provides instructions on "*How to run a camp for children with disabilities*", which Ms Maskiell utilised. In coordinating all of the camps at Hale School, Ms Maskiell worked with staff

[21] Exhibit 4, Tab 4
[22] Exhibit 2, Tab 94

members and a number of community members, as a committee.[23]

Through Ms Maskiell, a range of preparatory measures were undertaken to select students with special needs for participation in the camps. The camps were open to children with a physical and/or intellectual disability. The proposed participants were initially nominated by their own schools. The deceased's school had been nominating students for the Hale School Sony Camps for many years and the nominators were aware of the criteria for participation. Ms Maskiell personally visited the various nominating schools to finalise the selection of students. By early August 2011 Ms Maskiell and her committee had selected 24 children to participate in the camp. That was the maximum number of participants. In Ms Maskiell's experience the Sony Camp had often been made available to children with epilepsy.[24]

The evidence discloses that Ms Maskiell took a careful and considered approach to the selection of children for participation in the camp. She was rigorous in sourcing, recording and disseminating the relevant information concerning the overall care of the special needs children whilst at the camp, including medical needs. There were processes in place for induction for carers and volunteers, as required.

[23] Exhibit 2, Tab 1; Exhibit 3, Tab 1
[24] Exhibit 3, Tab 1

In the deceased's case, Ms Maskiell attended at her school to gather information about her and she spoke with her teacher and her Carer. After these enquiries, Ms Maskiell provided the relevant information (including her own observations) about the deceased to Nurse Thomas, a registered nurse who was employed as nurse manager at Hale School, and who assisted with the Hale School Sony Camps. This same procedure was utilised for all the children being considered for participation in the camp. Nurse Thomas would assess that information and advise Ms Maskiell on whether any of the children required special aids. Consideration was given to children's level of disability, in the context of whether the Hale School Sony Camp was able to make proper provision for each child's needs.[25]

Identification of children's medical needs

Nurse Thomas' evidence confirmed that in deciding which children should attend the Hale School Sony Camp, medical considerations, as well as a child's known behaviour, were taken into account. Consideration was given as to whether a child had a level of disability that the Hale School Sony Camp was unable to provide for, and these matters were discussed with Ms Maskiell.[26]

[25] Exhibit 4, Tab 4
[26] Exhibit 4, Tab 4

Nurse Thomas formulated a Care Plan for all the participating children including the deceased. Copies were placed on the door of each room where the children slept at the Hale School Sony Camp, another on the wall at the nurses' station close by, and a further copy was configured into a laminated card on a lanyard that each child wore. The deceased's lanyard was colour coded to denote epilepsy, in order to facilitate an immediate visual reference to her needs.[27]

The deceased's Care Plan listed "*epilepsy*" under the heading "*MEDICAL PROBLEMS*"; under the heading "*SLEEPING*" it was noted that the deceased "*May have a night seizure*"; and under the heading "*MEDICATION*" the following was provided for:

- Epilum – 200mg in the morning and 400mg at dinnertime;
- Topamax – 50mg in the morning and 100mg at dinnertime;
- Lamictal – 50mg in the morning and 100mg at dinnertime.

These medications were used to manage the deceased's epilepsy.[28]

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[27] Exhibit 4, Tab 4

[28] Exhibit 3, Tab 1, JM26; Epilum is a reference to Epilim, the brand name for sodium valproate;
Topamax is the brand name for topiramate; Lamictal is the brand name for lamotrigine.

Consistent with Ms Maskiell's recollections, the evidence discloses that the Hale School Sony Camp had previously catered for children with epilepsy and night seizures. Such children were usually placed in the sleeping accommodation closest to the nurses' station and those nurses had ready access to information relevant to the children's needs. Nurse Thomas had reviewed the deceased's medical information and had formed the opinion that the deceased's epilepsy was controlled by medication and that it did not require the administration of emergency medication, nor the constant presence of a companion. She was aware of the reality that any child with epilepsy might have a seizure, and potentially, a seizure at night.[29]

Nurse Parsons had gathered the relevant information concerning the deceased's medication regime. As a registered nurse assisting with the Hale School Sony Camp, one of her roles was to meet with the children and their parents/guardians when they arrived, before the children went off with their student companion. By this stage, Nurse Parsons was in possession of the Care Plan that had been formulated for each child by Nurse Thomas. Nurse Parsons met with the deceased and her Carer, and she observed the Carer's hand written notation regarding the possibility of a night seizure. Like Nurse Thomas, Nurse Parsons formed

