



IN THE CORONERS COURT  
OF VICTORIA  
AT MELBOURNE

Court Reference: COR 2014 4868

**FINDING INTO DEATH WITHOUT INQUEST**

*Form 38 Rule 60(2)*

*Section 67 of the Coroners Act 2008*

*Amended pursuant to s.76 of the Coroners Act 2008 on 31 October 2017<sup>1</sup>*

Findings of:	Paresa Antoniadis Spanos, Coroner
Deceased:	ALJW <sup>2</sup>
Date of birth:	June 1993
Date of death:	Between 15 and 21 September 2014
Cause of death:	Combined effects of heroin toxicity and plastic bag asphyxia
Place of death:	Newport

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<sup>1</sup> The Finding was amended to redact the name of a family friend of Mr ALJW.

<sup>2</sup> In accordance with the wishes of Mr ALJW's family, identifying information has been redacted.

I, PARESA ANTONIADIS SPANOS, Coroner,

having investigated the death of ALJW without holding an inquest:

find that the identity of the deceased was ALJW

born in June 1993

and that the death occurred between 15 and 21 September 2014

at a residential premises on North Road, Newport, Victoria 3015

**from:**

I (a) COMBINED EFFECTS OF HEROIN TOXICITY AND PLASTIC BAG ASPHYXIA

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

#### BACKGROUND

1. Mr ALJW was the 21-year old son of AR and MR and the youngest of their three children.<sup>3</sup> He was born with a complex congenital heart disease, tricuspid atresia with hypoplastic right ventricle, atrial septal defect and ventricular septal defect. He underwent bi-directional cavo-pulmonary shunt surgery when he was three months old and an extra-cardiac Fontan procedure shortly before his fifth birthday.<sup>4</sup> Mr ALJW required lifelong anticoagulation medication, regular cardiac surveillance and annual review, and some restrictions on the types of physical activities in which he engaged.<sup>5</sup>
2. Mr ALJW is remembered by his family as a courageous, inquisitive, intelligent and humourous young man who was determined not to be defined by his cardiac condition or the weight of his own mortality. Nonetheless, Mr ALJW's condition both bound and tested his family. Throughout his childhood in Daylesford, primary schooling in Ballarat and secondary schooling in Melbourne, they were acutely aware of his sadness at being sidelined for sport, self-consciousness about having a large chest scar and that fundamentally he felt 'different' from his peers.<sup>6</sup>
3. Mr ALJW's oldest sister, AS, recalled an occasion when he was just nine years old and had sought her support when upset about explaining his cardiac condition to his class mates after collapsing during a basketball game at school. AS remembers that her brother was uncharacteristically tearful and that this was the first time he had talked about wanting to die or kill himself.<sup>7</sup>

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<sup>3</sup> Coronial brief of evidence [CB], Statement of Mr ALJW's father.

<sup>4</sup> CB, Statement of Dr Pavithra Naidu.

<sup>5</sup> CB, Statement of Mr ALJW's father.

<sup>6</sup> Family correspondence with the Court dated 24 October 2015. See also statements made by family members contained in the CB.

<sup>7</sup> CB, Statement of Mr ALJW's oldest sister.

4. During a cardiology review at the Royal Children's Hospital [RCH] when he was 14 years old, Mr ALJW and his family were provided with prognostic information. Although perhaps intended to highlight the need for Mr ALJW to look after himself, the clinician painted a bleak picture of reduced career prospects, ill-health and sudden and early death.<sup>8</sup> Within days, Mr ALJW had attempted to overdose on his mother's medication and following an evaluation in hospital, his parents arranged for him to receive psychological counselling.<sup>9</sup>
5. During adolescence, Mr ALJW experienced a period of ambivalence about high school resulting in poor attendance. He also became involved with a peer group that experimented with the use of cannabis and other drugs. However, with his family's support and the involvement of a psychologist through Orygen Youth Mental Health Services, Mr ALJW extricated himself from the group and resumed his secondary education at another school.<sup>10</sup>
6. In 2011, towards the end of his final year in high school, Mr ALJW researched avenues through which he could pursue his interest in writing. He aspired to become a journalist and ultimately persuaded his parents to allow him to commence a 12-month cadetship in South Africa.<sup>11</sup>
7. In a letter dated 14 October 2011, Dr Robert Weintraub of the RCH Cardiology Department referred Mr ALJW to Dr Leeanne Grigg of the Royal Melbourne Hospital [RMH] for ongoing cardiac care at the Adult Congenital Health Disease Service at RMH.<sup>12</sup> A letter of introduction to the specialist clinic was sent later the same month but as it was anticipated that Mr ALJW would be overseas for the following year, his first appointment at RMH was provisionally scheduled for January 2013.<sup>13</sup>
8. Mr ALJW left for South Africa late in 2011. During his cadetship he wrote articles on a diverse range of local issues and in his spare time worked in a wild cat reserve, took up skydiving and explored the country with new friends.<sup>14</sup>
9. In 2012, Mr ALJW relocated to London where one of his sisters was living. Another opportunity for exploration, Mr ALJW worked as a steward at the Royal Albert Hall, attended slam poetry events and spent hours in antique bookshops. He also secured an internship at an international online publication specialising in investigative journalism.<sup>15</sup> Whilst overseas, Mr ALJW remained in regular contact with his family.

