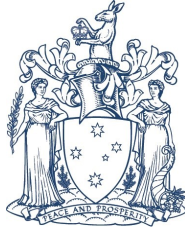

IN THE CORONERS COURT

OF VICTORIA

AT MELBOURNE

Court Reference: COR 2016 1992

FINDING INTO DEATH WITHOUT INQUEST

Form 38 Rule 60(2)

Section 67 of the ***Coroners Act 2008***

Findings of:	Paresa Antoniadis Spanos, Coroner
Deceased:	Tyla Jade Hovenbitzer
Date of birth:	8 September 1997
Date of death:	4 May 2016
Cause of death:	Multiorgan failure complicating malnutrition in a female with liver cirrhosis, obesity and Trisomy 21
Place of death:	Box Hill, Victoria

I, PARESA ANTONIADIS SPANOS, Coroner,

having investigated the death of TYLA JADE HOVENBITZER without holding an inquest:

find that the identity of the deceased was TYLA JADE HOVENBITZER

born on 8 September 1997

and that the death occurred on 4 May 2016

at Box Hill Hospital, 8 Arnold Street, Box Hill, Victoria, 3128

from:

1 (a) Multiorgan failure complicating malnutrition in a female with liver cirrhosis, obesity and Trisomy 21

Pursuant to section 67(1) of the *Coroners Act 2008*, I make findings with respect to the following circumstances:

Background

1. Tyla was the daughter of Denise and Tony Hovenbitzer and the sister of Corrine and Rhys. She was born with Trisomy 21 (commonly known as Downs Syndrome) and was diagnosed in early childhood with autism spectrum disorder and a moderate intellectual disability. Tyla also had a medical history of a past small atrial defect and current super obesity, with a Body Mass Index of 52.
2. Tyla had limited language skills and communicated with single words only or by pointing. Her mother described her as a very stubborn person, which would become evident when she did not want to do something. Tyla would bite, throw things, spit, and throw herself on the floor and go limp. It became increasingly difficult to manage these behaviours as her weight increased with age.
3. In 2003, Tyla was diagnosed as being in the severe range on the autism spectrum with a score of 38[1]. At the time of her diagnosis, she would make growling sounds for hours on end, interspersed with the insertion of the occasional label word if she wanted something such as chips or a sandwich. Any degree of change was extremely distressing for Tyla and strict routines needed to be adhered to including meals, the

[1] A score of 30 to 36 indicates mild to moderate autism and a score of 37 to 60 indicates severe autism.

placement of her car-seat and the location of her classroom. Tyla required constant supervision and a structured and supported environment to prevent injury to herself and others.

4. Tyla began attending Croydon Special Development School (CSDS) at the age of four and initially engaged well and attended regularly. Between 2002 and 2012, Tyla attended school regularly and made progress with her learning goals.

5. Tyla was referred to the Royal Children's Hospital (RCH) development and cardiology clinics over the course of 2007 and 2008. Her last review at the RCH was in June 2007.

6. According to Michelle Nolan, team leader of the Department of Health and Human Services (DHHS) Disability Client Support Services, Eastern Division, Tyla's last contact with DHHS was in 2007 when Ms Hovenbitzer requested family support services. The application was accompanied with letters of support from a social worker and a paediatrician at the RCH, which detailed the impact that Tyla's behaviour was having on her family. They recommended that Tyla be referred to the DHHS Behaviour Intervention Support team for psychological and behaviour assistance.

7. A Target Group Assessment was completed that confirmed Tyla's eligibility to access disability services however at the time of the referral, family support was not available in the Eastern region of the then Department of Human Services and the family were referred to RCH for support from a psychologist.

8. Tyla's mother was provided with a list of psychologists who could provide the requested support via a referral from Tyla's GP with funding available through Medicare. It was also agreed that a referral to the Respite Service Coordination Service was appropriate for assistance with ongoing access to regular or episodic respite.