[29] Exhibit 4, Tab 4

the view that there was nothing that stood out in relation to the deceased's epilepsy, such as emergency medication.[30]

Nurse Parsons' evidence concerning the deceased's Medication Chart reflects that the instructions concerning the deceased's medication regime were conveyed by the deceased's Carer. The medications were provided to Nurse Parsons in a Webster pack upon the deceased's arrival by her Carer. Nurse Parsons checked that there were no changes required to the deceased's Medication Chart, and satisfied herself that the recorded medication matched the medication actually being taken.[31]

The administration of the deceased's medication at the Hale School Sony Camp was recorded on the deceased's Medication Chart. The evidence establishes that the deceased was administered her medication on 8 and 9 December 2011 in accordance with her Carer's instructions.[32]

The deceased's first day at the Hale School Sony Camp

After seeing Nurse Parsons on the morning of 8 December 2011, the deceased and her Carer met the student companion. She was a female year 12 student from St Mary's Anglican School for Girls (the Companion). They

[30] Exhibit 4, Tab 3
[31] Exhibit 4, Tab 3
[32] Exhibit 1, Tab 15; Exhibit 4, Tab 3; Exhibit 5, JP3; Exhibit 6, JET8

went with her to unpack and settle the deceased into the Sony Camp. The Companion had received a half days' training the day prior to the Hale School Sony Camp. She understood her role was to keep an eye on the deceased, and if anything happened, to raise the alarm and do what she could until the nurse arrived. The Companion was to also assist the deceased with her ablutions. She had received an information pack concerning the deceased. From that pack, and her discussions with the deceased's Carer, the Companion was aware the deceased had a history of epilepsy, with seizures at night-time. She was aware that the nurse would administer the deceased's medication at the Hale School Sony Camp.[33]

Shortly after meeting the Companion, the Carer left, explaining to the deceased that she would be back in a few days to collect her. On all accounts, the deceased was happy to be at the Hale School Sony Camp. On the afternoon of 8 December 2011 the deceased and other children from the camp went to a scheduled horse-riding session at a nearby horse-riding centre. It was a supervised event. It is evident from the material before me that the deceased was being carefully monitored and that she was enjoying herself. The deceased had been medically cleared to take part the horse-riding session at the centre and her Carer had provided her consent.[34]

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[33] Exhibit 1, Tab 11
[34] Exhibit 1, Tab 11; Exhibit 2, Tabs 36 and 40

After the horse-riding session, the children including the deceased returned to Hale School. With her Companion, the deceased participated in some other sporting activities, and then together they did some puzzles, arts and craft. Dinner was served at approximately 6.30pm, and afterwards the children took part in a disco. At about 8.00pm, the Companion began to assist the deceased with her preparations for bedtime. Having settled the deceased in her bed, her Companion read to her.[35]

At approximately 9.00pm on 8 December 2011, the Companion left the deceased in order to attend the scheduled one-hour meeting with Ms Maskiell at the end of the day. This was a de-briefing meeting that occurred at the end of each day at the Hale School Sony Camp. The arrangements were that the student Companions slept in the same room as the children attending the camp, on a mattress on the floor next to their allocated child's bed. The role of the Companion was to stay with their allocated child at all times, except during the evening de-briefing meeting with Ms Maskiell. When this occurred, a volunteer parent would sit outside the children's rooms in case assistance was required. Also, at any time if a Companion required a break, the procedure was to ask another assistant to look after their allocated child. It was understood that the

[35] Exhibit 1, Tab 11

Companions would step in and help out with any of the children if possible, when asked to do so.[36]

The purpose of the daily de-briefing meeting was to provide the companions and assistants with the opportunity to discuss issues they had in dealing with the children. It was integral to the level of care provided to the children, and the pastoral care of the companions and assistants.[37]

The deceased's Companion returned from the daily de-briefing meeting on 8 December 2011 at approximately 10.00pm and slept on a mattress on the floor next to the deceased. The night was quiet and passed without disturbance.[38]