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<sup>8</sup> CB, Statements of Statement of Mr ALJW's father and oldest sister.

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> Ibid.

<sup>12</sup> CB, Statement of Associate Professor Michael Cheung.

<sup>13</sup> Letters from RMH to Mr ALJW dated 31 October 2011 included as attachments to the Statement of Associate Professor Leeanne Grigg dated 1 February 2016.

<sup>14</sup> Correspondence from Mr ALJW's parents dated 13 November 2015 (attachment).

<sup>15</sup> Ibid and CB, Statement of Mr ALJW's oldest sister.



10. Mr ALJW returned to Australia in November 2013 and took up residence in the family home in Newport. He commenced a screen writing course at Royal Melbourne Institute of Technology, continued to write for VICE and work on his own short stories and second novel, obtained work as a book keeper and volunteered at the Wheelers Centre. He also formed a Melbourne Writers Meet Up group, prepared for his driving test and took up salsa dancing.<sup>16</sup>
11. In December 2013, he formed a relationship with GJ whom he had known during secondary school. The couple spent a lot of time together. According to GJ, Mr ALJW confided in her that he had experimented with a number of illicit drugs while overseas and that while he was in South Africa he had attempted suicide twice.<sup>17</sup>
12. In early July 2014, Mr ALJW and GJ broke up for a period of about three weeks.<sup>18</sup>
13. On 8 July 2014 Mr ALJW underwent a transthoracic echocardiogram in advance a cardiac review at the Adult Congenital Cardiac Clinic at the RMH.<sup>19</sup>
14. On 11 July 2014, Mr ALJW consulted general practitioner Dr John Haddad at The Clinic Williamstown. He requested a new prescription for his regular anticoagulation therapy and reported that although he had suffered depression for many years, he felt that his symptoms were worse recently. He disclosed taking an overdose of drugs the previous week in an attempt to self-harm. He admitted experiencing suicidal ideation but denied any current intention to harm himself. Dr Haddad referred Mr ALJW for counselling with psychologist Robert Chatfield.<sup>20</sup>
15. Mr ALJW attended three 50-minute sessions with Dr Chatfield on 18 and 21 July and 2 August 2014 for treatment of depression.<sup>21</sup> Mr ALJW reported that although he was feeling better, two weeks earlier (5 July 2014) he used Ketamine bought over the internet, had been 'out of it' for days after and though he had 'no serious intention of killing himself' had been struggling with feelings of loneliness and self-criticism in the preceding days.<sup>22</sup>
16. Dr Chatfield conducted a mental status assessment<sup>23</sup> in the first session<sup>24</sup> which assessed Mr ALJW as being moderately depressed, moderately anxious and severely psychologically

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<sup>16</sup> CB, Statement of Mr ALJW's father.

<sup>17</sup> CB, Statement of GJ.

<sup>18</sup> Ibid.

<sup>19</sup> CB, Statement of Dr Naidu.

<sup>20</sup> CB, Statement of Dr John Haddad.

<sup>21</sup> CB, Statement of Dr Robert Chatfield.

<sup>22</sup> Ibid.

<sup>23</sup> Dr Chatfield administered the Kessler Psychological Distress Scale [K10] and the Depression, Anxiety and Stress Scale [DASS 21].

