



**CORONERS COURT
OF NEW SOUTH WALES**

Inquest: Inquest into the death of EW

Hearing dates: 25 to 29 July 2022

Date of findings: 4 November 2022

Place of findings: Coroner's Court of New South Wales at Cessnock

Findings of: Magistrate Robert Stone, Deputy State Coroner

Catchwords: CORONIAL LAW – mandatory inquest – whether the assessment, care, and treatment of, and decision making of Regional Assessment Service and Aged Care Assessment Team staff was adequate and appropriate in the circumstances – whether a referral to dementia care and support services may be made without a formal diagnosis of dementia

File number: 2019/00217102

Representation: Ms H Bennett, Counsel Assisting the Coroner, instructed by Ms T Higgs and C Livanos (Department of Communities and Justice, Legal)

Ms K Alexander, Counsel for the Australian Government Department of Health and Aged Care instructed by Ms R Levak (Australian Government Solicitor)

Ms V Thomas, Counsel for Hunter New England Local Health District instructed by Ms L Blair (Crown Solicitor's Office)

Ms K Doust, Solicitor, NSW Nurses and Midwives' Association for Ms Maryanne Matthews and Deborah Tillitzki

Non-publication orders: Non-publication orders made on 25 July 2022 prohibit the publication of various information and particular evidence within the brief of evidence. The orders can be obtained on application to the Coroner's Court Registry.

Findings:

Identity

The person who died was EW (a pseudonym).

Date of death

EW died between 11 and 12 July 2019.

Place of death

I find that EW died in Stockton, NSW.

Manner and cause of death

EW's death was caused by actions of a person known with the intention of ending life.

Recommendations:

See pages 40 to 43 of these Findings in respect of Recommendations directed to:

- (1) The First Assistant Secretary of the Australian Government Department of Health and Aged Care, Home and Residential Division.
- (2) The Chief Executive of Hunter New England Local Health District.

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Introduction

1. Section 81 of the *Coroners Act 2009* (**the Act**) requires a Coroner presiding over an Inquest to confirm that the death occurred and make findings as to:
 - (a) the identity of the deceased
 - (b) the date and place of the death; and
 - (c) the manner and cause of the death.
2. Under s. 82 of the Act a Coroner may make such recommendations as are considered necessary or desirable in relation to any matter connected with the death, including in relation to public health and safety.
3. By reason of the Non-publication Orders I will refer to the deceased as “EW” and her husband as “MW”. I intend no disrespect by doing so.
4. EW died at her home in Stockton (a suburb of Newcastle at an address known to the Court) on 11 or 12 July 2019. As EW’s death was not from natural causes, it was reported to the Coroner who has an obligation to investigate matters surrounding the death. A Coroner’s primary function is to establish firstly, the identity of the person who died, secondly, when and where that occurred and thirdly, the cause and the manner of death. The manner of a person’s death refers to the circumstances surrounding the death and the events leading up to it.
5. Sadly, and tragically EW’s death came about from the intention to end her life at the hands of her husband MW who then went on to end his own life. I describe it as a tragedy because the husband, MW was by all the evidence a loving and devoted husband who cared for his wife in a considerate and compassionate manner. Sadly, he saw both he and his wife suffering with ever increasing health-related issues arising from ageing and he believed there was no solution to the problem of providing care to his wife.
6. The background for this decision arises from being members of the religious faith known as Christian Scientists. EW and MW did not consult medical practitioners for treatment of any ailments believing that praying and their faith would heal them. They had no medical history and no contact with a General Practitioner. In their seventies they had successfully raised two children who were at the time of their death’s, adults living independently of their parents.
7. EW’s health issues included obesity, an ever-increasing loss of mobility, and some memory and other lapses around cognition. MW was her carer and by 2018 his role of carer was full-time, looking after EW in a two-storey home where she effectively remained on the second level. MW was himself becoming less physically able to assist EW – particularly in transitioning her from the bed to stand and attend to personal hygiene and dressing activities, cooking and some cleaning of the home.

Factual Summary

8. The summary is drawn from information contained in the Coronial Brief of Evidence (**Brief**)¹ and also a Statement of Agreed Facts (**Agreed Facts**).² The Agreed Facts document was prepared by Counsel Assisting and her instructing Solicitors with a contribution from legal representatives of the Hunter New England Local Health District (**LHD**). Although all parties were given an opportunity to make suggested amendments or additions, no other party suggested amendments. The Agreed Facts was tendered as an Exhibit at the Inquest.
9. Some information contained in the Brief falls under the terms of “Protected Information” of the kind covered by the provisions of Division 86 of the *Aged Care Act 1997* (Cth). A Public Interest Certificate for that material was signed by the relevant delegate on the 25 May 2022 permitting disclosure of the information noting it is “*necessary in the public interest for the purpose of this Inquest*”.
10. I acknowledge what follows is drawn from Counsel Assisting’s submissions.

Background

11. EW was born in 1944. She resided with, and was cared for by, her husband MW (born in 1943), at Stockton NSW (**the matrimonial home**).
12. Each of EW and MW’s deaths reportedly took place between 5:00pm on 11 July 2019 and 6:00am on 12 July 2019. EW’s death reportedly took place at the matrimonial home, and MW’s death in the ocean off Stockton Beach, Stockton.
13. EW and MW had two adopted children, a daughter and son.
14. According to the daughter:
 - (a) her parents were longstanding Christian Scientists who “*did not believe in modern medicine*” including taking medication or receiving medical treatment or in natural remedies as an option and believed that “*people got sick because of fear*” and “*that if you got sick you would pray for God to help you get better*”.
 - (b) her mother would always control any decisions her father made, and he would always do anything she wanted.
 - (c) when she lived with her parents at Castle Hill, EW and MW were part of the First Church of Christian Science in Hornsby and attended Church on Sundays and Wednesdays.
 - (d) in 2008, her parents moved to Brisbane for around 5 years.

¹ Exhibit 1.

² Exhibit 2.

- (e) in 2013, her parents returned to NSW and moved to their matrimonial home in Stockton. She would have dinner with her parents once a fortnight.³
15. According to the partner of the daughter, MW maintained contact with the Christian Science Church in Newcastle when MW and EW moved to Stockton, albeit to a limited extent, due to being full-time carer for EW “*for the last 3 years at least*”.⁴
16. According to the son, “*at the end of their time at Brisbane*”, MW and EW’s health declined, and he suspected EW had a stroke. Each of the children considered they were devoted parents.
17. On 3 April 2014, EW appointed MW, the daughter and the son as enduring Guardians with MW, and either the daughter or the son, to act jointly. On page 4 of the Appointment of Enduring Guardians Form, the following directions have been recorded:
- Call a Christian Science Practitioner listed in the Christian Science Journal
 - In conjunction with the Christian Science Practitioner, engage Christian Science Nurses where appropriate
 - If medically based care is sought, minimise medical intervention intended to extend my life, except where medical treatment is intended to keep me comfortable and minimise pain
 - I would prefer to be cared for at home (or in a nursing home if I am resident there) rather than in a hospital.⁵
18. In relation to services potentially available from Christian Science Nurses (or Christian Science Carers), in addition to spiritual reassurance, the scope of their services included physical care services such as helping people to bathe, preparing modified foods, bed care, bandaging wounds, and helping people who needed assistance moving about.⁶
19. EW also appointed MW, the daughter and the son jointly as enduring power of attorneys.⁷
20. According to Margaret McClelland (also known as “Marti”), a Christian Science Carer who was visiting and caring for EW from about March 2018 until her death, EW’s physical movement was in decline during that period and EW only wanted MW to assist her. She said that “[EW] and [MW] did not go to a doctor or want to get a medical opinion” and was “*unsure of the reason for this as the Christian Science Carers have no reason not to receive care*”.⁸
21. According to the daughter, in the year prior to her parents’ deaths, her mother’s health had declined significantly, and she did not talk much, could not keep up with conversations and her father had to assist her mother getting in and out of bed, with bathing, feeding, and attending the bathroom.⁹

³ Exhibit 1: Tab 4 at [5], [7], [12], [17].

⁴ Exhibit 1: Tab 6 at [25].

⁵ Exhibit 1: Tab 122.

⁶ Exhibit 1: Tabs 9 at [6]; 120 at p.2059.

⁷ Exhibit 1: Tab 123.

⁸ Exhibit 1: Tab 9 at [14], [16], [19].

⁹ Exhibit 1: Tab 4 at [18].

22. According to the son, his father pretty much did everything for EW and was not sleeping at all as EW had a doorbell next to her that she would ring at different times of the day and night.¹⁰

EW and MW and Aged Care and the Aged Care System

23. MW maintained a folder of material including notes related to his and EW's interactions with the aged care system (**MW's folder**).
24. On 9 February 2018, MW undertook online research into home care subsidy rates for home care packages (**HCP**).¹¹
25. MW recorded that on 21 August 2018, he spoke with a representative from My Aged Care (**MAC**). He notes, weeks to have an assessment and weeks following assessment for approval, in respect of home care packages "*12 months*" and in the interim, being able to access services from the Commonwealth Home Support Programme (**CHSP**).¹²
26. On 27 August 2018, MW received an email from The Heights [a home for up to 12 senior Christian Scientists situated in Victoria, according to their website]¹³ advising him that "*they do not feel that they would be able to give the time required to care for an additional resident with high care needs*" but that moving to one of their units would enable him to access help from the CS Visiting Nurse who resides in one of the units in the village.¹⁴
27. In a handwritten note dated 28 August 2018, MW refers to an ACAT comprehensive assessment for EW and a Regional Assessment Service (**RAS**) assessment for himself.¹⁵

Aims of RAS and ACAT and Types of Assessment

28. Various MAC documents, in force at the time that MW initially made contact with MAC, set out the aims and functions of RAS and ACAT assessments. The RAS is operated by organisations that are directly engaged by the Australian Government Department of Health and Aged Care (**Department**). The aims of the RAS and ACAT, are, amongst other things, to:
- (a) Ensure that older people from special needs groups have equitable access to assessment services; (with the Australian Government recognising the special needs of people with dementia and their carers);
 - (b) Ensure that assessments of older people are holistic, incorporating physical, medical, psychological, cultural, social, environmental and wellness dimensions;
 - (c) Provide short-term linking assistance or care coordination to vulnerable clients to address barriers that affect their access to aged care services.