The deceased's second day at the Hale School Sony Camp

The next morning the deceased and other children from the Hale School Sony Camp went on a scheduled fishing expedition at the South Perth foreshore. It was a supervised event. Again it is evident that the deceased was carefully monitored and that she was enjoying herself. After morning tea in the park the children returned to Hale School. Together with her Companion the deceased participated in arts and craft activities in the afternoon. Dinner was again served at approximately 6.30pm and the deceased's food

[36] Exhibit 1, Tabs 12 and 14; Exhibit 3, Tab 1
[37] Exhibit 4, Tab 4
[38] Exhibit 1, Tabs 11 and 12

portions were checked. The older students put on a pantomime and the deceased did puzzles with her Companion. At approximately 7.30pm, the Companion began assisting the deceased with her preparations for bedtime. Once the deceased had been settled in her bed, she read to her.[39]

The night of 9 December 2011

Due to the timing of the events leading to the deceased's death, I examined the supervision, treatment and care of the deceased on the night of 9 December 2011.

Just before attending her daily de-briefing meeting, at approximately 9.00pm on 9 December 2011, the Companion checked on the deceased, who was asleep in her bed. Then she left for the meeting, and the volunteer mothers monitored the deceased, along with the other children.[40]

I am satisfied that up until 9.00pm on 9 December 2011, the deceased had not demonstrated any symptoms consistent with seizure disorder at the Hale School Sony Camp and that there was nothing in her observable behaviour that would have given cause for concern or closer monitoring. This includes the observations her Companion made of her shortly before she left for her de-briefing meeting.

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[39] Exhibit 1, Tab 11
[40] Exhibit 1, Tab 11

Each night at the Sony Camp a registered nurse was on duty. The additional duties of the night duty nurse were contained within the written nurses' guidelines kept in a Sony Camp file at the nurses' station. The night duty nurses received a small remuneration for their services. Their duties included supervising the children and companions during sleeping hours via regular patrol of the boarding house dormitories, checking the resuscitation equipment and dispensing required medications at 7.00am the following morning. On this particular camp, there was no specific orientation day for the volunteer nurses; it was considered unnecessary due to the same group of nurses having attended the Hale School Sony Camps each year.[41]

On 9 December 2011, Nurse Abbott was the only nurse on duty on the night shift. On two previous years she had been a volunteer helper at the Hale School Sony Camps. She has a background in paediatric cardiac intensive care. The night shift commenced at 9.00pm and ended at 7.00am. Nurse Abbott arrived early and from the handover, she was aware that the deceased had a history of epilepsy. Upon arrival she checked the children's photos, their recorded notes and their medication packs.[42]

In previous years, Nurse Thomas had also slept on site during night shift as a backup, but on this occasion she did

[41] Exhibit 2, Tab 8; Exhibit 4, Tab 4
[42] Exhibit 1, Tab 12

not do so. The procedures required that there be one night nurse on duty. Over a period of eight years when Nurse Thomas had slept at the Hale School Sony Camp, she was only awoken on one occasion, to assist with an unsettled child.[43]

Each night at the Hale School Sony Camp, there were also volunteer parents on duty. The volunteer parents were informed of the Care Plans that were attached to the door of each room, but they were not expected to familiarise themselves with the medical requirements of each child. At night shift, their role was to listen for anyone who was crying or distressed and to call the nurse if it appeared necessary to do so.[44]

On 9 December 2011 there were two parent volunteers on night duty for the girls. They were responsible for checking on between 12 to 16 girls while the Companions were having their evening de-briefing meeting. The parent volunteer responsible for assisting with the deceased arrived shortly after 8.00pm on 9 December 2011 and was instructed in her role by Ms Maskiell. When she arrived, most of the children were sleeping in their beds, the corridor lights were on, and the lights in the dormitories were off. She noted the information relevant to each child that had been placed on the doors of each room, which had been left ajar. The checking of the children comprised walking far

[43] Exhibit 4, Tab 4
[44] Exhibit 3, Tab 1

enough into the room to see the children without physical contact, and otherwise listening for any child making a noise. When she was not checking on the girls, she sat on a chair in the middle of the dormitory corridor. The deceased's room was closest the nursing station, in recognition of the fact that she was regarded as one of the "*difficult medical cases*".[45]