<sup>24</sup> Dr Chatfield advised in a letter to the Court dated 24 February 2015 [Chatfield letter], that K10 and DASS 21 surveys are typically administered on the first and sixth session and as Mr ALJW only attended for counselling twice, the tests were not re-administered.

distressed.<sup>25</sup> Mr ALJW reported that he was relatively relaxed and confident (not anxious or angry), though he sometimes felt lonely and was not overly positive about the future. When specifically asked about suicidality, Mr ALJW admitted infrequent suicidal thoughts but that he had no plan or intent to suicide.<sup>26</sup>

17. In the course of counselling, Mr ALJW reported a 'normal' childhood and upbringing<sup>27</sup> and while he did mention taking an anticoagulant for a cardiac condition, he gave no indication that he had a short life expectancy or that his condition was of particular concern. Indeed, Mr ALJW's cardiac condition did not arise again in discussions.<sup>28</sup> He reported no history of psychological issues, reported drinking alcohol rarely but excessively when he did so and, in relation to drug use, admitted using 'everything except Meth'.<sup>29</sup> He said he had a number of interests and a small social group but that he felt he did not really have a strong network of support.<sup>30</sup>
18. In early August 2014, Mr ALJW and GJ reconciled and he confided that he had felt suicidal while they were apart.<sup>31</sup>
19. When contacted on 4 August 2014 to schedule his next psychological counselling session, Mr ALJW declined to make a fourth appointment.<sup>32</sup>

#### REVIEW AT RMH'S ADULT CONGENITAL CARDIAC CLINIC

20. On 19 August 2014, Mr ALJW was seen by Dr Pavithra Naidu of the RMH and A/Prof Michael Cheung, Director of Cardiology at the Royal Children's Hospital [RCH], at RMH's Adult Congenital Cardiac Clinic for review.<sup>33</sup> Having previously been followed-up by the cardiology team at RCH, sometimes with his whole family in attendance, Mr ALJW had declined his parents' offer to accompany him to his first review as an adult.<sup>34</sup>
21. Mr ALJW underwent an electrocardiogram on the day of the appointment which showed sinus rhythm with left axis deviation and normal QT corrected interval. The results of the echocardiogram performed in July 2014 were also available and it showed normal left

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<sup>25</sup> Mr ALJW's score on the stress scale was within the normal range.

<sup>26</sup> CB, Statement of Dr Robert Chatfield.

<sup>27</sup> Ibid.

<sup>28</sup> Chatfield letter.

<sup>29</sup> Ibid.

<sup>30</sup> CB, Statement of Dr Robert Chatfield.

<sup>31</sup> CB, Statement of GJ.

<sup>32</sup> Chatfield letter.

<sup>33</sup> CB, Statement of Dr Pavithra Naidu.

<sup>34</sup> CB, Statement of Mr ALJW's father (see also the statement of his oldest sister).



ventricular size and systolic function, normal aortic and mitral valve function and that the Fontan circuit was normal.<sup>35</sup>

22. On examination, Mr ALJW's heart rate was 72 beats per minute, blood pressure was 105/70, jugular venous pressure was not elevated, and he had 93% oxygen saturation on room air. There were dual heart sounds with no additional sounds and his lung fields were clear. There was some peripheral cyanosis but no peripheral oedema.<sup>36</sup> Mr ALJW reported good exercise capacity, with twice-weekly salsa dancing for up to an hour, no shortness of breath on exertion and long-standing intermittent palpitations unassociated with any dizziness or syncope.<sup>37</sup>
23. Mr ALJW was considered by his clinicians to be stable from a cardiac perspective. During the consultation, they discussed the importance of continuing warfarin therapy and regular monitoring of liver function and management of prolonged palpitations.<sup>38</sup> When Mr ALJW asked about his life expectancy, his clinicians informed him that they did not have concerns about his short or medium term prognosis given his good exercise capacity and normal heart function.<sup>39</sup>
24. In relation to long-term prognosis, the clinicians explained that there was not much long term data about Fontan patients because the operation was relatively recently developed – in the 1970s – and so the oldest patients are now only in their 40s. Moreover, they anticipated better results from the newer extra-cardiac Fontan procedure that Mr ALJW underwent than the older types of Fontan operation. Dr Naidu considered that Mr ALJW had understood the prognostic information provided and as he did not appear depressed given the overall good outlook, he was not referred to support services.<sup>40</sup> There was a plan for Mr ALJW to return for review in 12 months' time.<sup>41</sup>
25. Mr ALJW telephoned his mother soon after his cardiac review. He sounded anxious and laughed nervously as he relayed what he had understood from the consultation: his liver and kidneys were going to pack up when he was in his 30s and he'd be dead by this 40s.<sup>42</sup> When discussing the appointment with his father, Mr ALJW said it had been 'confronting' and reported that he 'would become very sick in his 30s and that his life expectancy was 40 years old'.<sup>43</sup> His parents offered reassurance by suggesting that technological advances may assist Mr

