Coroners Act 1996
[Section 26(1)]

Western *Australia*

RECORD OF INVESTIGATION INTO DEATH

Ref: 16 /18

I, Sarah Helen Linton, Coroner, having investigated the death of ***Pamella Leslie REES*** *with an inquest held at the* ***Perth Coroner's Court, Court 51, CLC Building, 501 Hay Street, Perth*** *on* ***5 April 2018*** *find that the identity of the deceased person was* ***Pamella Leslie REES*** *and that death occurred on* ***30 June 2014*** *at* ***36 McNairn Cross, Leda*** *as a result of* ***disseminated metastatic carcinoma of unknown primary in a woman with multiple sclerosis*** *in the following circumstances:*

Counsel Appearing:

Mr T Bishop assisting the Coroner.

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INTRODUCTION

1. Pamella Rees lived with multiple sclerosis for many years. Over time her symptoms increased and she spent the last eight or nine years of her life in a wheelchair. Her friend and housemate, Mr Graham Hall, acted as her carer for most of that time, with some assistance from services such as MSWA (formerly the Multiple Sclerosis Society of WA) and Silver Chain.

2. In the last year of her life Ms Rees' health deteriorated significantly. While one would expect this would result in further involvement by external agencies in her care, the opposite occurred. As Ms Rees became increasingly unwell she also became increasingly reluctant to allow outside people to help her. Instead, she preferred to rely entirely upon Mr Hall for her day-to-day care, apart from input from her neurologist and general practitioner as to her medication regime and general monitoring of her health.

3. By June 2014 Ms Rees' care needs had become so great that Mr Hall had to stop working in order to care for her. She ate less and less, had trouble breathing and was reportedly in pain all the time. She was unable to go to the toilet or shower without assistance. In the final days of her life Ms Rees stopped eating and drinking altogether. Mr Hall did not seek any medical assistance for her for a number of days.

4. It was only on the morning of 30 June 2014, when Mr Hall found Ms Rees in what he described as "a hell of a state," that he called MSWA for advice. They told him to call an ambulance but he chose to take her into the shower first as he wanted to make her presentable before what he thought would be a trip to the hospital. In the meantime MSWA staff had taken action to request an ambulance, but by the time the paramedics arrived at the house, Ms Rees was already dead. There were signs she had been dead for some time. A post mortem examination found Ms Rees died from cancer that was undiagnosed at the time of her death.

5. The circumstances of Ms Rees' death prompted a criminal investigation by the Major Crime Squad. Mr Hall was formally interviewed as part of the investigation. At the end of the investigation no criminality was identified and no charges were pursued against any person.

6. The police investigation into the death of the deceased was then continued by the Coronial Investigation Squad and a full report was ultimately provided to the Coroner's Court. Based upon the information provided, the State Coroner decided that it was desirable to hold an inquest.

7. I held an inquest on 5 April 2018. The focus of the inquest was primarily on the last month of Ms Rees' life and whether the care provided by Mr Hall and Ms Rees' GP was reasonable in the circumstances that were presented to them at the time. I have found that their conduct was reasonable in the circumstances that they faced, taking into account Ms Rees' unwillingness to accept help from outside services.

8. However, given the sad circumstances of Ms Rees' death, the inquest also explored the community services that could have been accessed to ease

Ms Rees' suffering in her dying days and support Mr Hall in managing her care, had they chosen to accept them.

PROGRESSION OF MS REES' ILLNESS

9. According to the records Ms Rees was first diagnosed with multiple sclerosis in 1991. In the early stages of her illness Ms Rees does not appear to have required a great deal of assistance. However, as her symptoms increased over time, the level of care required correspondingly increased.[1]

10. Mr Hall had known Ms Rees since 1985. They were initially in a relationship and they had remained good friends after their relationship ended and remained living together. They were still living together when Ms Rees was diagnosed with multiple sclerosis in 1991. Initially Ms Rees remained fit and healthy and it did not impact significantly on their lives. However, Ms Rees' symptoms of pain and fatigue eventually increased and she stopped working. She became wheelchair bound in about the year 2000.[2]

11. Even when using a wheelchair Ms Rees retained some independence for a time but eventually her condition deteriorated further and she was unable to drive and required a higher level of assistance with her personal care. Mr Hall became Ms Rees' carer as her condition deteriorated. He explained that Ms Rees was divorced and, although she had grown-up children, she had little contact with her family. As Ms Rees did not have a lot of family support, Mr Hall was really the only person close to Ms Rees who was in a position to take on the role of her carer.[3]

12. From about 2002 Mr Hall began to increase his level of involvement in Ms Rees' care, but he was generally still able to leave her alone for long periods while he went to work.

13. Ms Rees was first referred to Silver Chain for domestic assistance in November 2008 and they remained involved in her care until July 2013.[4]

14. In 2009 Ms Rees became a member of MSWA. The earliest interaction with staff from the society was a recorded home visit on 4 February 2009. Concerns were raised regarding Ms Rees sleeping on the lounge but Ms Rees indicated that she liked sleeping on the lounge as she found it comfortable and felt the bed was too high for her to get in and out of easily. An offer was made to have an occupational therapist look at lowering her bed, but she declined.[5]

15. Ms Rees had ongoing contact with MSWA staff but she generally declined offers for assistance.[6] In May 2012 a senior social worker from MSWA, Ms Irene Willis, conducted a home visit. During the visit Mr Hall expressed

[1] T 33 – 36.
[2] T 33 – 36.
[3] T 33 – 38.
[4] Exhibit 1, Tab 9, p. 4 and Tab 23.
[5] Exhibit 1, Tab 9, p. 2.
[6] Exhibit 1, Tab 9, p. 2.

concern about the fact that he was leaving Ms Rees at home when he went to work but Ms Rees shouted at Ms Willis that she did not want help and that Mr Hall should do it. Mr Hall reportedly looked exhausted and Ms Willis noticed he had tears in his eyes when he walked her to her car. As she was leaving Ms Willis suggested to Mr Hall that she could arrange respite care, and later tried to do so, but Ms Rees "blocked it."[7] Ms Rees would say she would go and a booking would be made, but she would then change her mind. Ms Willis did not have further contact with either Ms Rees or Mr Hall until she was contacted by Mr Hall on the day of Ms Rees' death.[8]

16. On 18 March 2013 Ms Rees saw a dietitian at Rockingham General Hospital and was noted to have lost 30 kgs in 11 months. She had weighed 87 kg in April 2012 and at that time weighed 57.8 kg. Her severe neuralgia had been causing her too much pain to eat.[9]

17. On 19 March 2013 Ms Rees was found by a Silver Chain nurse to be incoherent and difficult to rouse. The nurse rang Mr Hall, who said Ms Rees had been discharged from hospital the day before and would be sedated. He indicated he was at work and would not be returning home immediately. The nurse did not feel she could leave Ms Rees at home alone and called an ambulance but Ms Rees refused to go to hospital and the paramedics deemed her safe to remain at home. The nurse sent this information to Ms Rees' GP and indicated she was worried about Ms Rees' care and that she had lost weight recently also.[10]

