STATE CORONER'S COURT
OF NEW SOUTH WALES

Inquest:	Inquest into the death of Carney Schultz
Hearing dates:	13 February 2018 at Port Kembla
Date of findings:	16 February 2018
Place of findings:	NSW State Coroner's Court, Glebe
Findings of:	Magistrate Derek Lee, Deputy State Coroner
Catchwords:	CORONIAL LAW – cause and manner of death, epilepsy, midazolam, SUDEP, Outlook Drive group home at Figtree, epilepsy management plan, training of disability support workers, NDIS
File number:	2015/00118871
Representation:	Ms D Ward, Counsel Assisting, instructed by Ms J De Castro Lopo, Office of the General Counsel Mr T Davies for Ms G Schultz Mr M Lynch for the Department of Family and Community Services
Findings:	I find that Carney Shultz died on 21 April 2015 at Figtree, NSW. The cause of Carney's death was complications of epilepsy. Carney died from natural causes.

Recommendations:

To the Chief Executive Officer of the National Disability Insurance Agency:

I recommend that a copy of these findings be provided to the Chief Executive Officer of the National Disability Insurance Agency so that consideration can be given to:

(a) the identified shortcomings in the supported living services provided to Carney Schultz, and the lessons learned and improvements made as a result of her death; and

(b) the adoption of a multidisciplinary team approach to the drafting and implementation of appropriate Epilepsy Management Plans by supported living (group accommodation) disability service providers in the Illawarra Shoalhaven region.

To the Managing Director of the House With No Steps:

I recommend that a copy of these findings be provided to the Managing Director of the House With No Steps so that consideration can be given to:

(a) the identified shortcomings in the supported living services provided to Carney Schultz, and the lessons learned and improvements made as a result of her death; and

(b) the adoption of a multidisciplinary team approach to the drafting and implementation of appropriate Epilepsy Management Plans by supported living (group accommodation) disability service providers in the Illawarra Shoalhaven region.

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Introduction

1. In her 28 years of life Carney Schultz had defied medical opinion, overcome many challenges and proven many times, to those that did not know her, what her family had always known: that she was a fighter with a determined spirit. Despite the disabilities and medical conditions which she suffered from, Carney lived a fulfilling life and meaningful life and brought much joy to those around her. Sadly, that life ended suddenly and unexpectedly on 21 April 2015 at the group home where Carney was residing and being cared for by a number of disability support workers.

Why was an inquest held?

2. A Coroner's function and the purpose of an inquest are provided for by law as set out in the *Coroners Act 2009* (the Act). One of the primary functions of a Coroner is to investigate the circumstances surrounding a reportable death. This is done so that evidence may be gathered to allow a Coroner to fulfil his or her functions as provided for under the Act. A Coroner's primary function is to answer questions about the identity of the person who died, when and where they died, and what was the cause and the manner of their death. The manner of a person's death means the circumstances surrounding their death and the events leading up to it.

3. Following Carney's death a post-mortem examination was conducted by a forensic pathologist who later prepared an autopsy report. In that report the cause of Carney's death was recorded as being unascertained. As the cause of Carney's death had not been sufficiently disclosed an inquest was required to be held.[1] Furthermore, the circumstances surrounding Carney's death raised issues relating to the care that Carney was provided with. An inquest was also required to be held in order to examine and better understand the manner of Carney's death; what issues, if any, contributed to it; and whether these issues have broader implications for other members of our community living in situations similar to Carney's.

Carney's life

4. Coronial investigations and inquests are necessarily concerned with gathering and examining evidence that relates to the last period of a person's life. Sometimes that period encompasses weeks and days; at other times, because of the suddenness of a person's death, that period might be only minutes or seconds. Regardless of the length of these periods, voluminous amounts of documentary evidence are often gathered as part of the coronial investigation. However that evidence rarely tells us much about the person who died, their life, the way in which their death has impacted their family and friends, and what their loss means to those who loved and cared for that person, and knew them best. Therefore it is important to recognise the life of that person in some small, but hopefully meaningful, way.

5. Carney was born when her mother, Gail Schultz, was 34 weeks pregnant. Just two weeks earlier Ms Schultz had been told that Carney had a cerebral haemorrhage which would likely lead to brain damage at birth. Despite being advised to terminate the pregnancy Ms Schultz decided to give Carney the best chance of survival and continued the pregnancy. From this point on, and for the rest of Carney's life, Ms Schultz would be Carney's voice and would ensure that she gave Carney the best life possible.

[1] *Coroners Act 2009*, section 27(1)(d).

6. Carney was born with damage to her bowel and was cared for in an intensive care unit for the first few weeks of her life. However it was later discovered that Carney was experiencing intracranial pressure which required admission to hospital for further treatment. By the age of 14 months, Carney was diagnosed with cerebral palsy, hydrocephalus[2], paralysis down her left side, dislocated hips and poor vision.

7. Over the next few years Ms Schultz made arrangements for Carney to receive regular physiotherapy and occupational therapy at home. Carney progressed extremely well and by the age of 4 she started school, but still continued with her home therapy.

8. When Carney was about 5 years old she experienced her first seizure and was later diagnosed as suffering from tonic-clonic seizures.[3] Ms Schultz describes Carney's seizures as being unpredictable and inconsistent, both in their frequency and form.[4] As part of her care and treatment for her seizures Carney often received medication and was taken to hospital.

9. Over the subsequent years Ms Schultz continued to care for Carney at home with regular weekends of respite care. When Carney was about 10 years old she moved to a group home at Figtree. This is because, despite Ms Schultz's remarkable efforts, she was no longer able to provide the full-time care that Carney required. The nature of Carney's disabilities meant that she was completely dependent on others.

10. Despite the difficulties and challenges that Carney faced, she was always good natured and had a wonderful sense of humour. At the end of the evidence in the inquest, those present in the court were privileged to hear some heartfelt and moving words spoken by Carney's older sister. She highlighted Carney's innocence, and how her view of life and of those around her was always non-judgmental and pure. However, Carney's sister also spoke about Carney's mischievous nature, her infectious laughter, and how her smile could easily bring brightness and joy to the darkest of days and to the lives of others.

11. Carney had a love for music, which was a calming influence on her, and enjoyed dancing in her chair. She also enjoyed being on a trampoline, being in a spa bath and playing games and going out to dinner with her family. Carney delighted in being outdoors and visiting different places within her local community. Shopping was a favourite pastime of hers and she also loved to watch TV or DVDs with her housemates.

12. Carney had many wonderful personal traits and her determined spirit and spirit for life constantly reminded her mother and her sisters, Kelsey and Teagan, of important qualities such as tolerance, patience and acceptance, and also of the things that truly matter in life. To know that Carney's own life was cut short tragically and suddenly is extremely distressing. There is no doubt that Carney's qualities, her fighting spirit, her innocence, and memories of the joy that she brought to others will not easily be forgotten.

[2] Abnormal enlargement of the brain cavities caused by a build-up of cerebrospinal fluid.
[3] These types of seizures are often described as convulsions, and were formerly known as grand mal seizures. A person suffering from tonic-clonic seizures typically experiences loss of consciousness, stiffening of muscles (the tonic phase) and rhythmical jerking movements (the clonic phase).
[4] Exhibit 1, page 111A.