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<sup>35</sup> CB, Statement of Dr Pavithra Naidu.

<sup>36</sup> Ibid.

<sup>37</sup> Ibid.

<sup>38</sup> Mr ALJW did not report experiencing prolonged palpitations (those lasting more than an hour) but was advised if he ever did so, he should present to the emergency department of a hospital.

<sup>39</sup> Letter to the Court from Dr Naidu dated 1 March 2015.

<sup>40</sup> Letter to the Court from Dr Naidu dated 1 March 2015.

<sup>41</sup> Reporting letter from Dr Naidu to Mr ALJW's general practitioner dated 19 August 2014.

<sup>42</sup> Telephone communication between Mr ALJW's mother and the Court on 23 October 2015.

<sup>43</sup> CB, Statement of Mr ALJW's father.

ALJW's condition, noting that he seemed to accept the information he had been given and that he did not appear suicidal or depressed.<sup>44</sup>

26. On 29 August 2014, when his parents travelled to London to attend a family wedding, Mr ALJW remained at home given that he had only recently commenced work and wished to pursue his hobbies.<sup>45</sup>
27. On 7 September 2014, GJ ended her relationship with Mr ALJW. When he met up with his sister AS later the same day, Mr ALJW told her that the break-up was amicable and that the relationship had been deteriorating since he had discussed his recent cardiac review with her. GJ had apparently become very upset when he mentioned his prognosis and his belief that he ought not to have children (as he had wanted) because of it.<sup>46</sup> Nonetheless, AS recalled that her brother appeared future-oriented that evening, planning to travel around Australia and write.<sup>47</sup>
28. On 8 September 2014, AS thought her brother appeared more emotional when he left for work. As she was due to leave for London to join the rest of the family in London that night, she asked whether he would be alright staying home alone; Mr ALJW reassured her that it would be good for him to have some space. Later that day, when they spoke again, AS thought her brother still seemed sad, but not depressed.<sup>48</sup>
29. On 15 September 2014, Mr ALJW accessed his email account for the last time and corresponded with his parents.<sup>49</sup>

#### DISCOVERY OF MR ALJW'S DEATH & THE CORONIAL INVESTIGATION

30. On 21 September 2014, having uncharacteristically not heard from Mr ALJW for about a week, one of his sisters asked family friend, MT, to perform a welfare check.<sup>50</sup> MT set off straight away, arriving at about 8.30pm and entered the premises in Newport using a key. Turning on lights and checking rooms as he went, upon entering Mr ALJW's bedroom MT found him lying on his bed fully clothed with a plastic bag over his head, apparently deceased for some time. The emergency services were called.<sup>51</sup>
31. Attending paramedics confirmed that Mr ALJW was deceased and police commenced a coronial investigation. During an examination of the scene police found no signs of disturbance and, when searching Mr ALJW's bedroom, a laptop and mobile phone, warfarin prescribed to

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<sup>44</sup> Ibid.

<sup>45</sup> Ibid.

<sup>46</sup> CB, Statements of GJ and Mr ALJW's oldest sister.

<sup>47</sup> CB, Statement of Mr ALJW's oldest sister.

<sup>48</sup> Ibid.

<sup>49</sup> CB, Statements of Mr ALJW's father and his oldest sister.

<sup>50</sup> CB statements of MT and Mr ALJW's oldest sister.

<sup>51</sup> CB, Statement of MT.