9. At the time, Ms Hovenbitzer informed DHHS that she was accessing regular in-home support from her local council and occasional respite support from Interchange and Uniting Care Community Options. A letter from DHHS documented that Ms Hovenbitzer was content with the level of respite the family was receiving and would follow up the referral to the RCH. Records from the RCH do not contain any

information to suggest this occurred. Ms Hovenbitzer was encouraged to reconnect with the DHHS Intake team if Tyla had any additional need for support. There was no recorded contact with Tyla after 2007 and she did not come to the attention of the DHHS Child Protection Team.

10. During a review by paediatrician Dr Anthony Chin in 2008, it was noted that Tyla preferred to be by herself, had no appropriate play, needed to have a strict routine and her aggression had escalated in the preceding year. Further, that noises distressed her considerably and she would only eat chips or pasta.

11. In 2009, Tyla's general practitioner (GP), Dr Felicity Nolle, saw her in person for the final time. She was assessed for difficult behaviour, which included biting and kicking her family members, vomiting and possible reflux and disrupted sleep patterns. Tyla's medical records note that Ms Hovenbitzer was becoming exhausted and upset because she could never get enough sleep. Tyla would not go to sleep without her mother beside her and sometimes wandered the house waking up the family. Dr Nolle tried unsuccessfully to contact clinicians at the RCH development clinic and Tyla was re-referred to the RCH development clinic at this appointment.

12. It appears that thereafter Tyla's family were her sole carers with no organised respite care. Documentation made by Dr Nolle recorded in 2009 that Tyla has been on a waiting list for respite care for three years.

13. Dr Nolle did not review Tyla in person again, but about every six months, Ms Hovenbitzer attended an appointment to obtain a repeat prescription for temazepam (a sedative) for Tyla.

14. Parents usually inform CSDS of absences. If there were unexplained absences, CSDS would contact the family. Staff recalled calling Tyla's home, but the telephone would either go unanswered or to voicemail. Calls would be returned intermittently.

15. On 11 September 2008, the Primary Welfare Officer, Sharon Oularis attended Tyla's home and was informed that she had fractured her sternum about 10 weeks earlier. Ms Oularis formulated a support plan and wrote that a commode chair had been recommended, which was arranged shortly afterwards. A support plan for Tyla's return to school was written, which included a range of strategies. The school speech

therapist created a social story book and Ms Hovenbitzer was to buy an MP3 player with Tyla's favourite music recorded on it.

16. Lisa Garland took over Ms Oularis' position in 2009 and made contact with Tyla's family. Tyla was reluctant to engage with some activities of daily living and Ms Garland offered further support to discuss routines and services in the community, however her recollection was that Ms Hovenbitzer said she did not need assistance.

17. Tyla continued to have prolonged absences from school. Sometimes her family would indicate that she was unwell. At other times, the absence was documented as 'parent choice' because Tyla would refuse to leave the house and would engage in challenging behaviour such as sitting on the floor and refusing to follow instructions.

18. During Tyla's last paediatric appointment in 2010, Dr Dimi Simatos from the Eastern Health Outpatient Clinic reviewed her for abdominal pain, vomiting and violent behaviour. Dr Simatos documented that Tyla's family had been in contact with DHHS who offered behavioural management support and a psychological assessment at CSDS. Neither the DHHS or the CSDS documentation reflect that this occurred.

19. Tyla presented to Maroondah Hospital in 2011, 2012 and 2013. Those presentations were for abdominal pain and did not require admission to hospital.

20. Tyla began to refuse to attend school in 2013 but continued to enjoy school on those occasions when she attended, particularly music and art. Multiple efforts were made by CSDS to arrange transport for Tyla and to include in her in regular school activities. Communication between the school and Tyla's family was limited.

21. In Term 2, Tyla refused to get on the school bus. It was thought that the loud noise from the bus may have been an issue for Tyla. Ms Hovenbitzer tried driving her to school but Tyla would kick the back of her mother's seat and pull her hair while she was driving. To engage with Tyla, the school engagement officer would drive teachers that Tyla had a rapport with in the school bus to take her to school. These efforts were generally unsuccessful, and the trial was abandoned at the end of Term 3. At around that time, Tyla would sometimes wake at 2am, turn on all the household lights, watch television and then fall back asleep at about 7am. After such a night, Ms Hovenbitzer would allow Tyla to sleep in as she was extremely difficult to wake.