Background to the events of April 2015

13. At the time of her death Carney lived at a group home at 22 Outlook Drive, Figtree (**the Figtree home**). A group home is a typical suburban house in a local community which supports people with a disability who are unable to live independently or with their family. A group home is staffed by Disability Support Workers (**DSW**) who provide support and care 24 hours a day, 7 days a week to the home's residents (also known as clients).

14. At the time of Carney's death the Outlook Drive group home was operated by Ageing, Disability and Home Care (**ADHC**), which is part of the Department of Family and Community Services (**FACS**), and was one of a number of group homes in the Illawarra Shoalhaven District of FACS. Carney lived at the Figtree home with 3 other residents and the home was staffed with one team leader, 7 permanent DSWs and four casual DSWs.

15. Both casual and full-time DSWs worked at the Figtree home across 3 shifts: a morning shift from 6:30am to 2:30pm; an afternoon shift from 2:30pm to 10:30pm; and a night shift from 10:30pm to 6:30am. It was typical for two DSWs to be rostered on for the morning and afternoon shifts, but for only one DSW to be rostered on for the night shift.

What happened during the night of 20 April 2015?

16. Ms Shalisa Zattin was a casual DSW. On 21 April 2015 Ms Zattin was rostered to work a night shift at the Figtree home. Ms Zattin described the evening as "*a normal uneventful nightshift with all clients asleep*" at the start of her shift.[5] At 10:30pm Ms Zattin heard Carney vocalise loudly but then settle back to sleep shortly afterwards. At around 3:20am Ms Zattin heard light snoring coming from Carney's room followed by breathing which sounded heavier and more laboured. Ms Zattin then heard Carney's bed start to shake and recognised these sounds as being consistent with Carney having a seizure.

17. Ms Zattin went to Carney's room and turned on the light. She saw that Carney was not covered with any blankets and that her eyes were closed. Ms Zattin lifted up one of Carney's eyelids and saw that her eye was moving rapidly. Ms Zattin placed Carney in the recovery position, noting that about 90 seconds had passed by this time. Ms Zattin noted that Carney had sweat around her hairline and that her body was convulsing, but not as violently as she had seen during Carney's previous seizures.

18. Ms Zattin went to a nearby ensuite bathroom to dampen a face cloth. When she returned she saw that Carney's convulsions were less violent and that her breathing had slowed down. This lead Ms Zattin to believe that Carney was coming out of the seizure. Ms Zattin took Carney's pulse and noted it to be 75 to 80 beats per minute and she sat with Carney observing her for a further 2 minutes. During this time Ms Zattin saw Carney's body relax further and heard her breathing return to almost normal. Ms Zattin went to the kitchen to get a drink as she had been told by other staff that Carney was often thirsty following a seizure. When Ms Zattin returned she saw that Carney had rolled from her side onto her back, that her eyes were open and that she appeared alert. Ms Zattin sat Carney up and gave her the drink which Carney held independently and finished. By this time it was about 3:30am.

[5] Exhibit 1, page 88.

19. After Carney finished her drink Ms Zattin left her upright in bed with a bottle of water and the radio on. She left the room and returned about 10 minutes later and saw that Carney was still alert and relaxed. Ms Zattin lowered the bed so that Carney could get comfortable and fall back asleep, and then turned off the light and left the room.

20. Ms Zattin continued to check on Carney at approximately 30 minute intervals until the end of her shift. The remainder of the night was uneventful Ms Zattin documented that Carney had experienced a seizure which lasted 8 minutes in some records kept at the Figtree home.

21. After completing her documentation, Ms Zattin did one final round and noted that Carney was lying on her stomach, asleep. At the end of her shift Ms Zattin told Ms Lorraine Allen, one of the incoming morning shift DSWs, about Carney's seizure. Ms Allen asked if Ms Zattin had called Ms Schultz. Ms Zattin said that she had not, and that she had also not called an ambulance explaining that Carney's recovery had not been abnormal.[6]

What happened on the morning of 21 April 2015?

22. Trish Kenrose and Ms Allen were two full-time DSWs who worked at the Figtree home. They were rostered to work the morning shift on 21 April 2015. Shortly after signing on at 6:30am, Ms Allen went to Carney's room and saw her lying on her side and not covered with a blanket. Ms Allen stroked Carney's leg, felt that it was cold and covered Carney with a blanket.

23. As it was a Tuesday, Ms Kenrose and Ms Allen needed to arrange for the residents to be dressed and taken to their day placements. On this day Carney was scheduled to attend the House With No Steps at Balgownie. However, as Carney had suffered a seizure that morning the protocol at the Figtree home required that she have a day of recovery at home and not attend her day placement.

24. During the morning Ms Kenrose checked the Shift Changeover Checklist and saw that Ms Zattin had recorded that Carney had suffered an 8 minute seizure. Ms Kenrose asked Ms Allen if Carney had been given midazolam, a type of medication commonly used for the management of seizures. Ms Allen told Ms Kenrose that this had not occurred and so Ms Kenrose understood that Carney would still be able to receive midazolam as she could only receive it once in a 24 hour period. After being told that Carney had experienced a seizure Ms Kenrose was conscious of the possibility that Carney might experience a further seizure and remained close to Carney's room, ready to react to any noise from the room.[7]

25. At around 8:20am Ms Kenrose helped Ms Allen to see off two residents who left for their day placements with Ms Allen. Ms Kenrose went back inside and checked on Carney who was in bed, lying on her right side with her back to the door. The curtains in the room were drawn and the room itself was quite dark. Ms Kenrose placed her hand on Carney's back and brushed some hair out of Carney's eyes, feeling that she was warm to the touch. Ms Kenrose described Carney as being in "*the usual post seizure state*" but is uncertain whether she saw the rise and fall of Carney's chest as Ms Kenrose knew that Carney's breathing was usually shallow following a seizure.[8]

[6] Exhibit 1, page 91.
[7] Exhibit 1, page 83.
[8] Exhibit 1, page 81.

26. Ms Kenrose left Carney's room and went to the office to perform some administrative tasks. At 8:50am Ms Kenrose returned to Carney's room to check on her and decide whether to rouse Carney in order to administer her morning medication, or to allow her to continue recovering. Upon returning to the room Ms Kenrose saw that Carney was lying face down in her pillow.

27. Ms Kenrose immediately turned on the room light and rolled Carney onto her back. Ms Kenrose saw that Carney's face was blue in colour and attempted to feel for a pulse on Carney's neck. Before she could find one, Ms Kenrose decided to immediately begin cardiopulmonary resuscitation (**CPR**). After a number of compressions, Ms Kenrose ran to the office to call triple 0 and urgently request an ambulance. Ms Kenrose returned to Carney and continued CPR when the phone rang. Ms Kenrose answered the call (using a cordless phone) which was from an emergency despatcher. Ms Kenrose indicated that she was trained to give CPR and was told by the dispatcher that an ambulance was en route and to leave the house door open. Ms Kenrose continued with CPR, pausing only to open the front door, before returning to Carney and continuing CPR until paramedics arrived on scene.

28. Paramedics arrived at the Figtree home at about 9:13am. They saw that Carney had partial lividity in her right leg, but still felt warm to the touch. The paramedics commenced the cardiac arrest protocol and attempted for about 30 minutes to resuscitate Carney without success. At 9:45am Carney was, tragically, pronounced deceased.