Mr ALJW and a folded piece of foil were located along with a hand-written note. In the note, Mr ALJW explained that he had taken an overdose of heroin and his reasons for doing so. The coronial brief of evidence on which this finding is largely based was later compiled by Detective Senior Constable Olivia Dennison of Williamstown Police.

32. Forensic pathologist, Dr Linda Iles of the Victorian Institute of Forensic Medicine, reviewed the circumstances of the death as reported by police to the coroner, Mr ALJW's general practitioner's records, post-mortem computer assisted tomography [PMCT] scans of the whole body and performed an external examination. Among Dr Iles' anatomical findings were a midline sternotomy scar, signs about the neck consistent with placement of a clear plastic bag that remained *in situ*, and changes of decomposition.
33. Post-mortem toxicology detected alcohol (0.04g/100mL), heroin-specific metabolite 6-monoacetylmorphine, free morphine (~0.9mg/L),<sup>52</sup> codeine and warfarin.
34. Dr Iles advised that it was reasonable to attribute Mr ALJW's death to the combined effects of heroin toxicity and plastic bag asphyxia without the need for an autopsy. The forensic pathologist commented that she was unable to determine, with or without an autopsy, the relative contributions of heroin toxicity and plastic bag asphyxia to the death.

#### Family Concerns About Emotional Wellbeing in Transition Care and Prognostic Communications

35. In correspondence to the Court dated 24 October 2015, Mr ALJW's parents outlined their concerns about the management of their son's transition from paediatric to adult cardiac care and, in particular, their belief that his psychological and emotional wellbeing had been overlooked in the process, and in the delivery of prognostic information. While they acknowledged the complexity of their son's cardiac condition and his experience of it as well as the relative newness of the Fontan procedure, an emerging trend in academic and clinical literature tending to support an increased incidence of mental illnesses such as depression and anxiety among Fontan patients was also noted. Their fundamental concern was that the emotional health of Fontan patients, particularly during the transition from paediatric to adult care, be supported by psychologists and the empathic delivery of prognostic information lest they feel alone or 'scheduled to die' as had Mr ALJW.<sup>53</sup>
36. At my request, further information about the processes in place to support Fontan patients' transition from paediatric to adult cardiac care was obtained from the RCH and RMH.

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<sup>52</sup> The concentration of free morphine in deaths attributed to heroin have ranged from 0.01 to well over 1mg/L, with a mean of about 0.2-0.3mg/L. There is no clearly defined safe or toxic concentration of morphine in blood or any other tissue. Any concentration has the potential to be fatal, depending on the circumstances and the tolerance to the drug.

<sup>53</sup> Correspondence between Mr ALJW's parents and the Court dated 24 October 2015.



Associate Professor Leeanne Grigg, Director of Cardiology at the RMH, and Associate Professor Michael Cheung, Director of Cardiology at the RCH, responded each emphasising that the strategies in place now to support the transfer of cardiac care between these hospitals were not available at the time of Mr ALJW's transition.<sup>54</sup>

37. A/Prof Cheung noted that in 2013 the Cardiac Society of Australia and New Zealand ratified guidelines for standards of care in adult congenital heart disease in which planning of transition care from paediatric to adult cardiac services was one of the two key areas identified as requiring improvement. Both Cardiology Directors observed that significant changes to transition processes had been implemented at RCH<sup>55</sup> and RMH since 2014 to address advances in patient care and the changing context for care.<sup>56</sup>
38. A/Prof Cheung observed that at the RCH, discussions about transfer of cardiac care of adolescents generally starts around 14 or 15 years of age, depending on the paediatric cardiologist's approach and his or her assessment of the patient's maturity. During these years, the clinician will have more discussions about diagnosis, previous surgeries and prognosis directly with the adolescent to ensure s/he has an appropriate understanding of the condition and its management. It is generally when adolescents leave school that ongoing cardiac care is referred to an adult cardiology service, with relevant clinical information.<sup>57</sup>
39. A/Prof Grigg outlined the formal aspects of the transfer of cardiac care between the RCH to the RMH, much of which was evident in Mr ALJW's transition even if his was more protracted due to the time he spent overseas. That is, patients with complex cardiac disease reaching the age of 18 years are transferred from the RCH to the RMH by referral to the Head of the Adult Congenital Cardiac Service accompanied by complete clinical information, including operation notes, investigations and correspondence. The RMH corresponds with the patient to confirm that a referral was received and, nearer the date of their first appointment (given that most appointments are scheduled six to 12 months after referral as annual review is typical), sends another letter with instructions about the appointment and any investigations required in advance. The Congenital Liaison Nurse and Congenital Cardiac Secretary are identified as the primary contacts for patients.<sup>58</sup>

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<sup>54</sup> CB, Statements provided by A/Prof Michael Cheung dated 6 February 2016 and A/Prof Leeanne Grigg dated 1 February 2016.