¹⁰ Exhibit 1: Tab 5 at [16].

¹¹ Exhibit 1: Tab 116 at p.158-159.

¹² Exhibit 1: Tab 116 at p.26.

¹³ Exhibit 2: [16] (<https://www.vwa.net.au/the-heights-residence>).

¹⁴ Exhibit 1: Tab 116 at p.131.

¹⁵ Exhibit 1: Tab 116 at p.8.

29. In relation to the types of assessment, RAS or “Home Support Assessments” involve collecting information on the client’s:¹⁶
- family, community engagement and support
 - health and lifestyle
 - level of function
 - cognitive capacity
 - psychosocial circumstances
 - home and personal safety
 - level of complexity and risk of vulnerability; and
 - goals, motivations and preferences.
30. During the assessment, the RAS assessor and client are to work together to establish a support plan that reflects the client’s strengths and abilities, areas of difficulty, and the support that will best meet their needs and goals. This will include the consideration of formal and informal services as well as reablement pathways where appropriate.¹⁷
31. In relation to an ACAT assessment, a “Comprehensive Assessment” is undertaken which is said to build on the information already collected, and at a deeper level. The assessor will comprehensively assess the client’s physical capability, medical condition, psychosocial factors, cognitive and behavioural factors, physical environmental factors and restorative needs. The assessor and client are to work together to establish a support plan that reflects the client’s strengths and abilities, areas of difficulty, and the support that will best meet their needs and goals. This will include the consideration of formal and informal services as well as reablement and/or restorative pathways.¹⁸
32. ACAT assessments are conducted as part of the Department’s Aged Care Assessment Program (**ACAP**).¹⁹

Cognition and Decision making

33. MAC provides RAS and ACAT assessors with the “My Aged Care National Screening and Assessment Form (NSAF) User Guide” (**User Guide**) which is said to be “*A guide to the information required to be considered and recorded during the My Aged Care assessment proceed: Home Support Assessors and Comprehensive Assessors*”.
34. The User Guides in force in years 2018 and 2019 and specific information relating to “*Cognition*”, “*Changes in memory and thinking*” and “*Assistance with Decision Making*” are set out in Counsel Assisting’s submissions at paragraphs 42, 43, 44 and 45. While relevant they are not necessary to repeat in this decision.

¹⁶ Exhibit 1: Tabs 96 and 112 NH-24 at p.1335.

¹⁷ Exhibit 1: Tabs 96 and 112 NH-24 at p.1335.

¹⁸ Exhibit 1: Tabs 96 and 112 NH-24 at p.1335.

¹⁹ Exhibit 1: Tabs 96 and 112 NH-24 at p.1333.

Capacity to Consent and Authorised Representatives

35. In relation to the issue of consent, the “My Aged Care Assessment Manual For Regional Assessment Services and Aged Care Assessment Teams” (**the Manual**) in force in 2018 and 2019 provided that “*If the client is able to provide consent for someone else to speak and act on their behalf, they may nominate a regular representative*”.²⁰
36. In relation to any need for a substitute decision maker in the context of a lack of capacity to consent for someone to speak on their behalf, the Manual provides that:²¹

An authorised representative is needed if the client is not capable of providing consent for someone else to speak on their behalf. Legal documents are required to be in place for an authorised representative so that My Aged Care knows they can legally represent the client... An authorised representative is the primary contact for all communication with My Aged Care, and will receive all correspondence.

37. The “Legal documents” required to be in place for an authorised representative in NSW are not specified in the Manual, however, forms available on the MAC portal suggest that a copy of an Enduring Guardianship appointment document, together with a letter from a medical practitioner stating the client does not have the capacity to act on their own behalf, may be required.²²
38. The Manual also makes provision for the issue of “Consent” more generally:²³

Assessors must obtain consent, written or verbal, from the client prior to undertaking an assessment. If the client is not able to give consent, the consent should be obtained from a person who has the role of a regular or authorised representative in My Aged Care. Where there is no representative to assist with consent, the person will need to be referred to an organisation in their state or territory that is responsible for appointing a guardian.

ACAT “Linking Support/Care Coordination to Vulnerable Clients”

39. Once an assessment has been carried out, assessors may use a “match and refer process” wherein clients are referred to various service providers on the basis of their identified needs. However, for some people whose circumstances may impede their access to aged care services, MAC offers “Linking support”:²⁴

Most clients will be able to be assisted by assessors through the match and refer process offered through My Aged Care however facilitating linking support can greatly benefit some clients. Where an older person’s issues or circumstances may impede their access to aged care services, provision of linking support will assist in linking the client to one or more services they require in order to live with dignity, safety and independence. These may be formal or informal services. Linking support may also be seen as short-term case management or care coordination to the point of effective referral (see *10.3 Supporting a Successful Match and Refer Process*).

²⁰ Exhibit 1: Tabs 96 and 112 NH-24 at p.1337.

²¹ Exhibit 1: Tabs 96 and 112 NH-24 at p.1337.

²² Exhibit 1: Tabs 101 at p.800-804 (in force September 2018); 102 at p.805-809 (in force July 2019); 100 at p.792-799 (in force at time of hearing).

²³ Exhibit 1: Tabs 96 and 112 NH-24 at p.1337.

²⁴ Exhibit 1: Tabs 96 and 112 NH-24 at p.1362-1363.

Linking support activities are aimed at working with the client to address areas of vulnerability that are preventing access to receiving mainstream aged care support or care, to the extent that the client is willing or able to access aged care services. Issues leading to vulnerability could include homelessness, mental health concerns, drug and alcohol issues, elder and systems abuse, neglect, financial disadvantage and cognitive decline and living in a remote location.....

....The level of linking service support offered by assessors is time-limited, and is not designed to provide ongoing support services. The activities that an assessor chooses to undertake when providing linking support will be dependent on the needs, circumstances and preferences of the client and may include one or more of the following:

- **Information provision and tailored advice** – provision of clear, reliable, up-to date and relevant information and advice to clients regarding service options and pathways.
- **Guided referral** – facilitation and management of the process of linking a vulnerable client to appropriate service pathways within or outside the aged care system. This includes monitoring the success of the referral process, and ensuring that linking to the appropriate services is achieved
- **Service coordination** – where a client’s needs are complex and require a range of services spanning a number of sectors, the assessment organisation oversees the coordination of these services.
- **Advocacy activities** – in order for the vulnerable client to gain access to the identified support services, the assessment organisation may be required to speak, act and write to the identified service providers on behalf of the vulnerable client
- **Case conferencing/multidisciplinary service coordination** – provision of comprehensive, integrated service coordination for clients with high intensity needs. This involves using a case conferencing/multidisciplinary service coordination approach which brings together a number of team members and a suite of services across sectors in order to meet the client’s needs at different levels.

...

People with Dementia

40. MAC also makes provision for people with special needs, including those people with dementia, and their carers:²⁵

The Australian Government recognises the special needs of people with dementia and their carers. Assessors should foster links with dementia specific services, including Dementia Behaviour Management Advisory Services (DBMAS), and where relevant, include this expertise in the assessment process. This will facilitate an understanding of the needs of ageing people with dementia and their carers and assist improved linkages, integrated care and access.

Assessors must use their professional judgment if a client has dementia or is confused. In these cases, the input of carers and/or advocates is particularly important. Note that assessors should be aware that applying professional judgement might be especially difficult when dealing with patients from CALD backgrounds who might be suffering from dementia due to language barriers, lack of awareness of dementia among family members or due to stigma attached to dementia with some

²⁵ Exhibit 1: Tabs 96 and 112 NH-24 at p.1380-1381.

cultures. Some culturally appropriate dementia resources are included under further information below. ...

Assessors may find the National Health and Medical Research Council (NHMRC) approved Clinical Practice Guidelines and Principles of Care for People with Dementia (the Guidelines) useful. ...

Australian Government Department of Health and Aged Care and State Government Responsibility for ACAP

41. In relation to the issue of responsibility between the Department and the LHD for the administration of ACAP, the Manual states:²⁶

3.2. Aged Care Assessment Program (ACAP)

The **Commonwealth Government funds the States** and Territories to **administer** the Aged Care Assessment Program. Assessments under this program are conducted by the Aged Care Assessment Teams (ACATs). State and territory governments are **responsible for the day-to-day operation** of the ACAP including the timely delivery of assessments for care types under the *Act* as well as the **management, training and performance of individual ACAT assessors**. Each jurisdiction is required to manage workloads to ensure that priority is given to those in greatest need and that access to aged care services is not delayed unnecessarily.