On the night of 9 December 2011 the deceased's Companion returned from the daily de-briefing meeting at approximately 9.30pm. She had last checked on the deceased approximately 30 minutes earlier, and on that occasion observed her to be asleep in her bed. Upon her return the Companion again checked on the deceased, who was face down in her bed, by placing her left hand upon her back. On this occasion she could not feel the deceased breathing. She immediately sought the assistance of the parent volunteers, who were outside in the corridor, and together they turned the deceased over. At this point, the deceased appeared to vomit and the Companion ran to seek the nurse's assistance. A parent volunteer felt for a pulse but could not find one.[46]

At approximately 9.30pm whilst Nurse Abbott was with Ms Maskiell and some other teachers, she was informed that the deceased had vomited and her assistance was required. Nurse Abbott attended immediately. Upon arrival in the

[45] Exhibit 1, Tab 14
[46] Exhibit 1, Tabs 11 and 14; Exhibit 3, Tab 1

deceased's room, Nurse Abbott checked but could find no signs of life. She cleared the deceased's airway, arranged for her to be placed upon the floor and she commenced cardiopulmonary resuscitation, continuing to clear her airway. She gave instructions for a "*priority one*" ambulance to be called. She also gave instructions for the oxygen and the defibrillator machine to be brought into the room. Suction equipment was not available. Nurse Abbott was the only nurse present and the only person with advanced training in cardiopulmonary resuscitation.[47]

Throughout the time that Nurse Abbott was conducting cardiopulmonary resuscitation, there was no detectable pulse and no signs of breathing. Ms Maskiell sourced the defibrillator. When it was attached, there was no cardiac rhythm detected, and therefore it was not used. Whilst Nurse Abbott continued with the cardiopulmonary resuscitation, Ms Maskiell recalled Nurse Tucker to Hale School. Nurse Tucker was the nurse coordinator for the 2011 Hale School Sony Camp. Ms Maskiell also took steps to contact the deceased's Carer.[48]

Records reflect that the St John Ambulance paramedics received the emergency call at 9.40pm, and that they departed five minutes later and arrived at Hale School at 9.53pm. Upon arrival they found the deceased to be in full

[47] Exhibit 1, Tab 12; Exhibit 4, Tab 4
[48] Exhibit 1, Tabs 11, 12 and 14; Exhibit 3, Tab 1; Exhibit 4, Tabs 1 and 2; Exhibit 5, Tab 5

cardiac arrest. The paramedics took over the cardiopulmonary resuscitation, which Nurse Abbott had administered continuously up until that point. The deceased was intubated and her airway was cleared. She was administered adrenaline and conveyed by ambulance to Sir Charles Gairdner Hospital, accompanied by Nurse Tucker, who had returned to the school.[49]

The deceased was brought into the Sir Charles Gairdner Hospital Emergency Department with cardiopulmonary resuscitation in progress, at approximately 10.45pm on 9 December 2011. Approximately 400ml of vomit had been aspirated from her. Despite all attempts, tragically the deceased was unable to be resuscitated and she was pronounced dead at approximately 11.00pm on 9 December 2011.[50]

Nurse Tucker informed the Carer of the deceased's death upon her arrival at Sir Charles Gairdner Hospital. The Carer informed Nurse Tucker that the deceased had had a similar experience six months previously where she had aspirated vomit at night, and that since that time, the deceased had slept with a baby monitor at her home. Nurse Tucker had not previously been aware of this.[51]

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[49] Exhibit 1, Tab 21; Exhibit 3, Tab 1
[50] Exhibit 1, Tab 20
[51] Exhibit 4, Tab 5

Hale School's headmaster had been informed. He attended at the Hale School boarding house and commenced arrangements to contact parents and carers, in order to close the Hale School Sony Camp. Counselling and support was offered to those affected by the deceased's death.[52]

CONCERNS EXPRESSED BY HALE SCHOOL SONY CAMP STAFF

Concerns have been expressed about the number of persons who had training in cardiopulmonary resuscitation and who were available that night to assist the deceased.

It was not mandatory for Hale School staff members to have training in cardiopulmonary resuscitation or a first aid certificate. However, all available Hale School staff members had undergone a First Aid Course or First Aid requalification in June 2010.