18. An MSWA nurse noted two days later, on 21 March 2013, that Ms Rees had deteriorated and was in need of assistance with care and housework. At that time it seems Ms Rees was willing to accept domestic help, although this does not appear to have come to fruition.[11]

19. On 2 April 2013 the same Silver Chain nurse who had visited Ms Rees on 19 March visited Ms Rees again. The nurse had a conversation with Ms Rees and Mr Hall and told them that she would never leave Ms Rees without any assistance and she would always phone for an ambulance if faced with the same situation again as had occurred on 19 March 2013. She noted Ms Rees thanked her for phoning for the ambulance on that occasion. The nurse attended on six more occasions, up to 14 May 2013 until the services were put on hold while Ms Rees went to hospital. After that time Silver Chain were told their services were no longer required.[12]

20. Ms Rees' hospital admission in May 2013 occurred after home support staff telephoned her on 30 May 2013 and while speaking to her they thought they heard Ms Rees fall. They telephoned police, who found Ms Rees at home on the floor. She had reportedly fallen out of her wheelchair. Ms Rees was conscious but disorientated so they arranged for an ambulance to take her to Rockingham-Kwinana Hospital. She was found to have some cognitive

[7] Exhibit 1, Tab 20 [11].
[8] Exhibit 1, Tab 9, p. 3 and Tab 20.
[9] Exhibit 2.
[10] Exhibit 1, Tab 23.
[11] Exhibit 1, Tab 25.
[12] Exhibit 1, Tab 23.

impairment and constipation. She was admitted and her constipation was treated. It was noted that Mr Hall was working full time during the day and leaving Ms Rees at home. At that time Ms Rees and Mr Hall expressed some interest in increasing her in-home services, although later evidence shows they did not take up those services, and indeed took the opposite path.

21. A report by MSWA social worker Ms Dawn Burke, dated 12 June 2013, indicated that Ms Rees was still alone all day as Mr Hall worked 6 days a week from 6.00 am to 4.30 pm. She didn't eat much due to her neuralgia and it was thought that her cognition wasn't good. Ms Rees was felt to be in need of personal care and domestic assistance but it was noted that the many attempts to place services in the home had been unsuccessful. It was suggested that they try to get "a foot in the door" by offering one day a week of personal care, with the hope of increasing it to two to three days a week once the relationship was established. Urgent arrangements for a personal care alarm for her own personal health and safety was also emphasised, although this was never able to be put in place.[13]

22. An appointment was made to see the dietitian on 25 June 2013 but Ms Rees did not attend the appointment and did not respond to a follow up phone call and letter. A hospital referral for Ms Rees to attend day therapy services was followed up with Mr Hall in November 2013 but he reported that she was improving and didn't need the appointment.[14]

23. A hospital referral for Ms Rees to be seen at the geriatrician clinic was also followed up in November 2013 and declined by Mr Hall, despite her GP being supportive of the review. Mr Hall was recorded as saying that Ms Rees was much improved over the past four months since her hospital admission.[15]

24. It was around this time that Mr Hall says he started working less hours and took on more of Ms Rees' care, which prompted them to cease accessing Silver Chain or MSWA services entirely. The last record with Silver Chain was a letter to Ms Rees' GP on 9 July 2013 indicating the injections were now being done by a family member. Mr Hall advised that he was shown how to inject Ms Rees with her Avonex medication (for her multiple sclerosis), which had been administered weekly by a Silver Chain nurse, and he felt that he was in a position to also provide for her other needs, so they no longer saw any need for the services.[16]

25. Mr Hall was asked whether Ms Rees' desire for privacy also motivated the decision to cease in-home services, but he didn't think this was a primary factor in the decision.[17] Indeed, he wasn't able to give a clear explanation as to why.

26. MSWA staff had conducted a home visit on 1 July 2013 to discuss care services they could provide. Mr Hall and Ms Rees were both present during the visit, which last approximately 20 minutes. Unfortunately, it was noted

[13] Exhibit 1, Tab 25 and Tab 26.
[14] Exhibit 2.
[15] Exhibit 2.
[16] T 39 – 40.
[17] T 40.

that Ms Rees was not receptive to the idea of services being provided and twice told the MSWA staff they could "stuff" their services. They provided their contact details to Mr Hall before they left in case he wished to discuss the issue further.[18]

27. I note that the ceasing of services by Silver Chain coincided with concerns being raised by Silver Chain and hospital staff about Ms Rees being left at home alone for long periods and an indication by Silver Chain staff they would take action to call an ambulance if they were concerned about her welfare. At the same time MSWA was offering services on the basis they were concerned about the current personal care arrangements. It is open to draw an inference that Ms Rees and Mr Hall did not wish further scrutiny of their care arrangements in those circumstances, which prompted them to withdraw from the service providers. Ms Rees appeared to take an active role in that decision; indeed, she seemed less open to outside help than Mr Hall.

28. Mr Hall had been taking Ms Rees to her appointments with her neurologist every six months and to her GP regularly so that monitoring of her condition was available.

29. Ms Rees' regular GP was Dr Kong Liew at the Leda Medical Centre. Dr Liew had been seeing Ms Rees as a patient since 2009. She was the only patient he could recall seeing who had multiple sclerosis. Although he had little experience treating a patient with MS, he did not contact MSWA for additional information and relied upon direction from her neurologist. Dr Liew described his role in treating Ms Rees' multiple sclerosis as managing her symptoms and if there were changes then he would refer her back to her neurologist.[19] Dr Liew said he saw Ms Rees approximately six times a year, although it seems from Mr Hall's evidence she attended the practice itself more regularly.

30. Mr Hall recalled that Ms Rees liked Dr Liew and usually saw him, but she also saw other GP's on occasion.[20] According to Mr Hall, the main reason Ms Rees saw her GP was for her prescription medications, in particular her painkillers. However, there were other issues that arose from time to time.

31. On 10 October 2013 the deceased reported to Dr Liew that she had been experiencing intermittent shortness of breath over the past six weeks and Dr Liew referred her for a chest x-ray, echocardiogram, blood tests and spirometry. In November 2013 it was noted that Ms Rees had not yet attended for any of the requested tests.

32. Ms Rees saw her neurologist on 10 December 2013 and she indicated that she felt that the Avonex injections had stabilised her MS and she had not noticed any progressive downhill deterioration since starting the disease modifying therapy.[21]

[18] Exhibit 1, Tab 9, p. 3 and Tab 26.
[19] T 57.
[20] T 43 – 44.
[21] Exhibit 1, Tab 29.

33. On 24 January 2014 Dr Liew wrote a referral letter to Rockingham-Kwinana Hospital requesting assessment as Ms Rees had not been eating for a few days due to mouth pain attributed to her neuralgia. It does not seem that Ms Rees immediately attended hospital, but she was later brought into the hospital's Emergency Department on 20 February 2014 due to her ongoing mouth pain. She was given anaesthetic gel and her pain improved, so she was discharged home with more of the gel and told to return to hospital if her pain increased again.[22]

34. As indicated by Mr Hall, most of the GP appointments after that were for repeat prescriptions of medications. However, on 30 April 2014 Dr Liew updated Ms Rees' GP Management Plan and it was noted that she was not eating well due to mouth pain. Her weight was recorded as 63 kg at that time. She had still not had her blood tests that were ordered in October 2013 and she was advised to do so.