What was the cause of Carney's death?

29. Following her death Carney was taken to the Forensic Medicine Unit in Wollongong. On 23 April 2015 post-mortem examinations in the form a CT (computed tomography) scan followed by an autopsy, were performed. Dr James Raleigh, a radiologist, reviewed the imaging from the CT scan and later prepared a report describing his findings. Dr Alex Olumbe, a forensic pathologist, performed the autopsy and also later prepared a report of the autopsy findings.

30. The reports of Dr Raleigh and Dr Olumbe both raised a number of possibilities as to the cause of Carney's death:

    (a) Firstly, in his report Dr Raleigh noted that there were findings consistent with recent subdural haematoma and a suspected recent small left subgaleal haematoma. These findings raised the possibility that Carney had suffered a traumatic closed head injury. However, following internal examination, Dr Olumbe found "*no significant subdural or subarachnoid haemorrhage*".[9]

    (b) Secondly, Dr Olumbe noted that there was a moderate amount of atherosclerosis[10] in the left anterior descending coronary artery. However, Dr Olumbe noted that the extent of this coronary artery disease was limited and that there was no history of exertion prior to Carney's death.

    (c) Thirdly, as Carney had been found lying face down in a pillow this raised the possibility of asphyxia during an unwitnessed seizure sometime between about 8:20am and 8:50am.

[9] Exhibit 1, page 15.
[10] A build-up of plaque made up of fat, calcium, cholesterol and other substances in artery walls.

However, Dr Olumbe found that nothing seen at autopsy supported an asphyxia mode of death.[11]

(d) Finally, due to Carney's history of epilepsy, the possibility of her death being classified as Sudden Unexpected Death in Epilepsy (**SUDEP**) was raised. But this was later excluded due to the evidence of coronary artery disease and because of the neurological changes[12] identified in the neuropathology examination. However, Dr Olumbe concluded that the neuropathology findings were consistent with Carney's clinical history and "*showed nothing which could account for the sudden death*".[13]

31. In his report Dr Olumbe ultimately concluded that the cause of Carney's death could not be ascertained. This was because, in Dr Olumbe's opinion, the evidence of coronary artery disease and the possibility of asphyxia both meant that either could have caused Carney's death. In the autopsy report Dr Olumbe did conclude that Carney's epilepsy, congenital hydrocephalus, severe developmental delay and coronary atherosclerosis were all significant conditions that contributed to Carney's death.

32. As part of the coronial investigation, clarification was sought regarding the extent of Carney's coronary artery disease. As Dr Olumbe was not available to clarify this aspect of the autopsy report, further opinion was sought from Dr Isabel Brouwer, the State-wide Clinical Director of the Department of Forensic Medicine. In a report dated 19 June 2017[14], Dr Brouwer noted that the extent of the coronary artery disease was described as being between "*moderate*" narrowing of the lumen (the opening) of the coronary artery (by Dr Olumbe), and "*moderately severe*" luminal narrowing (by Dr Anthony Ansford, another forensic pathologist, who completed the histology examination and finalisation of the autopsy report). Dr Brouwer also noted that neither pathologist allocated a percentage, which would usually be expected, to describe the extent of the luminal narrowing.

33. However, Dr Brouwer noted that whilst examination of the heart muscle showed mild myofibre hypertrophy[15], there was no evidence of acute or chronic ischaemic changes and that the heart weight was within normal reference range values. Dr Brouwer concluded that it was therefore "*difficult to comment on the extent to which the focal coronary artery atherosclerotic disease may have contributed*" to Carney's death.[16]

34. In the course of an investigation into Carney's death conducted by the NSW Ombudsman, a report was prepared by Associate Professor Ernest Somerville, a consultant neurologist. Associate Professor Somerville was asked to consider whether Carney's epilepsy had any causative role in her death. In his report Associate Professor Somerville concluded that the cause of death was "*unclear*".[17] Dr Somerville referred to the fact that Dr Olumbe had excluded Carney's death as meeting the definition for SUDEP as the post-mortem examination findings had raised the possibility of other potential causes of death, namely coronary artery disease or closed head injury.

[11] Exhibit 1, page 12.
[12] Exhibit 1, page 29.
[13] Exhibit 1, page 12.
[14] Exhibit 1, tab 24.
[15] Thickening of a portion of the heart resulting in the heart being less able to pump blood effectively.
[16] Exhibit 1, tab 24.
[17] Exhibit 1, tab 26, page 2.

35. However, Associate Professor Somerville pointed out (as noted above) that there were no neuropathological findings that would have directly caused Carney's death. Associate Professor Somerville also explained that even though Carney's death may not meet the strict definition of SUDEP, the mechanism of death could still be the same as for deaths which did meet the definition. In evidence during the inquest Associate Professor Somerville said that there is growing agreement amongst neurologists that the usual mechanism of death is the failure of a person to resume breathing, for reasons not understood, following a convulsive seizure during sleep. Associate Professor Somerville also noted that cardiac arrhythmia, airway obstruction and trauma due to a fall are other mechanisms of death.

36. In his report Associate Professor Somerville referred to the possibility that Carney may have experienced an unwitnessed seizure between about 8:20am (when she last checked on by Ms Kenrose) and 8:50am (when Ms Kenrose found her to be unresponsive). This is because on some occasions Carney was known to experience a cluster of seizures. Associate Professor Somerville thought that the possibility of a second unwitnessed seizure between about 8:20am and 8:30am was less likely as Ms Kenrose heard nothing from Carney's room in circumstances where Carney's seizures were usually accompanied by some noise. However, in evidence, Associate Professor Somerville acknowledged that if the other possible causes of death raised during the post-mortem examination were excluded, the possibility of Carney's death being due to complications of her epilepsy increased.

37. **CONCLUSION:** The possibility of traumatic head injury, coronary artery disease and asphyxia as being causes of Carney's death can all be excluded on the available evidence. Whilst the radiology report referred to suspected cerebral haematoma, internal examination confirmed the absence of any evidence of traumatic head injury. Similarly whilst some degree of atherosclerosis was noted at autopsy, there was no history of exertion prior to Carney's death (which would be expected in the event of sudden cardiac death) and no evidence of acute or chronic ischaemic cardiac changes. Finally, there was no evidence supporting an asphyxia mode of death.

38. The standard of proof in coronial proceedings means whether the available evidence allows for a conclusion to be reached on the balance of probabilities. Whilst the post-mortem examinations were unable to ascertain the cause of Carney's death to a level of clinical medical certainty, having regard to the circumstantial evidence I conclude that it is more probable than not that the cause of her death was due to complications of her epilepsy. However, the precise mechanism of Carney's death cannot be determined on the available evidence. I have reached this conclusion because all other possible causes of death raised during the post-mortem examination can be excluded, thereby making the probability of Carney's death being due to complications of her epilepsy more likely. Furthermore the possibility of Carney experiencing a second unwitnessed seizure sometime between 8:20am and 8:50am on 21 April 2015 is not entirely inconsistent with what is known about Carney's history of seizure activity. That is, most of Carney's seizures occurred early in the morning and whilst they were usually accompanied by noises, this was not always the case.[18]

[18] Exhibit 1, page 126.