Whilst in hindsight the issue of the number of available nurses at night-time may usefully be explored, there is no evidence that the deceased received anything other than prompt attention from her Companion, who was diligent with her checking, and from Nurse Abbott who was both available and capable. In Dr Silberstein's opinion, seizures of the nature that the deceased likely suffered immediately

[52] Exhibit 4, Tab 2

before death do not necessarily respond to basic life support or even advanced resuscitative measures.[53]

I am satisfied that the cardiopulmonary resuscitation administered by Nurse Abbott, with the assistance of others present, was performed to a high standard. Nurse Abbott is to be commended for her efforts.

Concerns have also been expressed as to whether the deceased ought to have been permitted to attend the Hale School Sony Camp in light of her medical history and risk of night-time seizures.

There is evidence before me to the effect that neither Ms Maskiell, nor the nurses responsible for the deceased's care at the Hale School Sony Camp (Nurses Tucker, Parsons, Thomas and Abbott) were aware that the deceased had had a previous episode of aspiration of vomit during a seizure. Nor were they aware that the deceased slept with a baby monitor.[54] I accept their evidence on this point.

Mrs Maskiell stated that had she been informed of the deceased's previous episode of vomit aspiration during a seizure and the prior usage of the baby monitor, she would have discussed with Nurse Thomas whether the deceased was a suitable child to attend the Sony Camp.[55]

[53] Exhibit 1, Tab 26
[54] Exhibit 1, Tab 12; Exhibit 3, Tab 1; Exhibit 5, Tab 5
[55] Exhibit 3, Tab 1

Nurse Parsons stated that if she had known that the deceased had a history of vomit aspiration during a seizure, she would have sought details and made a notation to that effect on the deceased's Care Plan.[56]

Nurse Thomas stated that if she had been told of the deceased's previous episode of vomit aspiration during a seizure and the prior usage of the baby monitor, she would have discussed it with the deceased's Carer and made a note of it on her Care Plan.[57]

Nurse Abbott stated she was surprised at the higher acuity of the children, compared to previous years, and the number of children with feeding problems, which indicated to her the possibility of airway compromise. In hindsight she stated that had she known of some of these medical backgrounds before doing the Hale School Sony Camp, she would not have done the camp.[58]

I have no doubt that the tragic death of the deceased created deep feelings of sorrow and angst amongst the Hale School Sony staff.

It is natural for those staff members, when reflecting upon the events, to have questioned whether the deceased ought

[56] Exhibit 4, Tab 3
[57] Exhibit 4, Tab 4
[58] Exhibit 1, Tab 12

to have attended the Hale School Sony Camp. Indeed it would be surprising if such a question had not arisen in the minds of at least some of them.

At the inquest, Dr Silberstein was questioned in connection with two specific areas of concern that had been raised by the nurses and carers responsible for the deceased at the Hale School Sony Camp (the Sony Staff).

The first matter related to the Sony Staff's concern that the Carer had not provided them with any information about the fact that the deceased slept with a baby monitor at home. Dr Silberstein reported that prospective controlled trials had not proven that the use of audio monitors reduce the risk of death in cases such as that of the deceased. In his experience, it is very difficult to detect seizures reliably without a lot of false alarms generated by non-seizure movements, noises or other artefacts. The used of audio monitoring is to be weighed against false alarms producing considerable anxiety, disruption and sleep disturbances for patients and their carers. There is currently no seizure monitor reliable enough to be routinely recommended. Dr Silberstein agreed that a person would only know about the seizure if the level of disturbance were sufficient to wake that person from their sleep.[59]

[59] T 25, 26 and 29; Exhibit 1, Tab 26

It is reasonable for the Sony Staff to have wondered whether, in hindsight, the deceased ought to have had a baby monitor with her while she slept at the camp. However, I accept Dr Silberstein's evidence and am satisfied that there is no evidence to suggest that the utilisation of a baby monitor would have prevented the deceased's death. It follows that I am also satisfied that there can be no criticism of the Carer for not informing Sony Staff that the deceased had previously slept with a baby monitor.

The second matter related to the Sony Staff's concern that the Carer had not provided them with information to the effect that the deceased had a history of vomit aspiration during a seizure. Dr Silberstein was familiar with the Sony Camps and knew them to be very well run with sound procedures in place. Whilst he could not recall whether the Carer had discussed the deceased's planned attendance at the Hale School Sony Camp with him, and he had no record of any such discussion, his evidence was that he would "*most certainly*" have supported the deceased attending that camp, provided she was given her medications as prescribed and supervised in a reasonable manner.[60] His opinion was given in the context of his knowledge of the deceased's medical history, and the medication dosages listed on her Care Plan Summary.