35. Although they attended appointments with Dr Liew regularly, Mr Hall said that they did not discuss with Dr Liew Ms Rees' life expectancy or palliative care options. This was despite the fact he said they were aware she was slowly dying. Mr Hall acknowledged that in hindsight they should have discussed palliative care options with Dr Liew, as it would have been better for Ms Rees.[23]

36. Dr Liew's evidence was that he thought Ms Rees would have discussed these issues of her inevitable health deterioration and end of life options with her neurologist. Consistently with Mr Hall, he did not recall ever discussing such matters with Ms Rees.[24] Dr Liew said that he did not consider Ms Rees had reached that stage, in any event, so there was nothing to prompt the discussion.[25] If her cancer had been identified, this would likely have altered the situation.

37. Ms Rees last saw her neurologist, Dr Susan Ho, on 27 February 2014. She reported feeling better at that time although she had suffered a recent flare up of her trigeminal neuralgia. Her Lyrica and Tegretol medications were increased to twice a day to help manage her pain. Mr Hall said that Ms Rees was due to see Dr Ho again a few days after her death and he was hoping at the time that there might be a new medication or something that could help Ms Rees, as he was aware it was generally Dr Ho who prescribed the primary medications rather than Dr Liew.[26]

38. Dr Liew's evidence was that he did not see any marked deterioration in Ms Rees' health over the five years that he saw her other than some gradual muscle wasting that he attributed to the multiple sclerosis. He stated that if he had been concerned or worried that she couldn't eat in the last months of her life he would have sent her to hospital, as he had done in the past when she couldn't eat. He was aware that she still had mouth pain but he was not

[22] Exhibit 2.
[23] T 44 – 45, 48.
[24] T 58.
[25] T 61.
[26] Exhibit 1, Tab 10 and Tab 29.

aware that there was a particular issue with her eating at that time.[27] She was also always able to speak when he saw her for appointments.[28]

39. Dr Liew saw Ms Rees in late May 2014 when she presented with a complaint of chest pain after a fall, and again on 5 June 2014, and he said he did not observe any physically notable change that he was worried about. Unlike Mr Hall, Dr Liew did not believe Ms Rees looked like she was dying at that stage. Dr Liew's evidence was that if he had thought Ms Rees was close to death when he last saw her then he probably would have raised the issue of palliative care and other end of life matters, but this did not occur.[29]

40. Dr Liew generally indicated that he thought the neurologist played the greater role in explaining the course of Ms Rees' illness to her, in the sense of how multiple sclerosis would progress and limit her life. He did not consider he could get information from the neurologist himself to learn more about the condition of multiple sclerosis, and did not feel there was enough information easily available for him to access elsewhere.[30]

41. In relation to the issue of the deceased's undiagnosed emphysema, Dr Liew said that he had suspected it as the deceased was a smoker. He had sent her off for spirometry to explore this possibility as an explanation for her shortness of breath in October 2013 but Ms Rees didn't proceed with the investigation.[31] Dr Liew said that he asked Ms Rees why she did not do the tests and she told him that she was feeling better and didn't want to do the tests.[32] He said that he encouraged her to go ahead with the testing and also counselled her to quit smoking, although as far as he was aware she continued to smoke.[33]

42. Dr Liew also referred Ms Rees for a chest/ribs x-ray as she had reported having bruised ribs after a fall. Mr Hall said she had fallen out of her wheelchair when moving between the chair and a car.[34] The report for the x-ray was directed to Dr Liew and dated 23 May 2014. It indicated there was no intrathoracic injury. Dr Liew reviewed her on 5 June 2014 and she claimed her pain was improving.[35]

43. Dr Liew only became aware that the deceased had cancer after her death.[36] He said that he was surprised to hear that she had advanced cancer and looking back in hindsight he could not think of any signs he had missed that would have pointed to that diagnosis. He said he saw no visible signs such as sunken cheeks or eyes, for example.[37]

44. Dr Liew was asked whether he was surprised that Ms Rees had died on 30 June 2014, after he had seen her on 5 June 2014 and did not think her

[27] T 60.
[28] T 59 – 60.
[29] T 61.
[30] T 67.
[31] T 61.
[32] T 62.
[33] T 62.
[34] Exhibit 1, Tab 10, pp. 99 - 100.
[35] Exhibit 1, Tab 27.
[36] T 61.
[37] T 65.

condition had deteriorated at that time. Dr Liew indicated that he was surprised as he had not seen any notable change that would ring alarm bells. He theorised that Ms Rees experienced "very rapid decline"[38] from the time he last saw her.

45. Dr Liew was asked about his comment that Ms Rees was "generally in good health"[39] when he saw her in early June 2014. He clarified that he meant "her good health in the sense that there's no change"[40] rather than the good health of a person who is generally well.

46. Mr Hall's evidence was that Ms Rees looked very thin for about the last year of her life but that until the last month or so of her life Ms Rees was still eating, although her appetite was declining. He was aware that the pain in her head from the trigeminal neuralgia affected her significantly and she required a lot of painkillers as the pain was increasing.[41] She was still able to speak to Mr Hall and communicate to him what she wanted, although she often wrote notes to him as well.

47. Some notes were found by police after Ms Rees' death. Two in particular, were included in the coronial brief and were raised with Mr Hall. One read,

    Graham, I'm having such a lot of pain in my face that I can't live normaly (sic).

    The other read,

    Can't move tonge [sic], can't talk, nor drink, nor swallow (sic). Agony is max. Send me to hospital so you can go to work. I may get a real carer if you cancel the guy[?] for me.[42]

48. Mr Hall said that he would have taken Ms Rees to hospital if he had seen the second note as they were the same reasons why he had taken her to hospital in the past; because if she couldn't eat then he couldn't get her to take her pills because her mouth was so dry and she would also stop drinking water. Mr Hall said he saw those symptoms as the signal to take her to hospital.[43] Mr Hall agreed that Ms Rees would have written the notes but he did not recall if or when he saw those notes and it was not possible to identify from each note itself when they were written.