Each ACAT is multi-disciplinary and includes a range of health-related disciplines such as medical practitioner, registered nursing, social work, physiotherapy, occupational therapy and psychology. The Department has oversight responsibility for the ACAP including providing advice on Australian Government policy, the monitoring and reporting of performance against agreed service levels, and the management of regulatory and other administrative processes relating to the *Act*. **The Department and the state and territory governments are jointly responsible** for establishing communication protocols, working cooperatively to develop nationally consistent approaches to ACAP operations, and participating in regular forums to support the national administration of the ACAP [**bold** added].

My Aged Care: Screening on 28 August 2018

42. On 28 August 2018, a National Screening and Assessment Form (**NASF**) Screening was undertaken for each of EW and MW.
43. With respect to EW, the reason for contact is identified as EW requiring assistance with personal care and domestic assistance due to being overweight and unable to move around very much. Further it is recorded that EW has not seen a doctor for many years as both she and MW rely on their religion and pray for their healing.²⁷ MW was registered as a Regular Representative for EW.²⁸
44. With respect to MW, the reason for contact is identified as being the “*level of care that is currently available does not meet the client’s needs and not sustainable long-term*”. Further, it is recorded that MW feels very weak and vague but does not go to a doctor because he believes his religion and prayer will keep him well.²⁹

²⁶ Exhibit 1: Tabs 96 and 112 NH-24 at p.1333-4.

²⁷ Exhibit 1: Tab 48 at p.1, 4.

²⁸ Exhibit 1: Tab 22 entry 28/08/2018 15:41.

²⁹ Exhibit 1: Tab 42 at p.1, 3.

45. On the morning of 4 September 2018, the RAS Southern received a separate referral from MAC in respect of MW and EW.³⁰

My Aged Care: RAS Assessment of MW on 5 September 2018

46. On 5 September 2018, Laura Lubinski (Home Support Worker) visited and conducted an RAS assessment of MW at home using the NSAF Home Support Assessment Screening tool, with EW and the daughter in attendance. Ms Lubinski was not a registered health professional. Given the documentation completed before the assessment, Ms Lubinski knew, even before she saw EW, that she was very dependent on MW.³¹

47. MW was assessed by Ms Lubinski as scoring:

(a) 20 out of 20 in respect of Barthel Index of Activities of Daily Living

(b) 10 out of 13 for Caregiver Strain Index (CSI); and

(c) 10 in respect of his K-10 assessment.

48. Ms Lubinski made direct referrals for MW to Newcastle Community Transport for Transport Assistance, Integrated Living-Hunter for Transport Vouchers/Subsidies and Hunter Home Modifications for Home Maintenance Assistance.³²

49. Ms Lubinski also provided MW with referral codes for the following and a list of providers:

- *Domestic Assistance – General House Cleaning: Priority Medium.*
- *Transport – Direct (driver is volunteer or worker): Priority Low (it is noted services in place are Community Transport – Newcastle).*
- *Transport – Indirect (through vouchers or subsidies): Priority Low (it is noted that a referral to integratedliving Australia-Hunter was made).*
- *Home Maintenance – Minor Home Maintenance and Repairs and Major Home Maintenance and Repairs: Priority Low (it is noted that services in place are Hunter Home Modifications).*
- *Meals – At Home: Priority Medium.*³³

³⁰ Exhibit 1: Tabs 49 (EW); 44 (MW).

³¹ Transcript: 25 July 2022 at P33 L33-35.

³² Exhibit 1: Tab 46 at p.2.

³³ Exhibit 1: Tab 46 at p.3-6.

50. Ms Lubinski states at the end of the assessment she would have provided MW with brochures, such as the “My Aged Care” and “Carer gateway” brochures.³⁴ Relevantly, MW’s folder includes copies of the “Carer Gateway”, “Support for Carers” and “For aged care services contact My Aged Care” brochures, with the latter including handwritten notes relating to Ms Lubinski’s assessment of MW.³⁵ Ms Lubinski detailed in her notes, ‘*No further RAS intervention is required at the time of this report.*’³⁶

My Aged Care: RAS Assessment of EW on 5 September 2018

51. On 5 September 2018, Ms Lubinski also conducted an assessment of EW at home using the NSAF Home Support Assessment, with MW and the daughter in attendance.³⁷
52. EW was assessed by Ms Lubinski as scoring:
- (a) 10 out of 20 in respect of Barthel Index of Activities of Daily Living; and
 - (b) 10 in respect of her K-10 assessment.
53. Ms Lubinski also recorded, “*Strong belief system*”. MW’s CSI was recorded as 10 out of 13 and as being “*borderline overwhelmed*”.
54. Ms Lubinski recorded:
- (a) EW presents with declining function, and MW as carer provides assistance including toileting, transfers, moderate hands-on assistance with personal cares, online shopping, meal preparation, washing, light domestic tasks and is responsible for financial management.³⁸
 - (b) EW does not have any access to respite currently, and MW never has a break longer than 1-2 hours and that EW has stopped attending community activities due to difficulties with mobility and being comfortable at home.³⁹
 - (c) EW has no GP and that she may have some anxiety with attending health care practitioners.⁴⁰ Ms Lubinski says that EW and MW told her that because of their religion, EW did not have a GP.⁴¹
 - (d) in respect of cognition, that EW reported that she sometimes struggles with remembering things and the daughter reported that EW sometimes gets a bit confused and loses her train of thought.⁴²

³⁴ Exhibit 1: Tab 11 at [59].

³⁵ Exhibit 1: Tab 116 at p.70-76, 211-12.

³⁶ Exhibit 1: Tab 43 at p.3.

³⁷ Exhibit 1: Tabs 52; 50 at p.2-3; 53 at p.1.

³⁸ Exhibit 1: Tab 52 at p. 9-10.

³⁹ Exhibit 1: Tab 52 at p.4 & 6.

⁴⁰ Exhibit 1: Tab 52 at p.13-14.

⁴¹ Exhibit 1: Tab 12 at [22].

⁴² Exhibit 1: Tab 52 at p.13.

- (e) EW would like to continue living in her home with ongoing support for MW as carer and access to services to assist her to manage her needs and reduce stress on MW and concludes that EW would “*benefit from a variety of services, including personal care, meals assistance and in home respite.*”⁴³
- (f) that an Occupational Therapy Assessment of the home environment was urgently required for EW’s safety and independence and continued mobility, as well as MW’s safety and independence while assisting EW.⁴⁴

55. Ms Lubinski made direct referrals for EW to:

- *Newcastle Community Transport for Transport Assistance.*
- *“Integrated Living-Hunter” for Transport Vouchers/Subsidies.*
- *HNELHD-Allied-Occupational Therapy-Hunter for assessment as consented to by EW.*
- *ACAT-Hunter for Comprehensive Assessment for access to Residential Respite and eligible HCP, as consented to by EW.*⁴⁵

56. Ms Lubinski detailed she would provide EW with the following in accordance with EW’s wishes to discuss with MW before accessing any services subsidised under the CHSP:

- Referral codes for Home Modifications and Goods/Aids/Equipment.
- Referral code and provider list for Flexible Respite, Personal Care Assistance and Meals Assistance.⁴⁶

My Aged Care: ACAT Assessment of EW on 17 September 2018

57. On the afternoon of 13 September 2018, Hunter Aged Care Assessment Service (**HACAS**) received a referral from MAC in respect of EW and a Home / Facility Risk Assessment form was completed by Charlotte Cork (Clerical and Administrative Worker) based on information obtained in MAC Portal in consultation with MW.⁴⁷

58. On 17 September 2018, Maryanne Matthews (ACAT Clinician and Registered Nurse (**RN**) (Generalist)) visited and conducted a comprehensive assessment of EW at home using the NSAF, Comprehensive Assessment in the MAC Portal, with MW and the daughter in attendance.⁴⁸ RN Matthews was accompanied by Justin Mudford a student nurse.

⁴³ Exhibit 1: Tab 52 at p.1 & 16.

⁴⁴ Exhibit 1: Tab 11 at [41] & [65].

⁴⁵ Exhibit 1: Tab 53 at p.2-3.

⁴⁶ Exhibit 1: Tab 53 at p.2-3.

⁴⁷ Exhibit 1: Tabs 56; 57; 10 at [8], [11].

⁴⁸ Exhibit 1: Tabs 55 at p.2; 65.