22. Thereafter, Tyla's teacher, Ms Carol arranged for school work to be sent home including colouring, which Tyla enjoyed. She also uploaded pictures and class news to the school's online portal for Tyla to access and arranged excursions to parks near Tyla's house to attempt to engage her. According to Ms Hovenbitzer, however, Tyla would refuse to leave the house.

23. Tyla was recorded CSDS records as being in a 'home program' between Term 4 in 2013 and the end of the 2014 school year. Mrs Hovenbitzer described a progressive functional decline from about that period onwards.

24. During appointments with Dr Nolle to collect a temazepam prescription, in 2014 and 2015, Ms Hoveentbitzer reported that Tyla only slept for about three hours a night and would run around the house waking up the family. The last prescription was provided on 8 October 2015 and the only other entries in Tyla's medical records concerned applications for a carer's and a mobility allowance.

25. In 2015, CSDS made efforts contact Ms Hovenbitzer to discuss Tyla's possible transition to CSDS's adult education program, Futures for Young Adults (FFYA), but they were unsuccessful. The DHHS Future Planning Officer also made multiple unsuccessful attempts to contact Ms Hovenbitzer as well.

26. The same year, the Assistant Principal of CSDS, Judith McDonald, who also managed the FFYA program, discussed Tyla's future involvement. It was explained that Tyla could have a home-based program. Ms McDonald discussed Tyla with Jennifer Bourne, the DHHS Future Planning Officer. Ms Bourne offered to meet Ms Hovenbitzer in her home, but she was unable to connect with her.

27. At about the time when Tyla turned 17, her school refusal progressed to a refusal to get out of bed at all or even to allow her mother to bathe her or change her nappy. She would lie on her stomach on her bed for hours at a time and the television in her room was on 24 hours a day.

28. In the months leading up to her death, Tyla refused to eat on a regular basis and her diet was limited in its variety and contained minimal nutrient or protein content.

Circumstances immediately proximate to death

29. On about 18 April 2016, Ms Hovenbitzer noticed that part of the skin on Tyla's leg had split, revealing a gaping wound. Tyla was known to have a high pain threshold

and would not have been able to communicate that she was hurt. Ms Hovenbitzer requested an ambulance, but as the wound was not life threatening, there was to be a delay of some hours. As an alternative, Ms Hovenbitzer arranged for a GP to visit the home and the GP recommended that Tyla go to hospital for an urgent evaluation as it was too difficult to assess her mobility and neurovascular status.

30. After some unexpected delays, in the early hours of 20 April 2016, Tyla was admitted to the Maroondah Hospital Emergency Department (ED). The clinical examination findings consisted of a blood pressure reading of 122/33 mmHg, a heart rate of 110 beats per minute (BPM) and oxygen saturation of 97% on room air. Tyla was afebrile and examination of her right mid-thigh revealed a 6cm wound deep to the muscle layers with no clinical signs of infection. Tyla was referred to the Plastic Surgery Unit for admission.

31. Mid-morning on 22 April 2016, staff made a Medical Emergency Team (MET) call as Tyla was hypoxic with oxygen saturation of 70%, which improved to 96% on supplemental oxygen. Examination findings revealed bilateral upper and lower limb swelling and a review of her medical records showed ongoing tachycardia. Blood analysis revealed anaemia, a clotting abnormality, thought to be due to liver disease, and mild hypothyroidism. Vitamin C, D, K and folate deficiencies were also identified. A mobile chest x-ray film showed cardiomegaly and a small left pleural effusion. Tyla was commenced on Tazocin for a possible lower respiratory tract infection and was transfused with three units of packed blood cells. Regular Vitamin K was commenced and Tyla was transferred to the general medicine ward.

32. That evening, there was a second MET call for reduced consciousness, which was thought to be due to opioids administered for pain relief. Her conscious state improved with naloxone suggesting that this had been the case.