49. Mr Hall gave evidence that he had regularly taken Ms Rees to hospital emergency departments over the years and she often had a brief admission during which she was given intravenous fluids and her condition would improve. She would then be discharged on painkillers and return home, only to eventually deteriorate and have to return to hospital.[44]

50. Mr Hall said that he stopped work entirely about a month before Ms Rees' death to care for her 24/7 as her condition deteriorated and she could no

[38] T 64.
[39] Exhibit 1, Tab 27, p. 1.
[40] T 65.
[41] T 44.
[42] T 46 – 48; Exhibit 1, Tab 11.
[43] T 49.
[44] T 47.

longer get herself into her wheelchair without assistance.[45] Ms Rees had repeatedly indicated that she did not want to go into a nursing home and wanted to stay at home.[46]

51. Mr Hall also said that he talked to Ms Rees often in the last few weeks of her life about going to hospital again but she didn't want to go to hospital. He had told her that he would take her to hospital in a few days if she had not improved, but she died before this could occur.[47]

52. Mr Hall acknowledged that he was probably a bit worn out by this time. He said he was tired but kept going as he thought,[48]

> *Is that all my worry is, is being tired where she's going through all this pain, living all this horrible life and all I'm worried about is being tired so I didn't worry about it, I just kept doing it.*

53. He had thought about putting Ms Rees into a hospice or some other facility, which would be a more long term solution than hospital, and had even gone as far as going to a nursing home down the road to get an application form in the week prior to her death. However, Mr Hall said that he hadn't had time to fill in the application and take the matter any further.[49]

54. Although she had been deteriorating for a long time, Mr Hall described Ms Rees' final decline as sudden and dramatic over the last week or so of her life. He said that even though she was already thin, she suffered rapid weight loss and her deterioration in the last week shocked him.[50] He told police "in the last week she got so skinny it wasn't funny. It really just fell off her."[51] Although Mr Hall was aware that Ms Rees' condition was deteriorating significantly at that time, he did not realise that her death was imminent.

HOW AND WHEN DID MS REES DIE?

55. Mr Hall said he recalled that over the weekend prior to her death Ms Rees took in a small amount of food and water and medication on the Saturday. On the Sunday he was unable to give her anything as she slept the entire day. He said he was glad she slept because when awake she had been in agony. Mr Hall went to sleep early that night, around 8.00 pm, and he firmly believed Ms Rees was still alive when he went to sleep although she had not communicated with him all weekend.[52]

56. When he woke the next morning, being Monday, 30 June 2014, he thought she was still alive. However, at the time of the inquest Mr Hall accepted that it was now relatively clear that Ms Rees had already died. He believes now

[45] Exhibit 1, Tab 10, 9.
[46] T 38 – 39.
[47] T 48 – 49.
[48] T 48 – 49.
[49] T 49
[50] Exhibit 1, Tab 10, p. 111.
[51] Exhibit 1, Tab 10, p. 61
[52] T 50; Exhibit 1, Tab 10, p. 70 – 71, 75 - 80.

that she died just prior to him waking, although he accepts that he can't be sure when her death occurred.[53] One of the paramedics who attended indicated his belief, based on Ms Rees' appearance, she had died before Mr Hall got up at 9.00 am.[54]

57. Mr Hall said that he was usually an early riser but had slept late on this day as he had not been getting a lot of sleep because he was tending to Ms Rees. He woke at about 9.00 am. Mr Hall described Ms Rees as being in "a hell of a state."[55] Before he moved her he rang MSWA and asked to speak to the MSWA officer he had met before, Ms Willis, as he felt she would know what to do. Mr Hall said that when he called MSWA he had realised that Ms Rees was in a very bad way and he was panicking. Mr Hall agreed that in hindsight he would have been better served to call an ambulance first but he felt at the time there were staff at MSWA who might be able to help.

58. The evidence indicates Mr Hall left a message for the senior social worker, Ms Willis, who he had met back in May 2012 at their home. Ms Willis was in the office on the morning of 30 June 2014 and saw an email sent at 9.08 am asking her to call Mr Hall but it does not appear the urgency of his request was communicated. Prior to returning the call Ms Willis received another call from Mr Hall, at about 10.40 am, in which Mr Hall stated that Ms Rees was not responding and she had not eaten, drunk water or taken medication in several days. When Ms Willis questioned him, Mr Hall said that he thought she was breathing. Ms Willis advised Mr Hall to contact St Johns Ambulance.[56]

59. Mr Hall said in his oral evidence at the inquest that he thought that he did then ring an ambulance, although he accepted that he might be mistaken.[57] In an earlier interview he had recalled that MSWA rang for an ambulance on his behalf.[58]

60. The evidence from MSWA was that Ms Willis immediately referred the matter to two community access nurses at MSWA and asked one of them to telephone Mr Hall. One of the nurses, Ms Julie Mansell, called Mr Hall back straight away and ascertained that he had not rung and requested an ambulance. She asked him some questions about Ms Rees' condition and he indicated that she wouldn't open her eyes and wasn't talking. Ms Mansell told Mr Hall that he should immediately request an ambulance and offered to ring an ambulance for him. Mr Hall said he would do it but that he wanted "to clean her up a bit first." Ms Mansell tried to impress upon him the need to urgently call an ambulance and after ending the call she spoke to another nurse about the call. The other nurse, Ms Jillian Crombie, rang Mr Hall herself and confirmed that he still had not called St Johns Ambulance, so she called on his behalf.[59]

[53] T 50.
[54] Exhibit 1, Tab 13 [40].
[55] Exhibit 1, Tab 10, p. 10.
[56] Exhibit 1, Tab 9, p. 3.
[57] T 51.
[58] Exhibit 1, Tab 10, p. 12.
[59] Exhibit 1, Tab 9, p. 4 and Tab 19 and Tab 20.

61. Mr Hall said he took Ms Rees into the shower, which is something he did every morning, and in this case was particularly necessary as she had soiled herself overnight and he wanted to clean her up before she went to hospital. As he moved Ms Rees from the wheelchair and took her into the shower he realised that she wasn't moving or supporting her weight at all, but he doesn't seem to have fully understood even then that she had died.[60] Mr Hall must have then put Ms Rees back into her wheelchair as when the ambulance arrived she was sitting in her wheelchair inside the house.

62. Two paramedics attended at Ms Rees' house at 11.34 am, approximately 10 minutes after being allocated the job. They were met at the door by Mr Hall who led them inside to where Ms Rees was slumped in a wheelchair in the lounge room. Due to poor light in the room it was difficult to see clearly, but both men immediately formed the impression that Ms Rees was dead. This was confirmed when they wheeled her outside and tried to check for signs of life. Ms Rees was cold to the touch, pulseless and had lividity present in her hands and feet. The paramedics tried to ascertain from Mr Hall how long she had been in that state, so they could decide whether resuscitation was viable.[61]

63. One of the paramedics recalled that Mr Hall told him that Ms Rees had been deteriorating for about a week and had been unresponsive since Friday 27 June 2014, which was three days before.[62] Mr Hall later acknowledged to the other paramedic that he should have taken Ms Rees to hospital on that Friday and he said the same to police. He explained that he had been hoping she'd turn around and take her pills again, but this did not occur and he had waited too long.[63]

64. It became very apparent to the paramedics that Ms Rees had been showing signs of being deceased for some time and their assessment found no signs of life, so it would not be appropriate to attempt resuscitation. The paramedics communicated their decision to the St John Ambulance Communications Centre and requested the attendance of their Ambulance Manager and the police. There was some discussion about trying to obtain a death certificate from Ms Rees' GP, but it was eventually decided that in the circumstances such a certificate would not be appropriate and the matter should be referred to the coroner.[64]

65. When the paramedics told Mr Hall that Ms Rees had died, he appeared shocked. Mr Hall told them that prior to their arrival he had been readying Ms Rees and her belongings so she could be taken to hospital. This surprised them, given everything they had seen and been told suggested she had been obviously dead for hours.[65] Nevertheless, at least one of the paramedics believed Mr Hall's response was genuine and he had honestly believed she was still alive when he had been tending to her that morning, despite the fact she had been slumped and unresponsive throughout.[66]

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[60] T 51 - 52.
[61] Exhibit 1, Tab 9 and Tab 12 and Tab 13.
[62] Exhibit 1, Tab 12 [22] – [23], [39].
[63] Exhibit 1, Tab 13 [30] and Tab 10, p. 68 - 70.
[64] Exhibit 1, Tab 12 and Tab 13.
[65] Exhibit 1, Tab 12 and Tab 13.
[66] Exhibit 1, Tab 13 [42] and Tab 14.