<sup>55</sup> A/Prof Cheung referred to collaboration between the Cardiology Department and the RCH's hospital-wide transition team to improve patient transfer and the establishment, in 2014, of the Annual Cardiology Transition Forum.

<sup>56</sup> CB, Statements of A/Prof Cheung and A/Prof Grigg.

<sup>57</sup> CB, Statement of A/Prof Cheung.

<sup>58</sup> CB, Statement of A/Prof Grigg and its substance also appeared in the statement provided by A/Prof Cheung.

40. Prior to the patient's first RMH clinical appointment, ongoing care remains the responsibility of the RCH pursuant to an agreement between the hospitals.<sup>59</sup>
41. There are no formal processes for psychological support for young adult Fontan patients, although such services can be arranged via referral for psychological counselling when necessary at both the RCH and RMH.<sup>60</sup>
42. Patients new to the RMH Congenital Cardiac Clinic are usually seen by either A/Prof Grigg or A/Prof Cheung because both are aware that the transition to adult cardiac care is a significant one and both have a great deal of experience in managing these young cardiac patients.<sup>61</sup>
43. A/Prof Cheung recalled that during their 19 August 2014 consultation, Mr ALJW revealed that he had seen some prognostic data which suggested that Fontan circulation would fail after 20 years. In their subsequent discussion, A/Prof Cheung informed Mr ALJW that in his view the data to which he referred had been overstated and the prognosis for Fontan patients was better. The cardiologist reportedly tried to reassure Mr ALJW that there was a more positive outlook than his interpretation of the data he had seen, particularly given that his cardiac condition was stable (and he had the newer extra-cardiac Fontan).<sup>62</sup>
44. Both A/Prof Cheung and A/Prof Grigg (on the basis of clinicians' accounts of the consultation) were at a loss to explain how or why Mr ALJW would believe he was 'scheduled to die'.<sup>63</sup> A/Prof Grigg observed that no abnormal affect had been noted in Mr ALJW's medical record.<sup>64</sup>
45. Since December 2014, RCH and RMH have jointly convened an Annual Cardiology Transition Forum, to which patients undergoing transition in the following 12 months and their families are invited. The forum is attended by the Directors of Cardiology and Cardiac Liaison/Transition Nurses from both hospitals and provides general information about the RMH Congenital Cardiac Service and what to expect.<sup>65</sup>
46. The RCH operates Transition Clinics in conjunction with a Youth Mentor. The clinics are intended to be educational, providing patients due to transition to an adult service with skills and information about their own cardiac condition, history and treatment that will help them plan for and navigate the transition process and prepare them to access healthcare independently. Additional (psychological) support is available through family support groups

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<sup>59</sup> CB, Statements of A/Prof Cheung and A/Prof Grigg.

<sup>60</sup> Ibid.

<sup>61</sup> CB, Statement of A/Prof Grigg.

<sup>62</sup> CB, Statement of A/Prof Cheung.

<sup>63</sup> CB, Statements of A/Prof Cheung and A/Prof Grigg.

<sup>64</sup> CB, Statement of A/Prof Grigg.

<sup>65</sup> CB, Statements of A/Prof Cheung and A/Prof Grigg.



like HeartKids and Hearts4heart or through a formal referral for psychological counselling if necessary.<sup>66</sup>

47. In 2014 and 2015, RMH held a Fontan Education Day for patients in Australia and their families which provides an opportunity to inform them about Fontan follow-up, transition and research.<sup>67</sup>
48. A/Prof Grigg advised that the RMH is constantly trying to improve its transition processes through the above-mentioned regular education sessions and by endeavouring to secure increasing support for the Congenital Liaison Nurses so that they are the primary point of contact for transitioning patients, in conjunction with their counterparts at the RCH.<sup>68</sup>

## CONCLUSIONS

49. I find that Mr ALJW, late of North Road, Newport, died there between 15 and 21 September 2014 as a result of the combined effects of heroin toxicity and plastic bag asphyxia. I am satisfied by the available evidence that Mr ALJW intended to take his own life and that while there was nothing overt in his behaviour to suggest he was at particular risk of harming himself proximate to this death, it is tolerably clear that his perception that his long term prognosis was poor was a significant stressor contributing to his death.