[60] T 27

Again it is reasonable for the Sony Staff to have wondered whether in hindsight the deceased's medical records ought to have reflected a history of vomit aspiration during a seizure, and whether the Carer ought to have provided that information at the outset. The documentation does disclose that the deceased's Carer had informed a member of the Sony Staff that the deceased may have fits which last about two minutes and that this usually occurs at night.[61]

In all of the circumstances, I am satisfied that it was reasonable for the deceased to have attended the Hale School Sony Camp and that her Carer provided the Sony Staff with adequate information.

CAUSE AND MANNER OF DEATH

On 13 December 2011 forensic pathologist Dr G. A. Cadden made a post mortem examination of the deceased at the State Mortuary. At the conclusion of the examination he was unable to determine a cause of death. There was no gross primary pathology identified such as would explain the death. Accordingly further investigations were conducted to assist in identifying the cause of death.

The forensic pathologist noted that the deceased was a known sufferer of epilepsy, which was an ongoing medical

[61] Exhibit 2, Tab 46

issue. At post mortem examination pulmonary congestion was evident and food was found to be lying within the entrance to the larynx. Whilst no traces of food were obvious from a naked eye inspection of the bronchial tree, histologically vomit aspiration effect was evident.[62]

Toxicological analysis revealed a therapeutic level of lamotrigine (Lamictal, an anti-convulsant) and a sub-therapeutic level of valproic acid (sodium valproate/Epilim, an anti-epileptic agent). These were the deceased's usual medications. It is possible that the deceased's vomiting interfered with the absorption of the evening dose of Epilim. No alcohol or common drugs were detected.[63]

Upon examination of the deceased's brain, specialist neuropathologist Dr V. Fabian found areas of probable gyral abnormality in the frontal lobes. It was not established that these were the cause of the deceased's seizures.

After further investigations, on 10 February 2012, the forensic pathologist, whilst unable to ascertain a precise cause of death, concluded that in his opinion death was consistent with seizure disorder (epilepsy) with associated vomit aspiration.

At the inquest Dr Silberstein opined that the deceased's death is to be considered in the context of "Sudden

[62] Exhibit 1, Tab 7
[63] T 23; Exhibit 1, Tab 8

Unexpected Death in Epilepsy" or SUDEP, an uncommon but well recognised phenomenon. Seizures are very common in childhood with approximately four per cent of children experiencing at least one febrile seizure and two per cent at least one non-febrile seizure, with one per cent of children having a diagnosis of active epilepsy (two or more unprovoked seizures) by age 20. The vast majority of seizures cease spontaneously with full recovery.[64]

Death or serious injury can result either because of accidents such as drowning or a fall associated with the seizure (which is not included in SUDEP) or because the seizure causes respiratory obstruction, respiratory arrest or cardiac arrhythmia and arrest.[65]

Based upon Dr Silberstein's research and experience, SUDEP is more common in epilepsy refractory to treatment and when multiple medications are required. SUDEP can still occur when epilepsy is thought to be well-controlled. In patients such as the deceased, with chronic refractory epilepsy, annual incidence ranges between 1.1 - 5.9 per 1000.[66]

Based upon current research, some investigators distinguish SUDEP from cases where a patient is known or strongly suspected to have had a seizure at time of death.

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[64] T 21 – 22; Exhibit 1, Tab 26
[65] T 22; Exhibit 1, Tab 26
[66] T 22; Exhibit 1, Tab 26

Dr Silberstein was aware that the deceased was known to have vomited at the time of her death. He considered the post mortem findings for the deceased and at the inquest he opined that the vomit may have been a contributory factor to respiratory obstruction and arrest, although vomit was not found in her larynx or smaller airways. This was likely due to the 400ml of vomit aspirated from the deceased's airways during the resuscitation attempts. In Dr Silberstein's experience, seizures will sometimes provoke vomiting (as had previously been observed with the deceased). This is particularly so with seizures of occipital or temporal origin. No evidence of infection was found at post mortem examination, nor did the deceased display symptoms of infection prior to her death.[67]