59. An ACAT Assessment Consent Form, and an Application for Care under the Aged Care Act 1997 to receive aged care namely, residential care, home care and residential respite care was signed by EW herself.⁴⁹
60. The records state the assessment was triggered due to the increasing carer stress being suffered by MW arising from an increase in EW's care needs.⁵⁰
61. A Mini Mental State Exam (**MMSE**), a "*Memory and Cognitive Screening Test*" was administered by Mr Mudford at 1:30pm, in which EW scored 17 out of 30.⁵¹ She also completed a Standardised Mini Mental Status Exam (**SMMSE**) – Part B, Clock Drawing Task administered by Mr Mudford and scored 1 out of 4.⁵² An LHD form was used in respect of each of these assessments. RN Matthews commented in respect of cognition, "*Moderate cognitive issues evident*" and "*would benefit from geriatrician review*" and recorded EW as having short term memory problems regularly, and occasionally, long term memory problems, and disorientation with time.⁵³
62. EW was also assessed by RN Matthews as scoring 9 out of 20 in respect of Barthel Index of Activities of Daily Living.⁵⁴
63. MW was assessed against the CSI by RN Matthews. A hard copy CSI form records that MW scored 8 out of 13 and it is detailed "*[EW] likes to be in charge*".⁵⁵ This form details that in respect of counting yes responses, "*Any positive answer may indicate a need for intervention in the area. A score of 7 or higher indicates a high level of stress*".
64. The CSI form embedded in the NSAF completed by RN Matthews contains a different score, namely, 11 out of 13, with commentary of "*borderline overwhelmed*".⁵⁶
65. RN Matthews detailed in respect of her assessment:⁵⁷
- (a) "*[EW] has strong religious beliefs and practices as a Christian Scientist. She therefore does not have GP and his [sic] nil medical history. She attributes her functional decline to a combination of old age and obesity*". RN Matthews recalls telling EW "*You should really see a doctor*", which she "*politely declined*".
- (b) "*Recent optometrist visit confirmed cataracts in both eyes.*"
- (c) "*In order to alleviate carer stress it is suggested that [MW] has regular in-home respite to allow him some time away from the home. It is important to [EW] that she remains at home with adequate support to meet her needs. She does however consent to accessing residential respite care and/or residential care if required.*"

⁴⁹ Exhibit 1: Tabs 58; 60; 116 at p.304.

⁵⁰ Exhibit 1: Tab 65 at p.4.

⁵¹ Exhibit 1: Tabs 61; 66 at p.2.

⁵² Exhibit 1: Tabs 62; 66 at p.2.

⁵³ Exhibit 1: Tabs 65 at p.14; 66 at p.2.

⁵⁴ Exhibit 1: Tab 66 at p.2.

⁵⁵ Exhibit 1: Tab 63.

⁵⁶ Exhibit 1: Tab 65 at p.20.

⁵⁷ Exhibit 1: Tab 66 at p.1-2.

66. RN Matthews states her usual practice, after an assessment, is to explain how carers can access assistance through service providers and provide copies of information regarding local service providers.⁵⁸

67. EW was provided with referral codes which included the following.⁵⁹

- *Meals – At Home: Priority High.*
- *Allied Health and Therapy Services – Occupational Therapy: Priority High for safety, mobility, advice, and equipment (it is also noted that a referral to HNELHD – Allied Health – Occupational Therapy had been accepted with priority high).*
- *Personal Care – Assistance with Self-Care: Priority High, Priority Medium.*
- *Goods, equipment, and assistive technology – Support and mobility aids, self-care aids and reading aids: Priority High.*
- *Flexible Respite: In-home Day Respite: Priority High.*
- *Allied Health and Therapy Services – Podiatry: Priority Medium.*
- *Flexible Respite – In-home Day Respite, In-home Overnight Respite, Mobile Respite, and Other planned respite: Priority Medium.*
- *Residential Permanent: Priority Medium.*
- *Home modifications: Priority Medium.*
- *Residential Respite High Care: Priority Medium.*
- *Home Maintenance – Garden Maintenance, Minor Home Maintenance and Repairs: Priority Medium.*
- *Domestic Assistance – Unaccompanied Shopping (delivered to home), General House Cleaning and Linen Services: Priority Medium.*
- *Social Support Individual: Priority Low.*
- *Other Food Services – Food Preparation in the Home: Priority Low.*
- *Transport – Direct (driver is volunteer or worker): Priority Low.*
- *Transport – Indirect (through vouchers or subsidies): Priority Low (it is noted that a referral to “integratedliving Australia-Hunter” had been accepted).*
- *Meals – At Home: Priority Low.*

⁵⁸ Exhibit 1: Tab 13 at [20].

⁵⁹ Exhibit 1: Tab 116 at p.177-178, 182-189.

- *Specialised Support Services – Contingency Advisory Services and Vision Services: Priority Low.*
 - *Goods, equipment, and assistive technology: Priority Low.*
68. RN Matthews recommended EW as eligible for high level residential respite care and permanent residential care and HCP Level 4.⁶⁰
69. On 20 September 2018, Rachel Merten, ACAT, Delegate of the Secretary, Department, and Social Worker, HACAS, considered EW’s medical, physical, psychological, and social circumstances insofar as ACAT documentation.⁶¹
70. Ms Merten was of the view that:
- (a) EW needed help to perform daily living tasks.
 - (b) EW would benefit from increased social and community participation.
 - (c) the following ongoing assistance with everyday activities might be of benefit for EW: nutrition and hydration, personal hygiene, toileting, mobility/transfers as well as shopping, transport, social support, and domestics.⁶²
71. EW was approved by Ms Merten as eligible, by reference to the legislation and eligibility principles, to receive the following care types from 20 September 2018:⁶³
- Permanent Residential Care.
 - Residential Respite Care at High level (with such approval allowing up to 63 days of subsidised residential respite care in a financial year with a possible extension/s of up to 21 days upon application to ACAT).
 - HCP Level 4 (*Priority: Medium*) EW was placed on the national queue, to be notified when an HCP is assigned. Ms Merten states that EW’s medium priority had been determined using the information obtained during EW’s assessment.
72. The Support Plan further indicated that with respect to current care approvals, HCP Level 4, “*Minimum agreed interim package level: Home Care Package Level 3*”.⁶⁴

Community Services referrals: Occupational Therapy & Physiotherapy (September 2018 – January 2019)

73. On 18 September 2018, April Morsley (community Occupational Therapist (**OT**)) reviewed the referral for occupational therapy services for EW and had a discussion with Ms Lubinski and RN Matthews. Ms Morsley recorded that EW has a strong belief system (Christian Scientist) and does not believe in medical input (i.e., has no GP or medications) and that Ms Matthews was concerned about carer

⁶⁰ Exhibit 1: Tab 13 at [53].

⁶¹ Exhibit 1: Tabs 55 at p.1; 68 at p.2; 14 at [17].

⁶² Exhibit 1: Tab 68 at p.2.

⁶³ Exhibit 1: Tab 68 at p.1.

⁶⁴ Exhibit 1: Tab 66 at p. 13.

stress as EW was heavily reliant on MW for all ADLs and mobility. EW was ultimately seen by OT, Ms Katie Cook, who states she reviewed Ms Morsley's note in preparation for a home visit with EW and MW.⁶⁵

74. On 24 September 2018, Ms Cook conducted an initial assessment of EW's home environment for the purpose of improving safety and independence of EW and MW as carer, with EW and MW both present.⁶⁶
75. In her Initial Assessment Report, Ms Cook:
- (a) detailed in respect of the cognition section, "*Recent MMSE*".
 - (b) expressed concern over a ceiling track hoist MW had installed over the stairs for EW and MW utilising safe manual handling techniques in respect of bed transfers and mobility which MW was finding difficult at times (and noted EW seemed to have more physical capability than what she exhibited). She also expressed concern around why EW was unable to attend to perineal hygiene following toileting herself.
 - (c) concluded that "*[EW] is experiencing a decline in her overall strength and balance however due to not seeking medical advice the cause of same if unknown. She does not wish to seek preventative/rehabilitatory [sic] services such as Physiotherapy and was more open to compensatory strategies. OT is concerned regarding the care demands being placed on clients husband as well as manual handling risks. [MW] however does not present as concerned with same when this was discussed and is happy to care for client. He is open to advice from OT however has also many DIY interventions which are underway...*"⁶⁷
76. Following this, Ms Cook assisted EW and MW by way of sourcing assistive equipment and aids to assist MW care for EW; demonstrating use of same which included home attendances with them both present; and phone calls with MW up until 12 April 2019.
77. Ms Cook made a referral to Greater Newcastle Physiotherapy on behalf of EW, and Chris Baker, (Community Physiotherapist (**PT**)) conducted a Physiotherapy Initial Assessment on 14 December 2018 at EW's home for the purpose of reviewing EW's falls risk and ability to mobilise.⁶⁸
78. Mr Baker recorded that EW presented with a falls risk, was deconditioned, had difficulty with bed transfers, and often required a lot of assistance from MW to transfer and to mobilise. Mr Baker noted that she sometimes presented as challenged to follow instructions and/or lacked motivation to mobilise and that MW had expressed concern about his own physical condition due to the manual handling. Mr Baker provided EW with a Home Exercise Program including a daily regime of exercises to assist with mobilisation which he was of the view was deteriorating.⁶⁹

⁶⁵ Exhibit 1: Tabs 71 at p.6; 15 at [19].

⁶⁶ Exhibit 1: Tab 71 at p.6-7.

⁶⁷ Exhibit 1: Tab 15, Annexure A.

⁶⁸ Exhibit 1: Tab 16 at [10].

⁶⁹ Exhibit 1: Tab 16 at [25]-[26], [29].