66. Mr Hall's evidence was that he was aware Ms Rees was declining and was going to die eventually, but at the same time he was shocked as he hadn't realised she was so close to death. He had never seen someone die before, so this was his first experience of such an event.[67]

Cause of Death

67. On 4 July 2014 a forensic pathologist, Dr A.V Spark, performed a post-mortem examination on the body of Ms Rees.[68]

68. Ms Rees' body was described as of cachectic appearance with widespread wasting of the muscles. Her body weight was recorded as 41 kg, which was 20 kg less than she had weighed two months earlier.

69. There was ulceration and evidence of infection of the skin around the anogenital area. Unusually, there were scraps of newspaper around Ms Rees' anogenital region and the imprint of newspaper on the backs of her legs, which was not really explained at the inquest. Multiple bruises were present on the upper limbs and the right upper eyelid.[69] It had been suggested by one of the attending police officers that some of the bruising on Ms Rees' arm looked like finger mark bruising. Examination of the subcutaneous tissues of the arms and back of hands found haemorrhage underlying the bruises seen externally, with no evidence of other further injury.[70]

70. Internally tumour nodules were noted within the pancreas, liver, thyroid, left lung, spine, ribs and pelvis. Microscopic examination of the tissues showed metastatic tumour in those areas and the heart. There was severe emphysema within the lungs with possible changes of pneumonia bilaterally. There were erosions of the stomach lining.[71]

71. Neuropathology examination reported multiple demyelinating lesions in keeping with the history of chronic multiple sclerosis. No metastatic lesions were found in the brain.[72]

72. Toxicology analysis reported the presence of the drugs codeine, morphine, carbamazepine and paracetamol within the blood.[73]

73. At the conclusion of all investigations Dr Spark formed the opinion the cause of death was disseminated metastatic carcinoma of unknown primary in a woman with multiple sclerosis.[74] I accept and adopt the conclusion of Dr Spark as to the cause of death.

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[67] T 51 - 52.
[68] Exhibit 1, Tab 4.
[69] Exhibit 1, Tab 4.
[70] Exhibit 1, Tab 8, p. 1.
[71] Exhibit 1, Tab 4.
[72] Exhibit 1, Tab 4 and Tab 7.
[73] Exhibit 1, Tabs 4 – 6.
[74] Exhibit 1, Tab 4.

Manner of Death

74. It follows from the cause of death that the manner of death was by way of natural causes.

APPROPRIATENESS OF THE CARE PROVIDED

Police investigation

75. After the SJA paramedics certified Ms Rees' life extinct at 11.37 am they notified police. Senior Constable Chance and Constable Palmer were the first police to attend the scene, arriving at 1.16 pm. The attending police officers noted the deceased appeared emaciated and had a bruised right eyelid and what appeared to be finger mark bruising on her arm. They understood from information given at the scene that Mr Hall had reportedly told one of the attending paramedics that Ms Rees had "not been eating, moving, talking, taking her medications or drinking for days, possibly since Friday, 27 June."[75]

76. After conversations with the SJA paramedics and Mr Hall and an initial assessment of the scene a protected forensic area was established in accordance with the *Criminal Investigation Act 2006* (WA) and a forensic examination was then completed.[76] Mr Hall was also taken to the Rockingham Detectives office for questioning about the matter.

77. Mr Hall openly and willingly spoke to police, both in the car and later on video in a formal interview. En route to the office Mr Hall volunteered that he had been caring for Ms Rees for 10 years and said he had eventually stopped work to care for her. He discussed cleaning her morning and night and having to move her to do this. He explained that she bruised easily during these interactions. He talked of Ms Rees probably being "better off dead" but denied any involvement in Ms Rees' death.[77] He later said that she herself didn't want to die, so there was no suggestion she had asked him to help her end her life.[78]

78. During the recorded interview Mr Hall gave an account of Ms Rees' declining health and indicated that he believed she was "crook"[79] but not near death on the weekend preceding her death. He acknowledged that she had not been able to eat, drink or talk over the weekend and in hindsight he probably should have taken her to hospital on the Friday.[80] There was discussion about their financial situation and it did not appear that Mr Hall stood to gain financially from her death, other than potentially a share in the house they had bought and owned together.[81] He again said he believed she

[75] Exhibit 1, Tab 8, p. 5.
[76] Exhibit 1, Tab 9.
[77] Exhibit 1, Tab 9.
[78] Exhibit 1, Tab 10, p. 81.
[79] Exhibit 1, Tab 10, p. 9.
[80] Exhibit 1, Tab 9, p. 7.
[81] Exhibit 1, Tab 9, p. 8.

was probably "better off where she is"[82] although he also said he would have preferred she was still alive.

79. Investigating police spoke to neighbours who reported that they had previously expressed concerns about the deceased's welfare and sounds of verbal abuse overheard coming from the home. One neighbour suggested he had raised his concerns previously with police, although no record of this complaint was located.

80. Another neighbour said she had raised her concerns with MSWA. Records showed a telephone call had been received by MSWA on 7 April 2014 from the neighbour raising concerns that Ms Rees had been heard begging for help and Mr Hall being verbally abusive in response. Community access nurse Ms Mansell, who spoke to Mr Hall on the day of Ms Rees' death, recalled receiving that call on 7 April 2014. Ms Mansell said she spoke to a colleague about the call and together they formulated a plan for an MSWA staff member who had previous contact with Mr Hall to contact Mr Hall.[83]

81. It is not clear why there was a three week delay, but eventually on 1 May 2014 an MSWA staff member tried to call back the neighbour to advise her to make a report to police but the number given was disconnected. Ms Willis followed up with a call to Mr Hall on 8 May 2014, who said that Ms Rees' condition had stabilised and she was coping well. Mr Hall was reminded of the supports available, if he chose to avail himself of them. Nothing seems to have been done to speak directly to Ms Rees about the allegation or to physically check on her.[84]

82. Mr Hall was asked by police about the neighbours' observations. He admitted to yelling at Ms Rees sometimes out of frustration and that he yelled on a regular basis but denied hitting Ms Rees other than once many years before and prior to her illness.[85]