33. The next day, 23 April 2017, Tyla was noted to have peripheral oedema, and a transthoracic echocardiogram (TECG) was arranged to assess her cardiac function. A dietician review diagnosed Tyla with malnutrition and it as decided that she should commence on parenteral nutrition.

34. Later that day, a third MET call was made in response to a reduced level of consciousness. Tyla was transferred to the Intensive Care Unit (ICU) for close monitoring and further investigations.

35. In the ICU, it was noted that Tyla had ongoing coagulopathy, hypoalbuminaemia and hyperbilirubinaemia. An abdominal ultrasound demonstrated fatty infiltration of the liver, but no hepatomegaly or ascites. CTs of the chest, abdomen and pelvis were planned.

36. On 27 April 2016, the TECG was performed and demonstrated moderate to severe pericardial effusion. By this time, Tyla was hypoxic with oxygen saturation of 90% and blood pressure of 130/40 mmHg. A clinical diagnosis of cardiac tamponade was made and following discussion with Tyla's cardiologist, she was transferred to Box Hill Hospital for urgent pericardiocentesis.

37. A few hours after Tyla's chest was drained at Box Hill Hospital, her respiratory state deteriorated further, and she was intubated and placed on mechanical ventilation.

38. Over the next six days, Tyla remained intubated and ventilated, with little change in her overall condition. Due to her obesity, lung mechanics, deconditioned state and reduced cognition level (not due to an acute medical issue), it became apparent that she would be unable to be weaned from the ventilator.

39. A meeting between clinicians and Tyla's parents occurred on 3 May 2016. Although Tyla's pericardial effusion had been drained, clinicians had been unable to identify a clear cause for the effusion and a chest x-ray showed minimal lung changes.

40. Despite these interventions, Tyla continued to require very high levels of ventilation support and clinicians considered it extremely unlikely that she would ever be weaned off the ventilator. Mr and Ms Hovenbitzer agreed that ongoing care in the ICU would not lead to an improvement in their daughter's state. Tyla was accordingly extubated on the morning of 4 May 2016 and passed away shortly afterwards.

Medical cause of death

41. On 10 May 2016, Dr Heinrich Bouwer, Forensic Pathologist, performed an autopsy of Tyla's body and reviewed the circumstances of the death as reported by police to the coroner, the eMedical deposition and medical records from Box Hill Hospital and post mortem computed tomography scans of the whole body.

42. The post mortem examination revealed evidence of multiorgan failure. There was residual pericardial effusion, bilateral pleural effusions, ascites and marked soft tissue oedema. The liver was cirrhotic and showed mild fatty infiltration but no significant

inflammation. In the absence of excessive alcohol intake, this was deemed to be most likely due to end-stage non-alcoholic fatty liver disease. However, Dr Bouwer considered that underlying causes should be considered.

43. There was no evidence of sepsis. Myocardial tissue showed no evidence of viral infection, no septic foci were identified, and a C-reactive protein was only slightly elevated while a procalcitonin was negative. Dr Bouwer noted that severe protein energy malnutrition is associated with pericardial effusions (cardiac tamponade), heart failure, electrolyte imbalances and sudden death.

44. The post mortem biochemical profile was consistent with marked renal impairment and showed elevated creatine and urea levels.

45. Routine toxicological analysis of post-mortem samples detected morphine, metoclopramide, paracetamol and lignocaine, consistent with therapeutic use and no alcohol or other commonly encountered drugs or poisons.

46. Examination of the brain by Dr Linda Iles, Specialist Pathologist/Neuropathologist, revealed a thickened corpus callosum and no other significant macroscopic abnormalities were detected.

47. In view of the reported circumstances and findings at autopsy, Dr Bouwer considered that the cause of death was best formulated as *multiorgan failure complicating malnutrition in a female with liver cirrhosis, obesity and Trisomy 21* and was due to natural causes.