79. Mr Baker further attended EW's home on two occasions after 14 December 2018 to review EW's progress, including 8 January 2019, where he provided a four wheeled walker (**4WW**) to reduce her falls risk.⁷⁰ He closed the referral on 25 January 2019 due to EW advising him that she did not wish to continue with further physiotherapy reviews as her mobility was the same and she already had a Home Exercise Program in place and had trialled the 4WW, but she felt did not need it as MW was there to help her mobilise as required.⁷¹

80. Select extracts of notes and/or emails as prepared by Ms Cook, Mr Baker, MW and other extracts are referred to in Counsel Assisting submissions at paragraph 91. I have not set them out in full. A brief summary is below:

- **8 October 2018 – Telephone call from Ms Cook to EW and MW:**

“Clients husband feels that client is not putting in effort in order to assist or improve same.”⁷²

- **25 October 2018 – Home attendance by Ms Cook:**

“Clients husband expressed ongoing concern with getting client in and out of bed. In particular getting client from sitting to lying and lying to sitting. He reports strain in his lower back... Client refused to practice transfers with OT ... Impression: Clients husband is committed to looking after client in their own home for as long as possible. Because client does not have a GP or medical diagnosis it is difficult to know how her mobility may continue to deteriorate and the progression of same.”⁷³

- **31 October 2018 – Telephone call from MW to Ms Cook:**

“OT ... expressed that it was difficult to understand the cause of why [EW] was unable to transfer in and out of bed when she is able to mobilise and sit to stand with minimal assistance.?neurological ? behavioural.”⁷⁴

- **13 November 2018 – Home attendance by Ms Cook:**

“Client advised that she and her husband had been disagreeing on many things relating to her care. Husband [MW] advised that [EW] did not seem to realise the extent of her care needs and that he was trying to continue to look after her... Client expressed that she does not like change and does not want to change anything... ..Impression: OT believes there is a large cognitive behavioural element of why client is able to perform some physical activities and not other. As client does not have a GP and is not seeking any medical intervention there is no diagnosis to support same. Client's cognition appeared to have deteriorated significantly in between last OT visit and now with client losing her attention and train of thought and therefore finding it difficult to participate in conversation.” EW agreed to a referral to a PT.⁷⁵

⁷⁰ Exhibit 1: Tab 80 at p.3-4.

⁷¹ Exhibit 1: Tab 16 at [45], [48].

⁷² Exhibit 1: Tab 71 at p.8.

⁷³ Exhibit 1: Tab 71 at p.9-10.

⁷⁴ Exhibit 1: Tab 71 at p.10-11.

⁷⁵ Exhibit 1: Tab 71 at p.11-13.

- **7 December 2018 – Telephone call from Ms Cook to MW:**

“...to review situation. [MW] advised clients condition and ability to function remains unchanged since last OT visit...”⁷⁶

- **7 December – Handwritten note of MW:**

“...Next Step Visit by physio, who can assess whether [EW's] weak strength is from inadequate muscles, or mental [? possibly blank or block]...”⁷⁷

- **7 December 2018 – Email from Ms Cook – PT referral**

“Client is having particular difficulties with bed transfers and is [sic] maximum assistance to go from lying to sitting on the edge of the bed. Clients husband is at risk of injuring himself during same...COGNITION/MEMORY ISSUES: Not formally assessed however some cognitive and behavioural components suspected by OT to be impacting on participation in transfers”.⁷⁸

- **10 December 2018 – Telephone call from MW to Ms Cook:**

“[MW] advised that while he appreciated the efforts in trying to understand what was going on for [EW], he is finding it increasingly difficult to transfer her in and out of bed. ...OT is concerned that along with strength there is a large cognitive or behavioural component which is impacting on her ability to transfer in and out of bed. OT expressed that it was difficult due to no understanding of clients medical history and what is going on for her. [MW] expressed that he understands that this may be the case however he is feeling that is [sic] unable to maintain the physical nature of the transfer and is at risk of injury.”⁷⁹

- **14 December 2018 – Home attendance by Mr Baker (Initial PT assessment)**

“Mobility restricted by excessive weight, sensory, cognitive, substance-related or motivational problems [risk factor] no... General/Cognition/Mood/ Appearance: sometimes challenged to follow instructions; lacks motivation... PROBLEMS: falls risk; deconditioned; difficulty with bed transfers – requires husband's close attention at all times; stays upstairs doesn't have a GP... Spoke to referring OT about client condition – appears client is physically deteriorating and mobilising less; husband stated he is concerned about his own physical condition as client requires a lot of manual handling.”⁸⁰

- **20 December 2018 – Client case conference (Ms Cook) with Community PT (Mr Baker) – Notes of Ms Cook:**

“Client case conference with Community Pt who visited client last week for first assessment. Concerns exist surrounding clients cognition which is significantly impacting on her ability to follow instructions and assist with transfers...Client also appears to have deteriorated quite significantly

⁷⁶ Exhibit 1: Tab 71 at p.13.

⁷⁷ Exhibit 1: Tab 116 at p.292.

⁷⁸ Exhibit 1: Tab 80 at p.2.

⁷⁹ Exhibit 1: Tab 71 at p.13-14.

⁸⁰ Exhibit 1: Tab 71 at p.3-4.

since OT's first visit in the way of her being able to communicate more effectively and answer more questions/follow instructions." ⁸¹

- **22 December to 28 December 2018 – Handwritten note of MW:**

On 28 December 2018, MW details he was informed, "*Westcott* [Stockton Residential Home (Presbyterian Aged Care (PAC)), also known locally as "Westcott"] *does not have an appropriate place at present. Said I could phone in week to see if situation had changed (so sounds like a shortage of accommodation or staff rather than [EW's] condition)*". ⁸²

- **8 January 2019 – Home attendance by Mr Baker:**

"... [client] still not able to follow instructions well and needs prompts." ⁸³

- **23 January 2019 – Home attendance by Ms Cook:**

"..OT sat with client and explained the equipment being delivered and set up and advised that it was being put in place due to significant difficulties with getting client in and out of bed. OT discussed that clients husband had expressed he was no longer able to lift her and that he was fearful of injury both himself and client. Client continued to express that there was not an issue and [MW] could do it.....

...Client wishes to remain at home with her husband caring for her. Client's husband wishes to remain caring for her. Client and husband do not have any family that can assist with daily care and they are on the waiting list for a home care package. Client's husband reported that he has enquired to Stockton Residential care regarding Respite which will be their next option. Client appears to display little/no insight into her physical limitations and the demands that it is placing on her carer.." ⁸⁴

- **25 January 2019 – PT referral closed:**

"Outcomes: client given a HEP; not willing to co operate fully to help self and husband with transfers; OT has ordered more equipment to aid transfers." ⁸⁵

- **29 January 2019 – Typed notes of MW:**

"NOTES BY [MW] ABOUT HIS ASSISTANCE WITH HIS CARING FOR [EW]

...What carer assistance do I need?

I (and my daughter) think I need assistance so I am not working such long hours. ([S]on) thinks my competency with hoist and sling is limited and we should have a skilled carer to do such duties every day...

Realistically I am probably tied to being on the carer night shift, which in turn means I need an hour or so sleep during the day. Currently I am doing this, sleep starting between 4 and 5 pm...

⁸¹ Exhibit 1: Tab 71 at p.15.

⁸² Exhibit 1: Tab 116 at p.13.

⁸³ Exhibit 1: Tab 80 at p.4-5.

⁸⁴ Exhibit 1: Tab 71 at p.18-19.

⁸⁵ Exhibit 1: Tab 80 at p.5.

.. However there is a well funded support organisation (Christian Science Nursing Services NSW Ltd) which provides financial assistance to CS nurses where the patient cant afford the full fee..... I don't think an aged pensioner patient would be expected to afford anything..."⁸⁶

- **30 January 2019 – Southern Cross – Hunter Personal Care rang MW (MAC Portal record):**

"[MW] is needing flexible respite rather than personal care for [EW] to allow him to go out one day a week. [MW] will explore the flexible respite options and call back if he decides he needs personal care".⁸⁷

- **1 February 2019 – Telephone call from Ms Cook to MW:**

"[MW] advised that he is finding the equipment [hospital bed and hoist] very effective and it has taken a big strain off him from a manual handling and fatigue aspect."⁸⁸

- **10 February 2019 – Handwritten note of MW:**

"SMH 10 Feb 2019

"Waiting list for Home Care has grown to 127,000.

Many waiting more than a year."...

- **15 February 2019 – Telephone call from Ms Cook to MW:**

"[MW] advised that he would be getting 2 carers in shortly who would be assisting him in caring for [EW] and would be using the hoist as would not be allowed to do the manual handling required. OT enquired as to which care agency they were through. Husband reported that they were through the couples church and therefore familiar with their beliefs and [sic] values. OT enquired as to whether they were trained carers in which [MW] advised they were. OT advised that these carers would need to be trained in the use of the hoist and to contact OT once more was known regarding their commencement."⁸⁹

- **22 February 2019 – Handwritten note of MW:**

"...For Katie Discussion

[EW] has used sling sometimes a couple of times to get into bed. Sometimes she managed to lift herself into bed without my assistance (with groans and complaints)→ take hoist away?

... As husband / carer I am very committed to helping her stay at home. The hoist / sling is a great comfort to me [original emphasis] without it I would feel inadequate helpless & vulnerable to strain

... Bottom line is I would like to have the hoist stay. This doesn't require any action by Katie, just leave things as they are.

Logical arguments are one thing, but I am dealing with feelings, not always rational and being supported by less than angelic thoughts including:

- resistance to change

⁸⁶ Exhibit 1: Tab 116 at p.217-218.

⁸⁷ Exhibit 1: Tab 22 entry 5/02/2019, 10:42.

⁸⁸ Exhibit 1: Tab 71 at p.19-20.

⁸⁹ Exhibit 1: Tab 71 at p.20.