83. More than one neighbour also reported that they had seen Ms Rees sometimes sitting outside the house in a vehicle and heard her sounding the horn on a regular basis.[86] Mr Hall explained that she sometimes would sit in the car for a change of scene and she would sound the horn when she needed something.[87]

84. It appeared to the police officers that Mr Hall was being honest and forthright although his recollection was not always precise.[88]

85. Mr Hall agreed to participate in another interview later that night to clarify some further issues in relation to Silver Chain services and the care he was providing to Ms Rees. Again he appeared to be honest and cooperative

[82] Exhibit 1, Tab 10, p. 80.
[83] Exhibit 1, Tab 19.
[84] Exhibit 1, Tab 26.
[85] Exhibit 1, Tab 9, p. 8 and Tab 10, pp 92 – 97.
[86] Exhibit 1, Tab 9, p. 5.
[87] Exhibit 1, Tab 9, p. 8 and Tab 10, pp 92 – 97.
[88] Exhibit 1, Tab 9, p. 9.

although his recollection appeared to be somewhat distorted and inaccurate as to the specific sequence of events.[89]

86. A police officer spoke to Ms Rees's regular GP, Dr Liew. He expressed surprise that there were concerns in regard to the deceased's care as Ms Rees usually attended appointments with Mr Hall and they appeared to have a good relationship. Dr Liew had observed that Ms Rees always appeared clean and presentable and never complained about her care or treatment by Mr Hall.[90]

87. This is at odds with the observations of Ms Rees at the time of her death and living environment generally. However, it was apparent that Mr Hall did his best to make her clean and presentable when she was going out, including even on the day of her death his priority appeared to be ensuring she was showered before the ambulance attended.[91]

88. The detectives investigating the matter formed the opinion that Mr Hall was an unworldly and somewhat naive man who did not have a good understanding of the options available to try to keep Ms Rees clean and comfortable and generally as to the best ways to manage her care. He was a plasterer by trade and had left school in either year 8 or 9 to take up his trade. He had no previous experience providing care to a person with the high care needs that Ms Rees eventually required.[92] Although there were services such as Silver Chain and MSWA who could have provided him with help in this regard, this was not taken up by Ms Rees and Mr Hall and other evidence suggests she actively resisted other people being involved in her care.

89. At the conclusion of the police investigation no criminality was identified in the conduct of Mr Hall towards the deceased[93].

Expert Review

90. Dr Barry Fatovich is a general practitioner with close to 40 years' experience in clinical practice. Dr Fatovich has a particular interest in aged care, palliative care, multicultural care and chronic diseases. Dr Fatovich attends several nursing homes and has always provided palliative care to patients in his general practice who required it. In more recent years he has also joined the Silver Chain Palliative Care Service on a contract basis and now works part of his working week in general practice and part of the week working with Silver Chain providing palliative care. Dr Fatovich also teaches medical students and young doctors entering general practice in relation to both general practice and palliative care.[94]

[89] Exhibit 1, Tab 9, p. 9.
[90] Exhibit 1, Tab 8, p. 6.
[91] Exhibit 1, Tab 9, p. 9 and Tab 10.
[92] Exhibit 1, Tab 9, p. 9.
[93] Exhibit 1, Tab 8, p. 11.
[94] T 4 – 5.

91. Dr Fatovich reviewed the care given to Ms Rees and also gave expert evidence about palliative care services available in the community to people such as Ms Rees when they are reaching the end of their life.

92. Dr Fatovich advised that generally, a person is referred for palliative care when their prognosis is that they have no more than three months left to live and there is nothing more that can be done for the patient in the curative sense. This may mean that patients are on palliative care for a much longer period of time, or a much shorter period of time, depending on the path of their illness, but the starting point is usually that they are believed to only have a few months left to live.[95]

93. As part of his palliative care service in the community Dr Fatovich performs home visits as many of the patients are people who have decided they wish to die at home.[96] The referral of the patient to Silver Chain is usually a medical referral made by hospital doctors, specialists or GP's. There is no cost to the patient as the Silver Chain Service is funded through a government grant and the home visits are paid for under the Medicare system.[97]

94. In relation to Ms Rees' case, Dr Fatovich noted that at the start of June 2014 the records indicate her general state of health was poor. She had advanced multiple sclerosis (having first been diagnosed over 20 years before in 1991). In hindsight it is now known that Ms Rees also had extensive metastatic cancer and severe emphysema, although neither condition was diagnosed at the time of her death. Ms Rees had been diagnosed with osteoarthritis in her neck and severe trigeminal neuralgia, which related to a cranial nerve in her face and caused trouble swallowing and severe mouth pain. She had required hospital treatment a number of times for the neuralgia.[98]

95. Ms Rees was on a number of regular medications for her known conditions and to manage her pain. She used a wheelchair for mobility. By mid-2014 she would have been severely disabled and required assistance with all aspects of daily living. Dr Fatovich noted that Ms Rees had anogenital skin infection that was related to her incontinence, which had left her vulnerable to secondary infection.[99]

96. Dr Fatovich noted the paradox of Ms Rees' regular GP describing her as in "good health' when he saw her in June 2014, about 28 days before her death, given the above. On the basis of the medical records Dr Fatovich formed the view that the deceased at that time would have been unwell and not in good health. However, he acknowledged that if a doctor sees a patient regularly with a known history of serious disease, but they remain relatively stable, then there is less cause for concern and their extensive disease forms the background of the assessment of their condition.[100]

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[95] T 6.
[96] T 5.
[97] T 6.
[98] T 8 – 11.
[99] T 7 – 12.
[100] T 12.

97. In this case, questions were raised about how the deceased's cancer and emphysema were not diagnosed prior to her death. Dr Fatovich suggested that in this case, there were not a lot of cues that the deceased had these conditions, and they could have been missed due to symptoms being linked to her other known conditions.[101]

98. In relation to the failure to diagnose the deceased's cancer, Dr Fatovich explained that the common symptoms are weight loss and tiredness. The weight loss could have been explained by her reduced eating associated with trigeminal neuralgia and tiredness is entirely typical in MS patients who are significantly disabled and is also commonly linked to the medication the deceased was taking for her neuralgia. Therefore, her GP could have been misled by her lack of complaint and the explanation of those symptoms by her other known conditions.[102] Dr Fatovich also suggested that until the last few weeks of her death, her condition suggested generally that she had experienced a gradual deterioration or slow decline that may not have been enough to cause alarm.[103]

99. As for the failure to diagnose her severe emphysema Dr Fatovich observed that it is not uncommon for emphysema to be missed[104] and the diagnosis depends on the degree of alertness to the symptoms. However, he also noted that it would be surprising if a long-term heavy smoker did not have emphysema and he was surprised that the radiologist did not comment on some aspect of chronic airway disease when the chest x-ray was performed. Given the reason for the request was due to tenderness over the ribs, Dr Fatovich felt it was possible the radiologist was focused on the injury aspect rather than the lungs, but he was still a little surprised no sign of the emphysema was observed and/or noted.[105]

100. Dr Fatovich agreed that the deceased must have deteriorated very significantly at some stage prior to her death, and was clearly dying in the last few weeks. In the last two months of her life it is known she lost 20 kg and appeared emaciated after her death. Dr Fatovich considered it likely that her weight loss would have escalated in the last month, and especially the last week, of her life, so it was unlikely to be noticeable to her GP.[106] Mr Hall's evidence is consistent with most of Ms Rees' weight loss occurring in the last week prior to her death. In any event, Dr Fatovich noted it would have been up to the deceased whether she wanted the cause of her dramatic weight loss to be investigated and she had not raised it with her GP when she last saw him.[107]

101. Dr Fatovich observed that there can be "a conspiracy of silence so that health professionals are not fully informed about what is really going on."[108] If the patient and carer do not identify a problem, the GP can be misled.