Dr Silberstein's evidence was that the deceased's epilepsy was only partially controlled by her multiple medications, a situation that occurs in approximately 25% of children with epilepsy. Had the deceased survived, in due course other medications or non-pharmacological modalities would have been tried, but it is a matter for speculation as to whether any would have been more effective or prevented her death. The EEG studies performed on the deceased showed diffuse background abnormalities, but were not able to locate the origin of her seizures to a particular area. Dr Silberstein reviewed the findings of the specialist neuropathologist, Dr V. Fabian, noting that upon examination she found at least

[67] T 23; Exhibit 1, Tab 26

three areas of abnormality in the frontal lobes. In Dr Silberstein's opinion, any, all or none of those areas of abnormality might have been the sources of at least some of her seizures.[68]

The deceased was found lying in bed unresponsive with vomit over her and the bed. The results of the post mortem examination, taken together with Dr Silberstein's evidence and the deceased's medical history reflect that it is likely that shortly before death the deceased had an epileptic seizure that caused her to vomit, with some of that vomit likely to have been aspirated. The deceased's death should be considered a SUDEP.

I accept the forensic pathologist's opinion and find that the cause of the deceased's death was consistent with seizure disorder (epilepsy) with associated vomit aspiration.

The manner of the deceased's death was by way of natural causes.

COMMENTS REGARDING MEDICAL CLEARANCE

I invited submissions from Hale School on the question of whether, in future, there should be a procedure that the attending child's doctor gives a general written medical clearance for the child to participate in the Hale School

[68] T 25; Exhibit 1, Tab 9

Sony Camp, which also records the child's medications and the times at which they should be taken.

By submissions dated 25 August 2015 Hale School adopted the proposed recommendation and advised that any future Hale School Sony Camp will include a procedure requiring a signed and dated certificate from the child's treating medical practitioner, certifying the child as suitable to attend. The certificate would include a description of the child's medical condition, its particular consequences for the individual child, the medical treatment needs and the special care needs for that child. It would be prepared by a medical practitioner with a high level of understanding of the daily living and care requirements for the special needs child and have a particular focus on the information that needs to be conveyed to those with the medical supervision of the child at the Hale School Sony Camp.

Hale School staff members quite properly reviewed their procedures following the deceased's death and will formally review their medical procedures at the completion of every future Sony Camp to see if they can be further improved.

CONCLUSION

For a number of years before her death the deceased child had lived with her Carer, who was loving towards her and diligent in attending to her special needs. The deceased's

cause of death was consistent with seizure disorder (epilepsy) with associated vomit aspiration. She died on the second night of her attendance at the Hale School Sony Camp, on 9 December 2011. Her Carer had given permission for the deceased to attend the camp.

The deceased's death was sudden and unexpected. The medical treatment that she had received over the years was of a very high standard, but the nature of her disorder was such that despite all treatment, it had not been possible to fully control her seizures. Nor was it possible to predict when a seizure would occur and what the consequences would be. The aim of the treatment had been to minimise the number of seizures and avoid adverse effects.

There have been considerable advancements in the management of epilepsy in recent years. The extent to which they have reduced the incidence of SUDEP remains unclear. Active research in this area needs to continue in the hope that more information can be obtained regarding the management of seizure disorders.

Within this context, it becomes vitally important for carers of children with epilepsy to take reasonable precautions, but to also, as far as possible, allow children to enjoy normal lives. It was reasonable for the deceased to have participated in the Hale School Sony Camp. Hale School is to be commended for conducting the Sony Camps and

providing an enjoyable experience for children with special needs. That commendation extends to the participating staff members, nurses, students and parent volunteers. The deceased's Companion and Mrs Maskiell deserve special mention for their contributions, as does Nurse Abbott for her dedicated and tireless efforts to assist the deceased.

The deceased had been enjoying herself at the Hale School Sony Camp and she was surrounded by people who cared for her. There was appropriate supervision and the children's program was well attuned to their needs and interests. There were no steps that could or should have been taken by the Department, the Carer or any of the Hale School Sony Staff, nurses and volunteers (including the Companion) to prevent the deceased's tragic and sudden death. Her death occurred by way of natural causes.

R V C FOGLIANI
STATE CORONER

4 May 2016