Health and Medical Investigation Team

48. In light of the circumstances in which Tyla died, I asked a paediatric doctor from the Health and Medical Investigation Team (HMIT) to review the adequacy of the clinical management and care provided to her during her past episode of care, and the support services provided to her family in the years preceding her death.

49. The HMIT is part of the Coroners Prevention Unit (CPU), which was established in 2008 to strengthen the prevention role of the Coroner. The CPU assists the Coroner to formulate prevention recommendations and comments and monitors and evaluates their effectiveness once published. The HMIT is staffed by practising physicians and nurses who are independent of the health professionals or institutions involved. They assist the Coroner's investigation of deaths occurring in a healthcare setting by

evaluating the clinical management and care provided and identifying areas of improvement so that similar deaths may be avoided in the future.

50. Tyla's background of Downs Syndrome, her place on the autism spectrum and moderate intellectual disability resulted in significant behavioural issues. Tyla's challenging behaviour and refusal to leave the house, in combination with her extreme obesity and functional decline, resulted in significant barriers for social engagement, school attendance and failure to attend medical appointments.

51. Although it was unclear which service provider was responsible for Tyla's overall case management, CSDS assumed appropriate responsibility for re-engaging her with school. At the time of Tyla's death, there were no support services involved with the Hovenbitzer family.

52. The HMIT considered that Tyla's complex medical issues may have been detected earlier and may not have culminated in her death if she had been medically reviewed on a regular basis. However, Tyla's behavioural difficulties would have significantly complicated efforts to engage with healthcare providers and were likely a major contributor to the failure to attend appointments, which were regularly missed. Similarly, it is likely that Tyla's behavioural issues directed her diet into one of extreme restriction, which led to malnutrition despite her extreme body weight.

53. The HMIT deemed the medical care at Maroondah Hospital and Box Hill Hospital to be appropriate. Tyla had complex medical problems and was at the end stages of chronic diseases related to obesity and severe protein energy malnutrition. These illnesses were identified incidentally through inpatient observations and assessments.

54. Tyla's escalating behavioural difficulties meant that a significant burden of care was placed on her family. It appears that the turning point for Tyla was in 2007 when a referral to DHHS was made but services were not available in her local area. Despite an awareness of significant issues and engagement by Tyla's family, no alternative supports were arranged, and nothing was initiated to assist with Tyla's deteriorating behaviour.

55. The HMIT considered that Tyla's GP and school would have been best placed to provide information about disability supports, particularly between 2013 and 2015 when Tyla disengaged with CSDS. There was no documentation of any offers for

further disability, behavioural or psychological supports and no evidence that the family sought supports. Nevertheless, CSDS made multiple attempts to engage with the family otherwise.

56. The their conclusions, HMIT did not identify any opportunities for prevention but commented that Tyla's case highlights multiple system failures and opportunities to improve the overall care of children with disabilities and the support of their families.

Information from DHHD about available disability support services between 2007-2012

57. I asked a representative from DHHS to provide a summary of the supports that were available under the previous State funded disability services and would have been available the current National Disability Insurance Scheme (NDIS) in relation to access, planning and supports. They advised as follows.

58. The DHHS Respite Coordination Service was a block funded program managed by the Yooralla Society, Victoria, which linked people with a disability and their families to a broad range of respite services within the home, community or residential settings. This service also facilitated access to more intensive levels of support when appropriate, including completing Disability Support Register (DSR) applications for individualised finding or facilitating referrals for case management.

59. Individual Support Packages (ISP) were allocated via the DSR for people with a disability requiring ongoing supports. These packages could be used flexibly to meet disability related needs including assistance with personal care, support to access community, and allied health and therapeutic supports. Allocation was based on priority criteria, which considered the circumstances of the individual and their family.

60. Case management support was available for people with a disability and their families who needed more complex support. A number of external agencies were also funded to provide case management. In the Outer East of Melbourne, Care Connect provided case management and a small amount of brokerage support for people with a disability.

61. DCS also directly provided a range of services that included a case management team, behaviour management support and outreach. A broad range of respite services were

available, including seven facility-based services, flexible brokerage services, host family respite and activity based social and recreational programs.