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[101] T 18.
[102] T 12 – 13, 17.
[103] T 13.
[104] Exhibit 1, Tab 31.
[105] T 10 – 11.
[106] T 13.
[107] T 14.
[108] Exhibit 1, Tab 31.

102. Mr Hall talked about how tiring it had been being Ms Rees' sole carer[109] and it was apparent that there had been times when he was open to receiving assistance but Ms Rees was not. Mr Hall explained that with the two respite bookings, Ms Rees had initially indicated that she was willing to go, but on each occasion she would renege and say that she didn't want to go as she didn't want to leave home. He felt she was a bit nervous about going to a strange place and was concerned about receiving her medications regularly. Mr Hall's evidence was that he wanted Ms Rees to go to respite but he wasn't prepared to force her, so he let her choose each time.[110]

103. Dr Fatovich was asked about whether a GP has a role to play in assessing the ability of the carer to manage, and monitoring how the carer is coping. Dr Fatovich noted that in undergraduate and postgraduate training doctors are generally not taught to consider this issue. His sense was that it falls into the broad category of topics such as domestic violence and elder abuse, which are things that doctors ought to be aware of but the ability to identify them generally comes from experience. In Dr Fatovich's view, awareness of carer fatigue and the vulnerability of palliative care patients has evolved in recent years, but it is still not something that many GP's have experience with or will be on the alert for when dealing with patients who have a carer.[111]

104. Where a GP does identify that a carer is not coping, Dr Fatovich said services such as Silver Chain and the MS Society can assist with in various ways.[112] For an older person there is also the local ACAT team who can do a home visit and assessment.[113] Nevertheless, they require the patient to be willing to accept these services.

105. Dr Liew's evidence was that he did not ever ask Ms Rees about the quality of care that Mr Hall was able to provide for her, and he did not recall if he made enquiry with Mr Hall as to how he was coping. He also did not ever discuss palliative care or end of life options with them.[114]

106. As mentioned earlier, it was not entirely clear in this case why Ms Rees did not wish to avail herself of the services of MSWA. The deceased had made contact with MSWA of her own initiative some years after her initial diagnosis, most likely as a result of a referral from her neurologist as it is a common way for people to become aware of the society and the suite of services and supports it can provide.[115]

107. Mr Hall, acknowledged that Ms Rees had been receiving information from MSWA in the form of a newsletter every month, which Mr Hall said that he read but generally Ms Rees did not. He believed she received information

[109] Exhibit 1, Tab 10, p. 126.
[110] T 41 – 42.
[111] T 19 – 20.
[112] T 19 – 20.
[113] T 21 -22.
[114] T 61 – 63.
[115] T 23.

from her doctor but Mr Hall did not attend the appointments so he found the information in the newsletter helpful.[116]

108. A nurse from MSWA went out to Ms Rees' home and did an assessment and then made recommendations. These included suggesting that the society could arrange a hospital bed, since at that time Ms Rees had been spending a lot of time on the sofa, and there were also suggestions for bathroom modifications that could be made and the offer of some in-home supports including carer support and carer respite. Although Ms Rees initially indicated some willingness to avail herself of these services, she then appeared to change her mind and stopped answering calls or attending appointments. This included two bookings for respite care that were cancelled at the last minute. The MSWA workers were not really able to understand why Ms Rees was so erratic in her decision-making and ultimately it was left in her hands to decide when or if she wanted to re-establish contact with the society.[117]

109. Ms Rees re-engaged with MSWA in around 2012, after a new nurse in the area made contact with her. The result was similar, with Ms Rees and Mr Hall initially appearing willing to make use of the service but then ultimately declining to take the recommendations further. Most of the contact then appeared to be when there was a crisis. As MSWA does not have doctors on staff and no afterhours service, any medical crisis requires redirection to healthdirect or a GP or emergency services in any event, so MSWA was generally unable to help directly in those instances.[118]

110. It was made clear that despite Ms Rees's erratic history with MSWA, if she had sought end of life care, it would definitely have been provided.[119]

WHAT OTHER SERVICES WERE AVAILABLE?

111. At the conclusion of his report Dr Fatovich noted that "Ms Rees was dying, and this was not identified. As a result, she did not receive the level of care that would be considered appropriate in our society."[120] I have set out above some of the reasons why her terminal illness was not identified and the evidence that shows Ms Rees played an active role in choosing the level of care she received.

112. All of the witnesses agreed that there were better choices available to her that could have allowed her to die with more dignity and in more comfortable circumstances, if she had been willing to accept help. Mr Hall agreed that, in hindsight, more should have been done in this regard, even though it would not have saved Ms Rees' life.

113. Dr Fatovich was asked what services could have been offered to Ms Rees, in home or out of home, if she had been willing to avail herself of them.

[116] T 36 – 37.
[117] T 26 - 27.
[118] T 28.
[119] T 31.
[120] Exhibit 1, Tab 31.

Dr Fatovich indicated that if Ms Rees had been referred to Silver Chain palliative care, she would have experienced nurses visiting her and providing comprehensive nursing care. Given her mobility issues she would also have been offered a hospital bed in the home that would enable automatic elevation and make it easier for her to be looked after. Her incontinence would have been identified and managed better, with options such as the insertion of a catheter and better bowel care to keep her dry and free of infection, as well as pressure care so that she didn't get pressure sores.[121]

114. Dr Fatovich explained that as well as doctors and nurses, Silver Chain palliative care service has a social worker and counsellors who could have assisted both Ms Rees and her carer. They could also potentially have arranged an aged care assessment team review, which would provide options if she was willing to come out of the home if her issues became too great and she required more comprehensive care, or alternatively a hospice was available if the cancer had been diagnosed. Dr Fatovich acknowledged that many people want to stay at home and will trade off some discomfort against being in a familiar environment where they feel safe and secure, so the aged care facility and hospice options may not have been taken up, but at the least the Silver Chain service could provide some assistance and support within the home to have kept Ms Rees clean and comfortable and provided her with more dignified treatment at the end of her life.[122]