How was Carney's epilepsy managed?

39. In general terms, Carney's epilepsy was managed collaboratively between a number of different people involved in her care: her neurologist, Dr Don Pryor; her GP, Dr Rene Dostal; the team leader at the Figtree home, Mr Shane Boland; the DSWs at the Figtree home; and of course, Carney's mother, Ms Schultz.

40. Before moving into the Figtree home Carney was often given Valium (diazepam) following a seizure.[19] According to Carney's Figtree home Client Profile, by September 2007 arrangements were in place for Ms Schultz to be notified in the event of any seizure, and for an ambulance to be called if Carney experienced a seizure which lasted for more than 5 minutes.[20]

41. In May 2010 Dr Pryor wrote to Dr Dostal advising that the administration of midazolam had recently been introduced in the treatment of Carney's seizures and that it had been a positive change.[21] Dr Pryor indicated that he had spoken to Ms Schultz and Mr Boland, and that they had both agreed to the use of buccal midazolam to shorten Carney's seizures and avoid the need to take Carney to hospital following a seizure. Part of the reason for this was to avoid the distress caused to Carney from waking up in a strange location (such as a hospital) after recovering from a seizure. As a result, Dr Pryor noted that ampules with 5mg of midazolam should be available for administration to Carney, and that he had helped to write a protocol for the Figtree home staff to administer midazolam when required.[22] It also appears that the use of midazolam would avoid the need for Valium to be used as it could not be administered by the Figtree home staff.

42. It appears that Dr Pryor's letter, and his discussion with Ms Schultz and Mr Boland, possibly led to the creation of two documents which were important for the management of Carney's epilepsy. The first document was Carney's PRN[23] Protocol for the administration of midazolam dated 23 September 2010 (**the PRN Protocol**). The PRN Protocol provided that the administration of midazolam was only prescribed for "*emergency treatment of seizures*".[24] It also stipulated that midazolam was to be administered via ampule into the buccal cavity, and that 000 was to be called if any seizure lasted more than 5 minutes. However, in my view, the PRN Protocol did not make clear if the period of 5 minutes applied to the entire duration of the seizure, or only to the duration of the seizure following the administration of midazolam.

43. The second document was a new Epilepsy Management Plan (**EMP**) for Carney. This EMP was dated February 2011 and appears to have been created following Dr Pryor's May 2010 letter. Having been signed by Mr Boland and other Figtree home staff in October 2104, it was in effect at the time of Carney's death and stipulated that:

    (a) If Carney experienced a seizure lasting longer than 3 minutes she was to be administered midazolam via ampule into the buccal cavity;

    (b) Only disability support workers trained in the administration of midazolam were able to administer it to Carney;

[19] Exhibit 1, page 111A.
[20] Exhibit 1, page 117.
[21] Exhibit 1, page 401.
[22] Exhibit 1, page 402.
[23] *Pro re nata*; as needed or as the situation requires.
[24] Exhibit 1, page 137.

(c) If Carney's seizure continued for a further 5 minutes after the administration of midazolam, an ambulance was to be called;

(d) If no midazolam was administered to Carney, and her seizure lasted longer than 5 minutes, an ambulance was to be called.

44. The EMP contained a section in which a description is given about the usual type of seizures that Carney experienced.[25] It noted that:

(a) Carney experienced tonic-clonic seizures which could vary in duration from 1 to 30 minutes;

(b) that the seizures were characterised by Carney sometimes making a groaning noise, accompanied by facial twitching, and upper body jerking;

(c) that Carney became non-verbal during her seizures and that she may drool, bite her tongue, experience laboured breathing, and show signs of cyanosis; and

(d) that most of Carney's seizures occurred in the early hours of the morning, that staff are usually alerted to the seizure knocking herself on the bedrails, and that Carney may go into *status epilepticus*[26] and have 2 or 3 seizures in a row.

45. It should be noted that, according to the EMP, the procedures described in paragraph 43 above was the prescribed response to a *usual* seizure (Section 3 of the EMP) as well as the prescribed emergency response to an *unusual* seizure (Section 4 of the EMP). It does not appear that the EMP draws any distinction between a usual seizure and an unusual seizure.

46. In May 2011 Dr Pryor again wrote to Dr Dostal noting that Carney had experienced 3 seizures in the previous 4 months, with each seizure lasting between 3 and 5 minutes, and that she had been given midazolam on each occasion. Dr Pryor noted that he had spoken to Carney's sister, Kelsey, and one of the Figtree home staff and indicated that he did not think it was necessary for Carney to be given midazolam with every seizure, only those that were "*prolonged*".[27] However, Dr Pryor noted that the administration of midazolam on 3 occasions in 4 months did not pose a problem and that the EMP would remain in effect.

47. On 28 August 2013 Dr Pryor wrote to Dr Dostal and noted that whilst Carney had been given midazolam about once a month for seizures lasting longer than 3 minutes, the midazolam appeared to have little effect in shortening the duration of Carney's seizures.[28] As a result Dr Pryor suggested amending the EMP to provide that midazolam should only be administered if Carney experienced a seizure lasting longer than 5 minutes. This amendment would, in turn, mean that an ambulance was to be called if either the seizure continued for a further 7 minutes following the administration of midazolam, or if the seizure lasted 7 minutes without midazolam being administered at all. Dr Pryor asked Dr Dostal to help the Figtree staff to make the proposed amendments to Carney's EMP and to send it to him to countersign.

[25] Exhibit 1, page 126.
[26] A seizure lasting longer than 5 minutes, or recurrent seizures with in intervening period of neurological recovery.
[27] Exhibit 1, page 404.
[28] Exhibit 1, page 409.

48. Despite this request it appears that, for reasons unknown, no amendment was ever made to Carney's EMP. In any event, in April 2014 Dr Pryor again wrote to Dr Dostal noting that Carney's epilepsy control over the previous 12 months had been as good as it had ever been and that midazolam had been rarely used. On this basis Dr Pryor indicated his view that Carney's EMP should remain unchanged.

49. In the same April 2014 letter Dr Pryor suggested that Carney attend for further neurological review in 6 months; that is, around October 2014. There is no evidence that this review ever took place. Despite the letter indicating that a copy of it had been sent to Mr Boland, in evidence Mr Boland said that he could not explain why the suggested review did not occur.

50. Carney's Client Profile[29] dated September 2007 provided that in the event that one of Carney's seizures resulted in an ambulance being called, Ms Schultz was also to be notified. Somewhat in contrast, the Figtree home Emergency procedures protocol for Carney[30], first implemented in August 2007 and last reviewed in September 2014, provided that if an ambulance was called *either* Ms Schultz *or* Carney's sisters were to be notified. Despite this inconsistency it appears that it was accepted and understood practice amongst staff in the Figtree home that if Carney's seizure led to an ambulance being called, Ms Schultz was to be notified.

51. **CONCLUSION:** A number of documents relevant to the management of Carney's epilepsy appear to contain inconsistencies. For example, Carney's PRN Protocol for the administration of midazolam dated 23 September 2010 did not stipulate if the requirement for an ambulance to be called for any seizure lasting more than 5 minutes applied to the entire duration of the seizure of the seizure, or only for the duration following the administration of midazolam. However, given that the EMP is dated February 2011 and signed by Mr Boland and a number of DSW in October 2014, it would appear that the EMP superseded the PRN Protocol for midazolam.