- telling lies
- tears
- criticism

[The daughter] who is very logically orientated (and has no children) says [EW] needs to suffer until she aligns with reality – like shutting the nursery down & leaving the baby to cry itself to sleep. I cant do that – is that being soft & manipulated & or unconditional love? ”⁹⁰

- **25 February 2019 – Typed and handwritten note of MW:**

“...The OT (Katie) is due this week to reassess our use of the hoist and sling we have on loan from the NSW govt. If they are not being used she may take them back for use elsewhere... If the hoist and sling are taken away and at some stage in the future [EW] cannot lift herself into bed [MW] will not be stepping in to do the lifting. He did that before and strained some muscles and risked other serious damage. [EW] will have to manage without getting into bed, which means sleeping in a chair if still living at home. Otherwise to sleep in a bed she will have relocate to a care facility.

To avoid this we need to immediately start lifting [EW] into bed with the hoist and sling.

[The daughter] email 25/2: .. we are getting in carers who will need to use it...”⁹¹

- **26 February 2019 – Handwritten note of MW:**

“Discussion with [EW] on need for carers [original emphasis]

[MW] will take 2 breaks for caring per week. Duration 4-6 hours...

[EW] will sit in the lounge during these time & manage without a carer...”⁹²

- **12 April 2019 – Telephone call from Ms Cook to MW:**

“[MW] advised that they were not using the hoist at present as [EW]'s bed transfers had improved significantly and he is only requiring to slightly lift the legs to assist her into bed... [MW] advised that they have not utilised the 'carers' from their church as yet as [EW] is very private and does not wish to have external help if not required. [MW] reports he is coping well [EW]'s care at present. He is able to leave her for several hours and has purchased a personal alarm for her to use if required. OT asked [MW] whether he felt comfortable using the equipment in place. He advised that he did ...

[MW] had several questions regarding Enable equipment and the HCP once it is in place. OT answered these questions. OT encouraged [MW] to contact My Aged Care should he have any further questions.

OT advised that I would now be closing [EW]'s service request but that she could be re-referred at any time.

[MW] thanked OT for input.’

SR [service request] to be closed.”⁹³

⁹⁰ Exhibit 1: Tab 116 at p.229-232.

⁹¹ Exhibit 1: Tab 116 at p.233.

⁹² Exhibit 1: Tab 116 at p.201.

⁹³ Exhibit 1: Tab 71 at p.20-21.

- **12 April 2019 – Handwritten note of MW:**

“Katie phoned today, asked how things were going. I said we were living day to day. [EW] getting weaker but still not using the hoist to get in and out of bed. The presence of the hoist seems a great motivation for her to try harder. She is doing most of the work, I give help a little, not straining myself.

She said she would “discharge” [EW] from her care because we were managing OK at present. This means we can phone her if we need more assistance & she will open a new referral...”⁹⁴

- **25 June 2019 – 8 July 2019:**

EW’s handwritten notes detail that he had been making enquires with Westcott (in respect of residential respite care and permanent residential care),⁹⁵ The Heights, Southern Cross, Baptist Care and CS Nurses.⁹⁶

The daughter states that her father had received an email from the CS Church advising they would speak with him on 16 July 2019 in respect of their CS Nurse services, however, with the main church in Sydney she was of the view that this would not have been a feasible solution.⁹⁷

In a typed note of 27 June 2019 [MW] details:⁹⁸

“...Family meeting 26 June 2019

Present: [MW] (chair), [EW], [the son], [the daughter], [the partner of the daughter]

Purpose: Ease [MW]'s carer load, possibly including

- an hour or two off during the day
- eliminate night calls
- a block of several hours off in a day
- 2 weeks holiday (complete break)
- [EW] in residential respite care
- [EW] in permanent residential care
- streamlining care...

Actions

1. arrange Westcott Coordinator visit
2. consider what days to have what in home care, fine tune with Coordinator
3. book up [sic] for in home care to commence
4. discuss with CS nurses how they can contribute to in home care
5. follow through but don't finalise on request for permanent residential care at Westcott to test process and likely future availability.

Short term vision firming up:

⁹⁴ Exhibit 1: Tab 116 at p.202-203.

⁹⁵ Exhibit 1: Tab 116 at p.32-69.

⁹⁶ Exhibit 1: Tab 116 at p. 3, 12, 18-19, 29-31, 132-133.

⁹⁷ Exhibit 1: Tab 4 at [16].

⁹⁸ Exhibit 1: Tab 116 at p.132-133.

Keep [EW] at home with 15 hours pw in home care for 2 months so she adjusts to this much change first. Then review whether [MW] can sustainably carry the remaining care load or whether more professional care is needed - if much more is needed then transfer [EW] to residential care, either to respite care to give [MW] a good break (then revert to in home care and monitor for sustainability) or to permanent residential care, which could be at Wescott or at The Heights (with [MW] also at The Heights on and off until Stockton home is sold).⁹⁹

- **27 June 2019:**

Southern Cross advised the daughter by email in relation to her enquiry concerning personal care assistance in the Stockton area, that they were at capacity for all of their CHSP funded services in the area including personal care. Further, they advised they were not funded for CHSP respite in the area. This email was forwarded by the daughter to MW.¹⁰⁰

BaptistCare advised the daughter by email that they could help in the future with services under a HCP level 4 once the HCP is assigned to EW and that unfortunately, their CHSP interim care personal care and respite services were at capacity. This email was also forwarded by the daughter to MW.¹⁰¹

- **28 June 2019:**

MW rang MAC Contact Centre Staff and requested approval for a high priority for the Home Care Package Level 4.¹⁰² MW recorded that he rang HNE Health to enquire about level 4 priority for HCP and interim level 2 package. "*Level 2 budget is \$15,000 p.a, wait time 3-6 months = 5 hrs pw.*"¹⁰³

On this day, the daughter emailed MW to advise that Australian Unity had rung her and advised that they have a waitlist that EW could be put on for funded personal care, domestic assistance, and respite subject to receipt of her referral codes. Further, Australian Unity anticipated they would be able to take on further clients in the new financial year.¹⁰⁴

The daughter also forwarded MW an email from Kinicare in which they provided a copy of some brochures and their price list and advised the daughter to make contact once EW was assigned a HCP.¹⁰⁵

- **Around 1 July 2019**

MW received a PAC package including a Consumer Service Agreement for flexible respite under CHSP for EW and had signed the Charter of Aged Care Rights attachment on behalf of EW on 1 July 2019.¹⁰⁶

⁹⁹ Exhibit 1: Tab 116 at p.132-133.

¹⁰⁰ Exhibit 1: Tab 124.

¹⁰¹ Exhibit 1: Tab 125.

¹⁰² Exhibit 1: Tab 22 entry 28/06/2019 10:15.

¹⁰³ Exhibit 1: Tab 116 at p.1.

¹⁰⁴ Exhibit 1: Tab 126.

¹⁰⁵ Exhibit 1: Tab 127.

¹⁰⁶ Exhibit 1: Tab 116 at p.32-69.

My Aged Care: ACAT Assessment of EW on 9 July 2019

81. On 2 July 2019, HACAS received a Service Request from [MW] to arrange a further assessment and a review of the HCP priority for EW.¹⁰⁷ On that day, Lynne Williamson, ACAT Assessor completed a support plan review and referred EW to ACAT for high priority HCP approvals and recorded “*complex care needs*” and “*carer strain evident*”.¹⁰⁸
82. On 3 July 2019, PAC received and accepted a referral for flexible respite and in-home day respite (priority high) in relation to EW in connection with the PAC Wescott Day Respite Service.¹⁰⁹ That same day, MW emailed Sharon du Toit, Christian Science Nurse, requesting her assistance with caring for EW five hours each Wednesday, noting he had recently arranged some in home care provision through Westcott for EW four hours, four days a week to attend to assist EW with meals for breakfast and lunch, showering, dressing, toileting, washing and providing company. MW indicated his current caring regime was exhausting him and unsustainable and stressed his need for assistance from Ms du Toit as “*pressing*”. Ms du Toit responded a couple of hours later, indicating that she will have availability to be in touch with him about his request after 16 July 2019.¹¹⁰
83. On 5 July 2019, the Home Care Division of PAC completed a MAC Intake for Flexible Respite (Service type) / In-home Day Respite (Service sub-type).¹¹¹
84. On 8 July 2019, a Home / Facility Risk Assessment form was completed by Ms Cork. Ms Cork states she would have obtained the information to complete the form from the MAC Portal.¹¹² On the same day, Deborah Tillitzki (ACAT Clinician and RN (Generalist)) completed the Privacy and Rights and Responsibilities Tool.¹¹³
85. That day, MW spoken with Ms Milburn, PAC about respite and private care and he had agreed to send her his draft instructions.¹¹⁴
86. On 9 July 2019, RN Tillitzki visited and conducted a comprehensive assessment of EW at home using the NSAF Comprehensive Assessment, with MW and the daughter in attendance.¹¹⁵ RN Tillitzki details that the assessment has been triggered due to MW as EW’s carer suffering increasing carer stress and her care needs having increased.¹¹⁶

¹⁰⁷ Exhibit 1: Tab 83 at p.1.

¹⁰⁸ Exhibit 1: Tabs 70; 19 at [13](c).

¹⁰⁹ Exhibit 1: Tab 118 at p.1, 3.

¹¹⁰ Exhibit 1: Tab 117.

¹¹¹ Exhibit 1: Tab 118 at p.1, 3.

¹¹² Exhibit 1: Tab 86 at [8], [16].

¹¹³ Exhibit 1: Tabs 82 at p.2; 86.

¹¹⁴ Exhibit 1: Tab 116 at p.3.

¹¹⁵ Exhibit 1: Tabs 92; 93.

¹¹⁶ Exhibit 1: Tab 92 at p.4.