## COMMENTS

Pursuant to section 67(3) of the *Coroners Act* 2008, I make the following comments connected with the death:

1. In its most recently published annual report, Fontan Registry notes that, on average, about 60 Fontan operations are performed each year in Australia and New Zealand. Almost all Fontan operations performed after 2000 were the extra-cardiac conduit procedure, a technique first used in the 1990s and the type Mr ALJW underwent as a child. The average age of the 1,466 Registry participants is 19.1 years, more than half of whom are aged 18 years or younger.<sup>69</sup> The importance and continuing relevance of optimal arrangements for the transfer of cardiac care from paediatric to adult health services is obvious.
2. Fontan Registry also reports post-Fontan survival rates, emphasising that survival of those with a Fontan circuit is much better than previously thought, particularly among individuals who underwent the two more recent versions of the Fontan operations (lateral tunnel and

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<sup>66</sup> CB, Statement of A/Prof Cheung.

<sup>67</sup> CB, Statement of A/Prof Grigg.

<sup>68</sup> CB, Statement of A/Prof Grigg.

<sup>69</sup> Australian & New Zealand Fontan Registry: Report 2015 (November 2016), available at <https://www.fontanregistry.com/annual-reports?lightbox=dataItem-iviqnmsg>.



extra-cardiac conduit). Moreover, predictions that Fontan circulation may deteriorate rapidly after an unknown number of years (leading to a sudden decrease in survival late after Fontan surgery) is apparently not borne out by data for a period 'as long as 30 years'.<sup>70</sup> However, 'survival statistics' – non-parametric statistics used to estimate the probability of surviving a given length of time – are complex and their significance likely interpreted differently by Fontan patients and researchers or clinicians.

3. Unsurprisingly, for many years academic and clinical literature about Fontan patients has focussed on refinement of the procedures, Fontan circuit functionality, post-Fontan cardiac care and interactions with other physical health conditions. In the last decade or so, however, researchers have started to undertake studies of Fontan patients' quality of life and, in particular, assessment of the relationship between congenital cardiac disease, mental health and emotional wellbeing.
4. Early indications from the available research suggests a higher incidence of depressed mood and anxiety disorders among adolescent and adult Fontan patients than their age-matched peers not having any congenital cardiac condition.<sup>71</sup> Patient-perceived health status and social support/adjustment were more predictive of depression and anxiety among Fontan patients than medical variables.<sup>72</sup> Suggestively, a pilot study of adults with congenital cardiac disease exhibiting no evidence of emotional or behavioural difficulties found that more than a third of these apparently 'well-adjusted' patients were experiencing a diagnosable psychiatric disorder and a little under a third showed signs of pathological emotional functioning, depression and anxiety being chief among the diagnosable disorders.<sup>73</sup>
5. These pioneering investigations highlight that clinicians should be alert for emotional difficulties – and the need for psychological intervention – among adult survivors of

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<sup>70</sup> Ibid and see also d'Udekem, Yves et al. 2014, 'Redefining Expectations of Long-Term Survival After the Fontan Procedure: Twenty-five years of follow-up from the Entire Population of Australia and New Zealand' *Circulation* 130: 32-38. I note that the longest period of follow-up for the most recent extra-cardiac conduit Fontan procedure was 13 years.