52. Further, even though Dr Pryor in correspondence to Dr Dostal in August 2013 raised the possibility of amending Carney's EMP, in effect to provide for an extension of 2 minutes before midazolam was administered and an ambulance called, there is no evidence that this suggested amendment was ever put into effect. The reason for this cannot be determined on the available evidence as Mr Boland had no recollection of ever seeing Dr Pryor's letter, despite the letter indicating that a copy had been provided to him.

53. I therefore conclude that as at 21 April 2105 compliance with Carney's EMP required that if she experienced a seizure of more than 3 minutes she was to be administered midazolam by a DSW trained in its administration. If the seizure either lasted 5 minutes without the administration of midazolam, or if it continued for a further 5 minutes following its administration, then an ambulance was to be called. Despite there being an inconsistency in the Figtree home documentary records, it was accepted practice that in the event of an ambulance being called in response to one of Carney's seizures, Ms Schultz was to be notified.

54. Finally, Carney was due to attend a neurological review in around October 2014. There is no evidence that this ever took place despite notification being apparently provided to Mr Boland. The available evidence does not adequately explain why the review did not occur. However it

[29] Exhibit 1, page 117.
[30] Exhibit 1, page 144.

does not appear that the absence of review contributed to the events of 21 April 2015 or to Carney's death.

Was Carney's Epilepsy Management Plan complied with on 21 April 2015?

55. The answer to this question depends on the duration of Carney's seizure, about which there is conflicting evidence. The duration of the seizure is recorded as lasting 8 minutes in a number of contemporaneous documents:

    (a) In Carney's Individual Client report which is required to be competed each day by a Figtree home DSW for each of the 3 shifts, Ms Zattin made the following entry for the night shift: "*Carney asleep on arrival. Approx. 0320 Carney had a seizure lasting 8+ minutes. Made comfortable, had a drink, long laboured recovery. Very drowsy & heavy headed*".[31]

    (b) In the Staff Communication Book entry for 20 April 2015 under the heading, "*Events*", Ms Zattin also wrote the following: "*Carney had a 8+ minute seizure, groaning, thrashing, bit her tongue so she dribbled blood. Kept comfortable and monitored*".[32]

    (c) In the Shift Changeover Checklist under the heading, "*Urgent Matter Alert*", Ms Zattin also wrote: "*Carney 8+ minute seizure 0330. Home today*".[33]

56. It should be noted that it appears that Ms Zattin was also required to record the seizure in 3 other documents: Section 8 of Carney's EMP titled "*Observation and Description of Seizures*"[34], in Seizure Charts attached to the EMP[35], and in the PRN medication chart for midazolam[36] (if administered). However, there is no evidence that Ms Zattin recorded the seizure in Carney's EMP, and there was no requirement for it to be recorded in the PRN medication chart for midazolam as it was not administered.

57. According to Ms Allen, she also recalls Ms Zattin telling her during the shift changeover that Carney's seizure lasted "*about 8 minutes*".[37] Ms Zattin said that she marked the end of Carney's seizure on 21 April 2015 to be at the point that Carney "*appeared lucid and alert and capable of holding her own drink*".[38] Ms Zattin went on to explain that she included this recovery period in the timing of Carney's seizure as she "*wanted to be assured that [Carney] was back to herself*".[39]

58. It appears that the possibility that Carney's seizure may not have lasted 8 minutes was first raised in a statement dated 30 April 2015 which Ms Zattin made to the police as part of the coronial investigation. In that statement Ms Zattin said that since Carney's death she had spoken to other DSWs and been advised that a seizure ends "*at the point at which the shaking stops*".[40] Ms Zattin went on to explain that if she had applied this timing to Carney's seizure on the morning of 21 April 2015 then she estimated that Carney's seizure lasted approximate 4

[31] Exhibit 1, page 267.
[32] Exhibit 1, page 284.
[33] Exhibit 1, page 398.
[34] Exhibit 1, tab 27, page 240.
[35] Exhibit 1, tab 16.
[36] Exhibit 1, page 143.
[37] Exhibit 1, page 100.
[38] Exhibit 1, page 89.
[39] Ibid.
[40] Ibid.

minutes. In another statement dated 6 May 2015[41], provided by Ms Zattin in connection with a separate independent investigation, she again referred to the end of a seizure being signalled by the end of the convulsive stage of the seizure. Ms Zattin went on to explain that Carney had not been convulsing for 8 minutes and that the seizure therefore lasted "*only around four minutes*".[42]

59. Ms Zattin explained that she had never been trained or advised how to measure the duration of a seizure and specifically, when the seizure ends.[43] This appears to have been a common issue amongst the Figtree home staff. Ms Allen also said that she had never received any training on this issue either and that it was only her "*understanding*" that the end of a seizure is marked by the cessation of convulsions.[44] Another DSW, Debra Burford, also confirmed that the Figtree home staff had not been trained regarding how to measure the duration of a seizure and that she was only aware of how to do so because of her background in nursing.[45] Mr Boland confirmed that he has never trained any staff member, nor has any staff member ever received training, regarding how to measure how long a seizure lasts.[46] He acknowledged that "*the end of a seizure is perhaps not so easily defined for Carney as the laboured breathing can continue and may [sic] stay in an altered state of consciousness and even have secondary/residual twitching*".[47] However, in evidence Mr Boland said that, despite the absence of relevant training, he had never received any report from a DSW at the Figtree home indicating that there was any confusion regarding how to accurately time the duration of a seizure.

60. In evidence Associate Professor Somerville was asked about the timing of seizures. He explained that even in clinical practice the timing of a seizure is difficult when there is no clear demarcation from an observational point of view. However Associate Professor Somerville indicated that for a seizure involving convulsions, the end of a seizure could easily be recognised by the end of the convulsions.

61. As Ms Zattin was not trained to administer midazolam the only significance of the duration of Carney's seizure is whether it was longer than 5 minutes, meaning that an ambulance should have been called. In his report Associate Professor Somerville concluded that there was no causative connection between the failure to call an ambulance on 21 April 2015 and Carney's death. Associate Professor Somerville explained that even if an ambulance had been called it is likely that because Carney's seizure had ended by the time of the expected arrival of the ambulance, and she had experienced no complications (such as trauma or aspiration), that the attending paramedics would not have administered any medication to her or transported her to hospital. In evidence Associate Professor Somerville did acknowledge that if Carney had been taken to hospital, and was therefore in hospital between 8:20am and 8:50am on 21 April 2015, then it is possible that any adverse event which Carney experienced during this period of time may have been observed by clinical staff at hospital. It follows that such observation may have in turn allowed for an appropriate clinical response to such an event.

62. **CONCLUSION:** At the time of Carney's death, Ms Zattin, and other DSWs at the Figtree home, had not been provided with training or education in relation to how to time the duration of a seizure. While it appears that no DSW ever raised the absence of training or education as an issue, this

[41] Ms Zattin's statement is signed "06.05.14". This is clearly an error given that the date precedes Carney's death. The front page of the statement contains what appears to be the correct date of 6 May 2015.
[42] Exhibit 1, page 223.
[43] Exhibit 1, page 89.
[44] Exhibit 1, page 99.
[45] Exhibit 1, page 211.
[46] Exhibit 1, page 95.
[47] Exhibit 1, page 94.

does not necessarily mean that all of the DSW were confident in how to accurately measure the duration of a seizure, or capable of accurately doing so. The evidence establishes that one DSW, Ms Burford, only had such knowledge because of her previous training and experience in nursing.