87. An ACAT Assessment Consent Form was signed by MW on behalf of EW and Y is circled in respect of Guardianship papers having been sighted by RN Tillitzki or a copy supplied to her.¹¹⁷ RN Tillitzki records in her assessment summary that EW has appointed “*[MW] and then [the daughter] and [the son] as Power of Attorney and Enduring Guardian*”.¹¹⁸
88. EW declined to attempt a further MMSE on this day and the scores from the previous MMSE are noted. EW was assessed as scoring a 5 out of 20 in respect of Barthel Index of Activities of Daily Living which according to RN Tillitzki indicates “*a high level of assistance requires [sic] with self-care tasks*”.¹¹⁹
89. MW was also assessed against the CSI and scored 11 out of 13.¹²⁰ The hard copy form details that in respect of counting yes responses, “*A score of 7 or more indicates a high level of stress and the need for more in-depth assessment to facilitate appropriate intervention*”.
90. RN Tillitzki detailed that:¹²¹
- (a) EW has declining function and cognition and has experienced a recent decline in her ability to independently attend to all tasks of daily living, now requiring full assistance from MW who is experiencing increasing carer stress.¹²²
 - (b) When MW attempted to use a residential respite at a nearby facility on short notice due to his ill health, he found it was not available.¹²³
 - (c) EW has a strong belief system (Christian Scientist), does not believe in medical input from a doctor or use medications and does not have a GP, nor does she or MW wish to engage with a GP, and has nil medical history.¹²⁴ She recalls raising with EW and MW her belief that EW should be seen by a GP and that they told her that due to their religious beliefs, EW would not consult a doctor.¹²⁵
 - (d) “*[EW] presented with increased vagueness with [MW] and [the daughter] reporting [EW] is experiencing short-term memory loss and slow speech. [MW] and [the daughter] both expressed that they believed that [EW] had dementia. They also stated that [EW]’s mother had suffered with dementia.*” Further, RN Tillitzki recorded that EW was having short term memory problems, apathy, impaired judgment and resistive behaviour “*regularly*”, and long term memory problems “*occasionally*”.¹²⁶

¹¹⁷ Exhibit 1: Tab 90.

¹¹⁸ Exhibit 1: Tabs 83 at p.2; 90 at p.2.

¹¹⁹ Exhibit 1: Tabs 83 at p.2; 93 at p.19.

¹²⁰ Exhibit 1: Tab 91.

¹²¹ Exhibit 1: Tab 83 at p.2-3.

¹²² Exhibit 1: Tabs 92, at p. 6 & 10; 17 at [6], [34]; 94 at p.1-2.

¹²³ Exhibit 1: Tabs 92 at p.6; 17 at [63].

¹²⁴ Exhibit 1: Tabs 92 at p.17; 93 at p.1; 17 at [29].

¹²⁵ Exhibit 1: Tab 18 at [37].

¹²⁶ Exhibit 1: Tabs 92 at p.13 & 14; 93 at p.2.

- (e) EW has emotional or mental health issues and a memory problem or confusion that significantly limits self-care capacity, requires intensive supervision and/or frequent changes to support and is exposed to risks or is self-neglecting of personal care and/or safety and likely to cause harm to herself and others.¹²⁷
- (f) EW warrants urgent intervention and/or support to minimise deterioration and presents with indicators that impede access to delivery of aged care services.¹²⁸
- (g) EW wished to continue living in her own home with ongoing support from MW as carer and would like services to assist her to manage her needs and to reduce some stress on MW.¹²⁹
- (h) “[MW] is experiencing a high level of carer stress”, had reported his own medical issues including with his prostate gland causing him to void second hourly and difficulty in assisting [MW] to transfer and walk due to his own health issues and [EW] gaining weight.¹³⁰
91. RN Tillitzki recommended EW as eligible for HCP Level 4, high priority and detailed that EW and MW had declined any direct referrals for any CHSP service and noted the CHSP approvals in place from the September 2018 ACAT assessment.¹³¹ RN Tillitzki states that, in accordance with her usual practice, she would have provided MW with a copy of the Carer Respite Service Brochure.¹³² Relevantly, MW’s folder includes copies of the “Carer Gateway”, “Support for Carers” and “Hunter ACAT Aged Care Services” brochures, with the latter including handwritten notes relating to RN Tillitzki’s assessment of EW.¹³³
92. The Support Plan details in respect of Flexible Respite (In-home Day Respite, Priority High) that a referral has been accepted by PAC Hunter Home Care.¹³⁴ Also, in respect of Residential Respite High Care (Priority Medium) that a referral has been issued to PAC – Westcott.¹³⁵
93. On that same day (9 July 2018), MW had been in touch with Lana Noble from Westcott as he details:
- Then must find (Lana can help with the names of regularly visiting GPs) GP willing to take on (“admit”) [EW] as a patient.
- These are pre requisites before going further – phone Lana back with answer [original emphasis] in a day or two. Lana would arrange a respite stay for a few weeks for a trial before permanent placement. Would be possible to transfer direct from respite to permanent.
- It is possible there may be a place available – depends on beds.”¹³⁶

¹²⁷ Exhibit 1: Tabs 92 at p.15; 17 at [48].

¹²⁸ Exhibit 1: Tab 92 at p.16.

¹²⁹ Exhibit 1: Tab 92 at p.16-17.

¹³⁰ Exhibit 1: Tab 93 at p 1-2.

¹³¹ Exhibit 1: Tabs 93 at p.3; 19 at [57].

¹³² Exhibit 1: Tab 17 at [68].

¹³³ Exhibit 1: Tab 116 at p.70-75, 160-61.

¹³⁴ Exhibit 1: Tab 93 at p.8.

¹³⁵ Exhibit 1: Tab 93 at p.10.

¹³⁶ Exhibit 1: Tab 116 at p.7.

11 July 2019

94. Ms McClelland states that on 11 July 2019 she attended EW and MW's home at about 4:00 pm and advised MW that Westcott [PAC Home] would be able to provide assistance for EW the following Monday. She was of the view that MW was so happy and seemed beside himself that there was relief on the way.¹³⁷
95. At 3:19 pm, MW emailed Ms Noble, Westcott, subject line "*residence application for [EW] - please defer*" stating "*I have been talking with you regarding my wife's application for permanent residency at Wescott. She has now decided to try in home care with a substantial number of hours per week, to see how that goes. Would you therefore please file away her application for the present*".¹³⁸ MW also prepared a file note to this effect.¹³⁹

12 July 2019

96. At 3:14am, on 12 July 2019 MW sent an email to his children with the subject outline entitled "*Farewell*" in which he stated that by the time they will have read the email "*I will have taken my own life after doing the same to Mum*".
97. He detailed that:

"Mum and I are in the decline of advancing years, both physically and mentally. Mum has difficulties with dizziness, strength, weight, sight, skin defects and mental clarity. I have sight shortcomings, incontinence and ominous growths, and I am forgetful (hence unreliable) and sometimes have dizzy spells too. These things will likely get worse and make our (and our carer's) lives more difficult and less enjoyable." He stated that, "I put Mum unconscious with a hammer blow to the head while she slept, so she didn't feel any pain or trauma from what I then did to ensure the required result".

98. In respect of his reasons, he stated:

"I have been pondering this option for some time, but the trigger point for this step was my rapidly worsening incontinence, which the ACAT assessor (former nurse) this week suggested was prostate related. My brief Google research confirmed this and indicated [sic] it probably wasn't a terminal condition, but there would be extensive testing and ongoing medicine. My feeling is that this would be the start of a series of ongoing age related traumas and treatments, including sedation...[EW] is in a similar but more dire situation, with complicated caring arrangements about to start, and has no desire to follow a medical path. Christian Science has served her well until recent years - she has been just a student doing her best but is not scoring good marks anymore. In my case I lost my way much earlier and have been talking the talk (of divine goodness governing all) but not walking the walk just being humanly good) for a number of years - I was a disaster waiting to happen!"

¹³⁷ Exhibit 1: Tab 9 at [17].

¹³⁸ Exhibit 1: Tab 118 at p.2.

¹³⁹ Exhibit 1: Tab 116 at p.2.

99. Upon reading the email, the daughter states she woke her partner who rang triple zero. At 5:44am, Ambulance Officers Michael Loadman and Chris Stebbing attended the matrimonial home where they found EW deceased in an upstairs bedroom in bed with a plastic bag tied over her head and face with tape and what appeared to be a head injury. Beside her on the right-hand side of the bed was a hammer. She had no radial pulse when examined.
100. NSW Police attended the matrimonial home, and the paramedics drew to their attention to a handwritten note which was situated on a wooden table upon entry to the home which stated *“I have gone to drown myself in the sea in front of Lexi’s Café, I will tie a concrete block to my neck, wade out, drop beneath the water. I will tie a plastic container on a long rope onto the besser block to mark the position and aid recovery of my body.[MW] AM Friday 12 July 2019.”*¹⁴⁰
101. MW was located by Police deceased in the ocean off Stockton Beach. He had a besser brick tied to his neck with a plastic floating drum attached by a black and yellow line to mark his position in the ocean.¹⁴¹

15 July 2019

102. On the afternoon of 15 July 2019, Kim Broadhurst, ACAT Delegate of the Secretary, Department and Social Worker, HACAS considered EW’s medical, physical, psychological, and social circumstances, insofar as ACAT and allied health documentation.¹⁴²
103. Ms Broadhurst was of the view that:
- (a) EW required assistance to make decisions about her living activities and arrangements; and
 - (b) Assessment information identified a need for urgent daily coordinated care to assist EW with her health and wellbeing: including general health and cognition monitoring and care, personal and continence care, assistance with safe transfers and mobility, review and provision of aids and equipment as required, shopping, provision of meals, monitor nutrition and appetite, family support and in home respite options and domestic tasks.¹⁴³
104. EW was approved by Ms Broadhurst as eligible to receive HCP Level 4 (High). A letter of that date was prepared advising same and setting out EW’s referral codes which were approved in September 2018.¹⁴⁴

EW’s Death

105. EW is likely to have died between 11 and 12 July 2019.¹⁴⁵ An autopsy was undertaken on 16 July 2019 by pathologist Dr Alison Ward, with the supervising and finalising pathologist being Dr Lorraine du Toit-Prinsloo. In the Autopsy Report for the Coroner, Dr du Toit-Prinsloo set out the following “Circumstances of Death” in relation to EW taken from the P79A:¹⁴⁶

¹⁴⁰ Exhibit 1: Tab 6A at [35].