115. Dr Fatovich also noted that the MS Society provides carers for people with MS and other neurological diseases. He had had experience with carers from the society caring for one of his patients and he considered they had done an "extraordinary job in terms of communication with the patient and providing a supportive, positive and caring environment as well as the practical elements of care, such as feeding, bowel care, skin care" and the rest.[123]

116. Dr Fatovich also advocated for home visits by GP's, which he acknowledged is much less common now but in his opinion is not done enough by GP's. Dr Fatovich said that he puts aside several half days a week where he is able to do home visits. Dr Fatovich acknowledged that from a financial sense it is less profitable than when he works in the practice but he enjoys the personal side of the home visits. Dr Fatovich said that when he offers patients from his GP practice home visits they are usually very grateful and appreciate that level of interest.[124]

117. Nevertheless, as Dr Fatovich noted, it is up to the patient to choose what level of in-home services they permit, provided they have the requisite capacity to make decisions.[125]

118. Ms Susan Shapland works at MSWA as the General Manager for Member and Client Services. She has worked for MSWA since 2003. As noted

[121] T 15.
[122] T 15, 17.
[123] T 15 – 16.
[124] T 21.
[125] T 16 – 18.

earlier, MSWA was formerly the MS Society of WA. It provides assistance not only for people with multiple sclerosis but also, in more recent years, for people with other neurological conditions.[126]

119. It is a member-only based organisation and membership is voluntary. Ms Shapland advised that, as the society is a charitable organisation, there is very little cost involved. Usually the society requests that a person fills in a membership form, which also includes a consent for the society to store their information, and they request a $20 membership fee. However, that fee can be waived for people who are unable to pay it. Membership then gives a person full access to a whole range of services.

120. Ms Shapland was not involved in providing any care to the deceased but had reviewed her records and spoken to some of the staff involved in home-visits to the deceased. The deceased had made contact with MSWA of her own initiative some years after her initial diagnosis. Ms Shapland thought it likely that it was suggested by her neurologist as it is a common way for people to become aware of the society and the suite of services and supports it can provide.[127]

121. The society use a multi-disciplinary health team approach, with the primary contact being an MS nurse. The nurse will receive the registration and then go and visit the person and do an assessment to find out how the MS is actually affecting them as an individual, because the disease is so variable. They then tailor the information and supports based on the nurse's interaction and assessment. The society will provide information and resources and also do referrals to the other members of the health team, as required. This might include referral to an occupational therapist for fatigue-management strategies, aids and equipment or to a physiotherapist or speech therapist. It could also include referral for either the individual or their primary carer to counselling or to a welfare officer to assist with access to government entitlements such as carer's allowance or to apply for disability payments. All of the health team professionals are employed by MSWA so they have a specific understanding of the needs of people with multiple sclerosis.[128]

122. There is also a large in-home care division that provides care support workers to go into people's homes to provide a range of supports for daily living activities. This can include showering, meal preparation, domestic tasks, and taking people out into the community.[129]

123. MSWA has volunteers who will sit with a patient and allow a carer to go out and tend to necessary tasks or just have a short break. Also the availability of respite care, which can provide a carer with a break and also sometimes crystallise health issues by a person being seen by medical staff in a different setting for a longer period as opposed to a GP seeing a person once a month for a short time.[130]

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[126] T 25.
[127] T 23.
[128] T 24 – 25.
[129] T 25.
[130] T 21.

124. The society also manages two residential respite facilities, one in City Beach and one in Australind, where people can go and stay for one to two weeks at a time to give the carer respite and to provide 24 hour support for a person who might require it for a period.[131]

125. It is up to individual which, if any, of these services they utilise and their needs for such services may vary over time.[132] Ms Shapland indicated that if MSWA staff are involved and have real concerns that the situation has deteriorated to a serious level then they can contact the neurologist or GP to raise their concerns and this might lead to a hospital admission, where more thorough assessments can be undertaken, or the involvement of Silver Chain palliative care. In many other cases, the level of support that can be provided is sufficient to ensure that people involved with the society can die with dignity and have a reasonable quality of life prior to death.[133]

126. However, as noted above, for the society to be involved they generally rely upon the person themselves or their carer or family providing that information to MSWA if their staff are not already regularly involved.[134]

127. In the specific case of Ms Rees, having heard the evidence of her situation at the end of her life, Ms Shapland indicated that there were many ways MSWA could have assisted to improve the quality of Ms Rees' final days if they had been asked. They could have helped with her personal care, loan equipment, domestic services and Silver Chain follow-up. Sadly in this case, those services were not taken up.[135]

128. Mr Hall's recollection was that Ms Rees had been happy with the services provided by Silver Chain in the past, and indeed had become friends with the nurse who had attended their home regularly, but after he stopped working she became focussed upon him and did not want other people coming in to care for her. Mr Hall indicated that if he had been unavailable he believed Ms Rees would have accepted help from other services, but her preference was to rely solely upon him when he was there.[136]

129. It seems that Mr Hall had come to realise in the last week of Ms Rees' life that she was coming to the limits of her endurance and they might need to transition her to a care facility. However, he still felt there was time to make those arrangements to put her in a care facility as he didn't realise her death was imminent.[137]

130. Mr Hall emphasised that nothing would have changed the outcome and saved Ms Rees' life, but he agreed that there were better options they could have utilised to ease her passing. He described her death as "pretty horrific,"[138] marked in his mind most profoundly by the level of pain she

[131] T 25.
[132] T 25 – 26.
[133] T 29.
[134] T 30 – 31.
[135] T 31 – 32.
[136] T 53.
[137] T 54 – 55.
[138] T 53.

experienced.[139] Mr Hall considered she would have been better served in a nursing home in her last three months of life, where they could have ensured she received better nutrition and a higher fluid intake, and perhaps also have managed her pain better.[140]

CONCLUSION

131. Pamella Rees died on 30 June 2014 after a long period of illness but her death was still unexpected as she had not been considered by her regular GP, her neurologist or her carer to be likely to die soon. However, they were all unaware that, in addition to her multiple sclerosis and other diagnosed conditions, Ms Rees had cancer that had spread throughout her body. The cancer ultimately caused her death.

132. The focus of this inquest was upon Ms Rees' care prior to her death, in order to understand how her cancer remained undiagnosed and how she came to die in circumstances that were agreed by witnesses to be less than what would be considered appropriate in our society.

133. The evidence before me explains that Ms Rees' cancer was not diagnosed largely because her obvious symptoms were explained by her other known medical conditions and she did not disclose any additional information to her GP that might have led to further investigations.

134. As for Ms Rees' care, the evidence establishes that Ms Rees had many services offered to her but she chose instead to rely upon her friend, despite his lack of nursing experience and the demands it placed upon him. In the end, this resulted in her last days being needlessly painful, undignified and uncomfortable. Whilst it was Ms Rees' right to make that choice, it was agreed by her carer that in hindsight there were better choices available to her. I have set out just some of those options in this finding. It important for people in similar situations to Ms Rees to know that there is help available in the community, for little or no cost, if they are only willing to accept that help.

S H Linton
Coroner
20 September 2018

[139] T 53.
[140] T 52 – 53.