63. Although the contemporaneous documentary evidence all record the seizure as lasting at least 8 minutes, Ms Zattin's explanation that her timing of 8 minutes included recovery time following the end of convulsions is not implausible. This is particularly so when consideration is given to the fact that both Ms Burford[48] and Ms Schultz[49] state that they had never known Carney to have a seizure lasting 8 minutes before. It also seems to be supported by the fact that according to Carney's Individual Client Report she experienced 6 recorded seizures[50] between 1 January 2015 and 20 April 2015, lasting from 2 minutes 15 seconds up to 5+ minutes.[51]

64. I therefore conclude that it is more probable than not that Carney's seizure on 21 April 2015 ended when her convulsions ceased after approximately 4 minutes. This in turn means that under Carney's EMP the 5 minute duration mark requiring the calling of an ambulance would not have been triggered. Even if there is some doubt about whether Carney's seizure lasted at least 5 minutes, thereby requiring an ambulance to be called, the expert evidence establishes that there is no direct connection between the absence of paramedic attendance and Carney's death. Whilst it is possible to speculate whether the attendance of paramedics would have resulted in Carney's hospitalisation, and whether admission to hospital would have made observation of an adverse event, and response to it, between 8:20am and 8:50am more likely, there is no conclusive evidence that this would have altered the outcome for Carney.

Why was an ambulance not called on 21 April 2015?

65. Notwithstanding the conclusions reached above, the fact remains that in the early hours of the morning on 21 April 2015 Ms Zattin believed that Carney had suffered a seizure lasting at least minutes. Ms Zattin's revised estimate of Carney suffering a 4 minute seizure only appears to have been given after Ms Burford called Ms Zattin sometime between 21 April 2015 and 30 April 2015, when Ms Zattin made her statement to the police.[52] During this call Ms Burford explained to Ms Zattin the correct way to measure the end of a seizure. If Ms Zattin believed on 21 April 2014 that Carney had suffered an 8 minute seizure this meant that, in accordance with the EMP, she was required to call an ambulance.

66. Ms Zattin explained that she did not call an ambulance or Carney's mother for two reasons.[53] Firstly, Ms Zattin did not think that the seizure was severe. Ms Zattin noted that Carney recovered quickly, and that her recovery was less difficult and more rapid than an earlier seizure on 14 January 2015[54] which Ms Zattin had also witnessed. Given the length of time it would take for an ambulance to arrive, Ms Zattin thought it was futile as Carney had recovered so well.

[48] Exhibit 1, page 211.
[49] Exhibit 1, page 111A at [11].
[50] On 14 January 2015, 10 February 2015, 14 March 2015, 20 March 2015, 27 March 2015, and 9 April 2015.
[51] Exhibit 1, tab 13.
[52] Exhibit 1, page 211.
[53] Exhibit 1, pages 89, 90.
[54] Although Ms Zattin in her statement thought that this incident occurred sometime in March 2015, a review of Carney's client report log book indicates that the only seizure recorded by Ms Zattin between 1 January 2015 and 19 April 2015 occurred on 14 January 2015: Exhibit 1, page 166.

67. Secondly, Ms Zattin said that the aftermath of the seizure on 14 January 2015 also influenced her decision to not call an ambulance. This incident is described in more detail below.

68. Ms Zattin was working by herself on a night shift on 14 January 2015. At around 5:50am Ms Zattin was performing a final check before the end of shift which involved going into each residents' room to check whether they were asleep and comfortable. Whilst in a bedroom next to Carney's Ms Zattin heard Carney breathing heavily and hoarsely. Ms Zattin went to Carney's room and saw that Carney's body was rigid and shaking considerably in what Ms Zattin described as a convulsion.[55] Ms Zattin saw that Carney's head was in a fixed position to her right and that Carney's lips were blue with blood coming from the right side of her mouth. Ms Zattin placed Carney in the recovery position (on her right side with her left arm across her body) and saw from a clock above Carney's bed that Carney had been experiencing a seizure for 30 to 45 seconds.

69. Ms Zattin left the room to retrieve Carney's Epilepsy Management Plan and the staff phone list. When Ms Zattin returned to the room she saw that Carney was still in a seizure with her breathing heavy and laboured. Ms Zattin rang one of the incoming DSWs, Ms Burford, for advice. Ms Burford told Ms Zattin that she could not offer any advice as she could not physically see Carney's seizure but told Ms Zattin that if she was unsure about what to do she should call for an ambulance. Ms Burford also told Ms Zattin to call the on call manager and Carney's mother.

70. Ms Zattin ended the call and, because more than 3 minutes had passed since the start of Carney's seizure, decided to call triple 0. The dispatcher told Ms Zattin to keep monitoring Carney's breathing and that an ambulance would be arriving from Oak Flats. After the call Ms Zattin saw that Carney appeared to be recovering from the seizure as colour was returning to her lips and her breathing sounded more relaxed.[56] Ms Zattin placed her hand on Carney's back and Carney appeared to acknowledge this by looking at Ms Zattin rather than having a fixed vacant stare as she had during the seizure. Ms Zattin then rang the on call manager to advise them of what had unfolded and the manager advised Ms Zattin to call Carney's mother.

71. Ms Zattin called Ms Schultz and informed her that Carney was recovering from a seizure and that an ambulance had been called. According to Ms Zattin Ms Schultz's tone was abrupt and aggressive and she asked Ms Zattin why she had called for an ambulance. Ms Zattin explained that she had done so because Carney's initial convulsions had appeared quite violent and because she had seen blood coming from Carney's mouth. Ms Schultz asked if Carney had been given midazolam and Ms Zattin told her that she had not been trained to administer it. Ms Schultz indicated that she may attend to check on Carney and asked to be kept updated regarding the outcome of the ambulance attendance.

72. Ms Zattin remained in Carney's room with the phone until about 6:10am. At around this time one of the morning staff, Angela Taylor, arrived. Ms Taylor asked Ms Zattin why she had called for an ambulance. Ms Zattin described Carney's seizure and Ms Taylor told Ms Zattin that this was a normal seizure for Carney. Ms Zattin said that Ms Taylor's tone of voice and body language gave her the impression that she had overreacted by calling the ambulance.[57] After the paramedics arrived they assessed Carney and were happy with her recovery.

[55] Exhibit 1, page 86.
[56] Exhibit 1, page 87.
[57] Ibid.

73. Ms Zattin believed that other staff members thought that she overreacted to the seizure on 14 January 2015, and Ms Schultz's perceived hostile response to this incident, influenced Ms Zattin's decision to not call an ambulance on 21 April 2015. Ms Zattin acknowledged that in hindsight it would have been better if she had followed the established protocol.[58]

74. **CONCLUSION:** Ms Zattin's experience of one of Carney's earlier seizures on 19 January 2015 influenced her decision to not call an ambulance on 21 April 2015. Ms Zattin's perception that Ms Schultz was critical of her actions on 19 January 2015, and Ms Zattin's perception that other staff at the Figtree home believed she had overreacted, were clearly the motivating factors behind her inaction. It should be made clear that Ms Zattin's descriptions of the reactions of Ms Schultz and other DSWs are based on Ms Zattin's *perceptions* alone. It is not necessary, and not possible on the available evidence, to reach any conclusion about whether Ms Zattin's perceptions were unfounded or not. This is because Ms Zattin herself has acknowledged that, with the benefit of hindsight, she should have followed the procedure mandated by the EMP and called for an ambulance.