<sup>71</sup> De Maso DR. et al, 2017. 'Psychiatric Disorders in Adolescence with single ventricle congenital heart disease,' *Pediatrics* 139(3): 201. Cohen, M et al, 2007. 'Quality of life, depressed mood, and self-esteem in adolescents with heart disease,' *Psychosomatic Medicine* 69(4):313-318. Bromberg, J. et al, 2003. 'Depression and anxiety in adults with congenital heart disease: a pilot study' *Heart Lung* 32(2):105-110. Kovacs, AH. Et al, 2009. 'Depression and anxiety in adult congenital heart disease: predictors and prevalence,' *International Journal of Cardiology* 137(2):158-164. Pike, Nancy A. et al, 2011. 'Clinical Profile of the Adolescent/Adult Fontan Survivor', *Congenital Heart Disease* 6(1):9-17. Pike, Nancy A et al, 2012. 'Quality of Life, Health Status, and Depression: Comparisons between Adolescents and Adults after the Fontan Procedure with health counterparts,' *Journal of Cardiovascular Nursing* 27(6): 539-546.

<sup>72</sup> Pike, Nancy A. et al, 2011. 'Clinical Profile of the Adolescent/Adult Fontan Survivor', *Congenital Heart Disease* 6(1):9-17.

<sup>73</sup> Bromberg, J. et al, 2003. 'Depression and anxiety in adults with congenital heart disease: a pilot study' *Heart Lung* 32(2):105-110. Cohen, M et al, 2007. 'Quality of life, depressed mood, and self-esteem in adolescents with heart disease,' *Psychosomatic Medicine* 69(4):313-318. Kovacs, AH. Et al, 2009. 'Depression and anxiety in adult congenital heart disease: predictors and prevalence,' *International Journal of Cardiology* 137(2):158-164.

congenital heart disease and Fontan patients, even among those seemingly emotionally well-adjusted.<sup>74</sup> They also reinforce the need for all clinicians – cardiologists, general practitioners, psychologists and the like – to treat Fontan patients holistically assessing both physical symptoms and psychosocial concerns serially, and contemplating multiple risk factor intervention strategies that improve the physical and emotional health of Fontan survivors.<sup>75</sup>

6. I note that the Australian Commission on Safety and Quality in Healthcare's revision of the National Safety and Quality Health Services Standards (version 2) requires health services to have in place policies, procedures and training to manage the risks associated with recognising and responding to acute deterioration, including deterioration of mental health. The work undertaken by the Royal Children's Hospital and Royal Melbourne Hospital has gone some way towards achieving this standard.

## RECOMMENDATIONS

Pursuant to section 72(2) of the *Coroners Act* 2008, I make the following recommendations connected with the death:

1. That, as part of the initial decision to transition a patient to the Royal Melbourne Hospital, clinicians at the Royal Children's Hospital formally refer a child/young adult to a social worker who remains involved as a support throughout the transition period and until after the first appointment at the Royal Melbourne Hospital.
2. That the Royal Children's Hospital and the Royal Melbourne Hospital introduce the routine, serial administration of an age-appropriate screening tool that measures a child/young adult's capacity and resilience for events such as the transition between health services and the possible future outcomes from Fontan surgery, such as the Royal Children's Hospital's Adolescent Resilience Questionnaire.
3. That the Royal Melbourne Hospital require the Congenital Liaison Nurses to complete mental health training to improve their capacity to identify and respond to their patients' mental health issues, such as Mental Health First Aid training.
4. That the Royal Children's Hospital and Royal Melbourne Hospital review and, if necessary, change their care pathways and systems to ensure there is a focus of the emotional and psychological impacts of the Fontan surgery and its implications for patients' quality of life.

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<sup>74</sup> Bromberg, J. et al, 2003. 'Depression and anxiety in adults with congenital heart disease: a pilot study' *Heart Lung* 32(2):105-110.

<sup>75</sup> Pike, Nancy A. et al, 2011. 'Clinical Profile of the Adolescent/Adult Fontan Survivor', *Congenital Heart Disease* 6(1):9-17.

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

The family of Mr ALJW

Dr Haddad, The Clinic, Williamstown

Dr Chatfield, Wisdom Mind Institute

Director of Cardiology, Royal Children's Hospital

Director of Cardiology, Royal Melbourne Hospital

Legal Counsel, Royal Children's Hospital

Legal Counsel, Royal Melbourne Hospital/Melbourne Health

The Australian & New Zealand Fontan Registry

Executive Officer, Cardiothoracic Surgery, Royal Australasian College of Surgeons

Det Sen Const Olivia Dennison c/o OIC Williamstown Police

Signature:



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**PARESA ANTONIADIS SPANOS**

CORONER

Date: 21 September 2017



Cc: Manager, Coroners Prevention Unit