62. Carers Victoria also provided a range of supports to parents and siblings of a person with a disability including non-recurrent flexible brokerage to assist families when they needed a break.

63. The Futures for Young Adults (FFYA) program provided support to young people with a disability leaving school to transition to an appropriate and meaningful daytime occupation, and to provide disability funding to enable this to occur (as needed). Access to the program was available for up to three years with young people allocated ongoing disability funding in the form of an ISP as required on exiting the program.

64. The practice of the FFYA team was to allocate one worker at each school and for that worker to provide planner support to all school leavers from their allocated schools enrolling in the program.

65. The FFYA could fund a range of supports to assist young people including pre-employment or pre-vocational programs, group-based activities and individual programs that could be delivered flexibly in a range of settings.

66. An FFYA planner would have considered Tyla's needs for access to other disability specific and mainstream services and facilitated referrals as needed. It was not uncommon for FFYA planners to refer young people to DCS case management when they required more intensive support.

67. The National Disability Insurance Agency (NDIA) is now responsible for access decisions for disability supports under the National Disability Insurance Scheme (NDIS). Once an individual has been found to be eligible, the NDIA or their partner, the Local Area Coordination Service would be in contact to arrange a meeting.

68. Through planning, it will be determined what the reasonable and necessary supports should be that will be funded in the individual's NDIS plan. Reasonable and necessary supports include a range of supports and services that may include education, employment, social participation, independence, living arrangements and health and wellbeing. Under the NDIS scheme, plans must be reviewed annually.

69. Planning includes identification of the person/institution who will manage the funding for supports in a participant's plan. If a family requires additional support to navigate

the service system and to coordinate services, it may be found reasonable and necessary for them to have funded Support Coordination in their plan. They would support the family to select service providers, monitor draw down on the plan and help build the capacity of the individual or the family to exercise choice and control. However, this is not a requirement and individuals, or families can refuse to engage the supports.

Findings

70. I find that Tyla Jade Hovenbitzer late of 12 William Road, Croydon, died at Box Hill Hospital on 4 May 2016 from *multiorgan failure complicating malnutrition in a female with liver cirrhosis, obesity and Trisomy 21*.

71. The available evidence supports a finding that the cause of Tyla's functional decline and eventual death was multifactorial. In the years prior to her death, medical care was limited, and support services were absent.

72. As no overtures were made by her family to access services, Tyla did not come to the attention of any public entity or other organisation that may have been able to assist her and her family by the provision of support services such behavioural management, assistance with personal care and nutrition, and respite.

73. I acknowledge that Tyla's special needs and difficult behaviours would have significantly complicated the efforts of her family to access medical attention or to care and provide for her more generally, and that they did their best in very difficult circumstances.

Comments

Pursuant to section 67(3) of the *Coroners Act 2008*, I make the following comments on matters relating to Tyla's death:

1. While I acknowledge that families and caregivers have the right to care for their loved ones independently, it remains unclear why Tyla's family did not seek or avail themselves of the support services available through DHHS in the years preceding her death, when they were obviously struggling to care for her with their own limited resources.

2. There is an onus on DHHS/Diability Services and the NDIS to be proactive in ensuring that people with disabilities and their families and caregivers can easily access information about the support services that are available to them and how support services can be accessed.

Publication of finding and comments

Pursuant to section 73(1A) of the Act, I direct that this finding and comments by published on the Internet in accordance with the rules of the Court.

Distribution of finding and comments

I direct that a copy of this finding and comments be provided to the following:

Mr and Ms Hovenbitzer

Dr Yvette Kozielski, Eastern Health

Ms Annabelle Mann, Royal Children's Hospital

Mr Arthur Rogers, The Disability Services Commissioner

Ms Leng Phang, Department of Health and Human Services

First Constable Daniel Black (#393223) c/o OIC Box Hill Police

Signature:

PARESA ANTONIADIS SPANOS

Coroner

Date: 1 August 2019

Cc: Leading Senior Constable Kelly Ramsay, Police Coronial Support Unit