Was appropriate and adequate training relating to Carney's care provided to the Figtree home disability support workers?

75. The evidence available to the inquest indicated that the appropriateness and adequacy of training of DSWs was relevant to 3 aspects of Carney's care: the induction of new DSWs; training DSWs in the administration of midazolam, and training DSWs in relation to how to accurately time the duration of a seizure. As the third issue has already been discussed above, I propose to only consider the first two issues below.

76. In relation to the first issue Mr Boland said that the relevant Figtree home protocols and procedures (such as the EMP) relevant to the home's clients are "*overviewed*" during the induction of a new DSW.[59] The induction process is conducted by Mr Boland and typically involves a new DSW shadowing Mr Boland and another DSW for about 4 hours. During this period the medical histories and highest priority needs of each resident are discussed with the new DSW. Mr Boland described the amount of information given to a new DSW to be "*overwhelming and almost impossible*" for them to fully recall.[60] As a result new DSWs are provided with active files and medical requirements for each resident and asked to read these documents when time permits.

77. In evidence Mr Boland agreed that at the time of Carney's death the Orientation to Unit booklet[61] provided to all new DSWs as part of the induction process was a lengthy document covering a broad range of topics. In addition, incoming DSWs were required to read individual Client Profiles, Current Health Care Plans, and Current Protocols for all clients that they would be caring for. Mr Boland acknowledged that as at April 2015 there were no guidelines to indicate when a new DSW would be ready for a solo shift, with that question mainly being determined by when an individual DSW felt comfortable in doing so. Mr Boland also acknowledged that there was no verification process to ensure that a new DSW had received sufficient opportunity to read and adequately comprehend all relevant information relating to clients of the Figtree home prior to being rostered to work a solo shift. Finally, Mr Boland agreed that presently the

[58] Exhibit 1, page 89.
[59] Exhibit 1, page 95.
[60] Ibid.
[61] Exhibit 1, page 27.

situation could still arise where an incoming DSW could complete their induction and be rostered to work a solo shift without reading and comprehending all information relevant to a client's care.

78. Some of these matters were explored in evidence with Helen Fuller, the Senior Manager, Accommodation and Respite Services, ADHC, in the Illawarra Shoalhaven and Southern NSW District. At the time of Carney's death Ms Fuller held an executive-level managerial role in relation to the operation of the Figtree home, and other group homes in the Illawarra Shoalhaven region. Ms Fuller explained that in 2015 and presently, if an incoming DSW requested additional time to allow them to read a client's individual file they could be granted access to additional shifts and rostered accordingly to allow them to do so. Notwithstanding this, Ms Fuller expressed concern at the possibility referred to by Mr Boland of staff being rostered to work a solo shift without having full knowledge of all of a client's individual care needs.

79. In his statement Mr Boland noted that there are always two staff members working during the morning and afternoon shift, and that there is usually one staff member working solo during the night shift. Mr Boland acknowledged that at the time of Carney's death DSWs working a solo shift were often not trained in the administration of midazolam to Carney. Instead, it appears that reliance was placed on what Mr Boland described as a "*backup procedure*" in accordance with Carney's EMP where an ambulance is called for any seizure lasting more than 5 minutes.[62]

80. It should be noted that in the 20 April 2015 entry in the staff communication book, Ms Zattin wrote "**Shane – could you please organise me so [sic] medazolan [sic] training*".[63] This was not the first occasion proximate to Carney's death where a DSW had requested training in the administration of midazolam.

81. On 5 March 2015 Nicole Souris, another DSW at the Figtree home, sent an email to Mr Boland asking for arrangements to be made for her to receive training in the administration of midazolam.[64] In her email, Ms Souris specifically noted her concern about Carney having a seizure when Ms Souris was rostered to work alone. In response Mr Boland sent an email on 13 March 2015 to Ms Jentina Van-Vuuren-Whildon (Mr Boland's acting Coordinator) asking if training for midazolam administration had been planned for any of the other group homes in the District. Ms Van Vuuren-Whildon forwarded the request to other Coordinators in Accommodation and Respite but was advised that no training was planned. Ms Van Vuuren-Whildon ceased in her acting role on 30 March 2015 and when the substantive position holder, Ms Bianca Jahn, resumed her role she was not told about the request from Mr Boland and Ms Van Vuuren-Whildon.

82. In her statement, Ms Fuller acknowledged that this was a breakdown in communication in relation to provision of training and that Ms Souris's request for training should have been followed up with Ms Jahn. Ms Fuller also acknowledged that training for casual staff at the time of Carney's death "*was not as accessible or as streamlined as current practices*" and that there was a culture within the Figtree home, and other group homes, "*for casual staff members to not be included in team meetings and communications*".[65]

[62] Exhibit 1, page 95.
[63] Exhibit 1, page 284.
[64] Exhibit 1, tab 27, page 123.
[65] Exhibit 1, tab 27 at [52].

83. **CONCLUSION:** Training of disability support workers at the time of Carney's death was less than optimal in certain respects. Whilst the evidence establishes that an overall good quality of care was generally provided to Carney, deficiencies in training meant that there was the possibility of adverse outcomes. Specifically, despite opportunities being available for newly inducted DSWs to be afforded additional shifts to ensure that they had understood all relevant information relating to a resident's care, it appears that these opportunities were not utilised in at least Ms Zattin's case, and probably others. Further, although these opportunities existed, there was no verification to ensure that DSWs had fully acquainted themselves with all relevant information relating to a resident's care. It also appears that casual DSWs were not afforded the same training opportunities as full-time staff, in particular in relation to administration of midazolam. This lead to potentially unsafe care practice where staff untrained in the administration staff were rostered by themselves on night shifts, a period during which it was well known that Carney frequently experienced seizures.

Have any systemic changes and improvements been made since Carney's death?

84. Prior to Carney's death all group home staff in the Illawarra Shoalhaven District were required, at a minimum, to undertake mandatory training in first aid, CPR and manual handling. At the time of Carney's death it was not compulsory for all staff working in a group home with a client who was prescribed midazolam to be trained in the administration of midazolam.

85. However, evidence provided from Ms Fuller confirmed that since June 2015 a number of changes have been introduced to address this issue, and others. A summary of the most relevant changes is set out below:

    (a) Compulsory training was introduced to ensure that all DSWs working in a group home with a client who required midazolam were trained to administer it. This training is provided to all new group home staff, both permanent and casual, as part of their induction. If, due to unforeseeable circumstances, a staff member has not received midazolam training then that staff member is not to be rostered on a shift alone.[66]

    (b) A change in culture within group homes since 2015 has resulted in directions that all casual staff are to be included in all communications as well as all team meetings.[67]

    (c) As part of the induction process, new staff members are required to sign an acknowledgment indicating that they have read all client files and client support plans for a group homes in which they work.[68]

    (d) Previously, there was a requirement for DSWs to record, in up to six locations, the fact that a client such as Carney had experienced a seizure: the Individual Client Report, the Staff Communication book, the Shift Changeover Checklist, the PRN medication chart, and the Seizure Chart and *Observation and Description of Seizure* Section contained in the EMP. A review of some of Carney's past seizure episodes revealed evidence of inconsistent record keeping with seizures recorded in some documents, but not others. In order to reduce confusion in documenting and recording seizures, changes were implemented requiring all staff to record all seizure activity in a client's EMP. The EMP is in turn monitored by the

[66] Exhibit 1, tab 27 at [65], [66].
[67] Exhibit 1, tab 27 at [52].
[68] Exhibit 1, tab 27 at [93].

Continuous Improvement Tool, which requires that quarterly reviews be undertaken for all support and medical plans for group home residents.[69]

86. **CONCLUSION:** Changes implemented by FACS in the Illawarra Shoalhaven District have led to an improvement in the quality of care for group home residents, particularly for those residents who suffer from epilepsy. Training in the administration of midazolam is now mandatory for all DSWs working in group homes with clients requiring midazolam. Steps have also been taken to ensure that DSWs fully understand the individual needs of their clients and that DSWs not trained in the administration of midazolam are not rostered on a shift alone.

Should any recommendations be made?

87. From a Coroner's perspective, the power to make recommendations which might lead to improvements in public health and safety is an extremely important one. This power is provided for by section 82 of the Act. Recommendations in relation to any matter connected with a person's death may be made if a Coroner considers them to be necessary or desirable.

88. The coronial investigation into the death of a person is one that, by its very nature, occasions grief and trauma to that person's family. The emotional toll that such an investigation, and any resulting inquest, places on the family of a deceased person is enormous. A coronial investigation seeks to identify whether there have been any shortcomings, whether by an individual or an organisation, with respect to any matter connected with a person's death. It seeks to identify shortcomings not for the purpose of assigning blame or fault but, rather, so that lessons can be learnt from such shortcomings and so that, hopefully, these shortcomings are not repeated in the future. If families must re-live painful and distressing memories that an inquest brings with it then, where possible, there should be hope for some positive outcome. The recommendations made by Coroners are made with the hope that they will lead to some positive outcome by improving general public health and safety.

89. The systemic improvements made by FACS since Carney's death are welcome and have led to an improvement in the model of care in group homes in certain areas. However, the evidence at inquest identified other areas of potential improvement. In particular, Associate Professor highlighted two areas:

    (a) Firstly, he described Carney's EMP as being unsatisfactory. This is because it was too long and contained unnecessary information. In Associate Professor Somerville's opinion it needed to be shortened and simplified so that relevant information (such as the description of the type of seizures which Carney suffered from) could be readily located. Furthermore, he noted that the EMP contained inaccurate and incomplete recording of the medication and dosages prescribed to Carney. By way of example. Associate Professor Somerville noted that if Carney were to be hospitalised and the EMP taken to hospital with her, it would convey inaccurate information regarding Carney's medication regime.

    (b) Secondly, Associate Professor Somerville highlighted the need for a multidisciplinary approach – amongst treating neurologists, GPs, clinical nurse consultants, group home managers, and DSWs – to develop an EMP that appropriately addressed issues such as dispensation of medication and neurological follow up.

[69] Exhibit 1, tab 27 at [66], [79].

90. Ordinarily, recommendations to address such areas of improvement would be made to the government department or Minister with ultimate oversight of the operation of group homes, such as the Figtree home, in the Illawarra Shoalhaven District (**the District**). However, the inquest learnt that in October 2017 the operation and management of almost all of the group homes in this District was transferred from FACS to the non-government sector. This occurred as part of the NSW Government's overall transfer of its disability services to the non-government sector to support the Australia-wide delivery of the National Disability Insurance Scheme (**NDIS**). Presently, only two group homes in the District are operated by FACS, with transfer of these homes to the non-government sector to be completed by June 2018. Specifically, the Figtree home is now operated by the House With No Steps, a non-government disability service provider.

91. In evidence Ms Fuller expressed some uncertainty regarding what safety framework will be in place in the future to ensure that the systemic improvements made by FACS since Carney's death would be subject to regular oversight and review. Ms Fuller explained that to her knowledge, FACS will have no role in establishing, and ensuring the continuance of, any such safety framework.

92. **CONCLUSION:** In such circumstances it seems that there is a degree of uncertainty regarding future clinical governance as it relates to group home clients in the District, and in particular those clients who suffer from epilepsy. Ms Fuller in evidence indicated that whilst disability service providers in the non-government sector might duplicate systems, procedures and protocols, that have been implemented by FACS, they are not required to do so and may well develop their own systems. If this is the case then the lessons learned from Carney's death can only serve to inform those responsible now, and in the future, for overall oversight to ensure that other clients who suffer from epilepsy are provided with adequate and appropriate care. Further, it is apparent from the evidence of Associate Professor Somerville that there is still scope for improvement. Having regard to these matters, in my view it is both necessary and desirable for the following recommendations to be made.

93. **RECOMMENDATION 1**: I recommend that a copy of these findings be provided to the Chief Executive Officer of the National Disability Insurance Agency so that consideration can be given to: (a) the identified shortcomings in the supported living services provided to Carney Schultz, and the lessons learned and improvements made as a result of her death; and (b) the adoption of a multidisciplinary team approach to the drafting and implementation of appropriate Epilepsy Management Plans by supported living (group accommodation) disability service providers in the Illawarra Shoalhaven region.

94. **RECOMMENDATION 2**: I recommend that a copy of these findings be provided to the Managing Director of the House With No Steps so that consideration can be given to: (a) the identified shortcomings in the supported living services provided to Carney Schultz, and the lessons learned and improvements made as a result of her death; and (b) the adoption of a multidisciplinary team approach to the drafting and implementation of appropriate Epilepsy Management Plans by supported living (group accommodation) disability service providers in the Illawarra Shoalhaven region.

Findings

95. Before turning to the findings that I am required to make, I would like to acknowledge and thank Ms Donna Ward, Counsel Assisting, and her instructing solicitor, Ms Janet De Castro Lopo. I am extremely grateful, not only for their tireless efforts and valuable assistance both before and during the inquest, but also for the compassion and empathy that they have shown throughout the coronial investigation and inquest process. I also thank Senior Constable Joanne Isaac for her efforts during the investigation into Carney's death and for compiling the initial brief of evidence.

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

Identity
The person who died was Carney Schultz.

Date of death
Carney died on 21 April 2015.

Place of death
Carney died at Figtree NSW 2525.

Cause of death
Carney died from complications of epilepsy.

Manner of death
Carney died from natural causes.

Epilogue

97. Throughout her life Carney constantly showed her remarkable resilience and proved time and again that she was a fighter. There is no doubt that her spirit will always remain with her mother and her sisters.

98. On behalf of the Coroner's Court, and the counsel assisting team, I offer my deepest and most respectful condolences to Ms Schultz, Kelsey, Teagan and all of Carney's family and friends for their tragic loss.

99. I close this inquest.

Magistrate Derek Lee
Deputy State Coroner
16 February 2018
NSW State Coroner's Court, Glebe