¹⁴¹ Exhibit 1: Tab 6A at [29].

¹⁴² Exhibit 1: Tabs 84, at p.1, 4; 19 at [13].

¹⁴³ Exhibit 1: Tab 84 at p.4.

¹⁴⁴ Exhibit 1: Tab 83 at p.4-5.

¹⁴⁵ Exhibit 1: Tabs 3 at p.2 of 11: Location details for Place of Death per s.81(1)(b) of the Act; Tab 21 (includes Incident Detail Report).

¹⁴⁶ Exhibit 1: Tab 3: The information provided at the time of autopsy was taken from the police form P79A.

“The deceased had resided with her husband. The deceased had suffered from Dementia and poor mobility in recent years and was cared for by her husband.

The deceased's husband recently became depressed and had self ~diagnosed himself with prostate cancer. He had confided with his daughter that he was finding it difficult to care for the deceased. Initial enquiries had been conducted to place the deceased in Palliative Care.

At approximately 3:14am on 12th July 2019, the deceased's husband forwarded an email to his daughter and son indicating that he had already taken the life of his spouse (the deceased) by striking her ... before ending her life and then taking his own life. The email explains his reasoning for his actions”.

106. In the Autopsy Report, Dr du Toit-Prinsloo gave her opinion on the cause of EW’s death, which she noted was based upon what she had observed, her experience and training, and the information supplied to her. The doctor listed the direct cause of EW’s death as being “*in keeping with plastic bag asphyxia in the setting of blunt force head injury*”.¹⁴⁷

Diagnosis of Dementia and Decision making Capacity

Family members

107. From the excerpt cited above, it will be noted that the pathologist stated that “[EW] suffered from *Dementia*”. Whilst the health professionals assessing EW did not themselves make this diagnosis, it was recorded by an ACAT assessor days before EW died that both MW and the daughter had expressed to her that they “*believed that [EW] had dementia*”, also noting that “[EW]’s mother had suffered with dementia”.¹⁴⁸

Neuropathologist

108. A Neuropathological Report dated 4 May 2020 was also provided by Associate Professor Michael Buckland following a neuropathological examination of EW’s brain. Associate Professor Buckland made the following comments in relation to his findings:¹⁴⁹

There is severe Lewy body pathology present, corresponding to neocortical (diffuse) Lewy body disease [2]. There is accompanying intermediate-level Alzheimer disease neuropathologic change.

In the context of the known history of dementia, it is considered that the neocortical (diffuse) Lewy body disease is the dominant process contributing to the deceased's dementia, with a lesser contribution of Alzheimer's disease.

Lewy body dementia signs and symptoms may include:

- -visual hallucinations
- possible slowed movement, rigid muscles, tremor or a shuffling walk which may result in falls;
- poor regulation of body functions such as blood pressure, pulse, sweating and the digestive process,

¹⁴⁷ Exhibit 1: Tab 3 at p.2.

¹⁴⁸ Exhibit 1: Tab 93 at p.2 of 15.

¹⁴⁹ Exhibit 1: Tab 2 at p.2.

- cognitive problems similar to those of Alzheimer's disease, such as confusion, poor attention, visual-spatial problems and memory loss,
- sleep difficulties, including physically acting out dreams,
- fluctuating attention, episodes of drowsiness, long periods of staring into space, long naps during the day,
- depression and/or apathy. [3]

Expert Psychiatrist Opinion

109. The Court was assisted by the provision of expert psychiatrist opinion on the issue of whether EW was suffering from dementia in 2018 and 2019, and also, in relation to EW's mental capacity to make her own decisions at various time points. Each of Associate Professor Christopher Ryan (instructed by the Counsel Assisting team) and Conjoint Professor Matthew Large (instructed by the LHD) (together, **the professors**) provided written reports dated 14 June 2022 and 26 June 2022 respectively, and also gave concurrent oral evidence in the course of the hearing.¹⁵⁰ The expert opinions provided by the professors was based on the documents contained in the Brief, with neither professor having assessed EW during her lifetime.
110. Both Associate Professor Ryan and Conjoint Professor Large were of the opinion, based upon the totality of the evidence, that it was likely that EW was suffering from dementia in both September 2018 and July 2019.¹⁵¹
111. Further, and flowing from this, both Associate Professor Ryan and Conjoint Professor Large were also of the opinion that in September 2018 and in July 2019, it was more likely than not that EW lacked decision making capacity with respect to, at least, some of the more complicated decisions that she was asked to make by the health professionals that saw her, in particular, the decision to refuse a consultation with a doctor.¹⁵²

Jurisdiction

112. Counsel Assisting submitted the Court has jurisdiction to hear this Inquest under ss.21 and 6(1)(a) and (c) of the Act. In view of this Factual Summary, that submission is accepted. Together, these sections confer jurisdiction to hear an inquest where a "*person died a violent or unnatural death*", and where their death was "*under ... unusual circumstances*".
113. Section 27(1)(a) of the Act provides that an inquest "*is required to be held*" if it appears to the Coroner concerned that the person died or might have died as a result of homicide.

¹⁵⁰ Exhibit 1: Tabs 3A, 3B; Transcript: 28 July 2022.

¹⁵¹ Transcript: 28 July 2022 at P243-245; Associate Professor Ryan also provided this opinion evidence in his written report at Exhibit 1: Tab 3A at p.19-21.

¹⁵² Transcript: 28 July 2022 at P262 L37 – P 263 L5; P272 L31-44; P275 L20-44; P287 L24 – P288 L8.

Issues

114. In holding this Inquest, s.81 of the Act requires that the Court make findings with respect to the identity, date and place, and manner and cause of death. As can be seen from the review of the Factual Summary set out above, the findings as to identity, date, place, and direct cause of death are not contentious. Notwithstanding a lack of contention, the Court is required to make findings as to this issue, and so is listed below as “Section 81 Findings”.
115. However, more complex issues remain for the Court’s consideration regarding the manner and circumstances of EW’s death, which is the focus of inquiry in this Inquest (see Issues No. 1 to 6 below).
116. More specifically, the issues (circulated in draft to the parties prior to the hearing and inviting consultation) became the agreed issues and are the primary focus of the Inquest. They are as follows:

1. **In September 2018**, was the assessment and care and treatment of, and decision making in relation to, [EW], as provided by the health professionals, adequate and appropriate in the circumstances?
 - a. Did the assessment, care, and treatment of, and decision making in relation to [EW], by the health professionals, **conform to the policy and procedure, and other related manuals and guideline documents (the Guidelines)** which were in force to instruct and otherwise guide the health professionals in their assessment, care, and treatment of, and decision making in relation to, [EW]?
 - b. Was the assessment, care, and treatment of, and decision making in relation to [EW], by the health professionals, otherwise adequate and appropriate, having regard to any **exercise of, or failure to exercise, independent clinical judgment?**
2. Over the period of **September 2018 to July 2019**, was the assessment and care and treatment of, and decision making in relation to, [EW], as provided by the health professionals, adequate and appropriate in the circumstances?
3. **In July 2019**, was the assessment and care and treatment of, and decision making in relation to, [EW], as provided by the health professionals, adequate and appropriate in the circumstances?
 - a. Did the assessment, care, and treatment of, and decision making in relation to [EW], by the health professionals, **conform to the policy and procedure, and other related manuals and guideline documents** which were in force to instruct and otherwise guide the health professionals in their assessment, care, and treatment of, and decision making in relation to, [EW]?
 - b. Was the assessment, care, and treatment of, and decision making in relation to [EW], by the health professionals, otherwise adequate and appropriate, having regard to any **exercise of, or failure to exercise, independent clinical judgment?**
4. In circumstances where the aims of the Regional Assessment Services (RAS) and Aged Care Assessment (ACAT) assessments include:
 - *Ensure that assessments of older people are holistic, incorporating physical, medical, psychological, cultural, social, environmental and wellness dimensions;*
 - *Provide short-term linking assistance or care coordination to vulnerable clients to address barriers that affect their access to aged care services;*

are there deficiencies or other limitations in the policy and procedure, and other related manuals and guideline documents which were in force in 2018 and 2019 to instruct and otherwise guide the health professionals in their assessment, care, and treatment of, and decision making in relation to, [EW]?

5. In circumstances where the aims of the Regional Assessment Services (RAS) and Aged Care Assessment (ACAT) assessments include:

- *Ensure that assessments of older people are holistic, incorporating physical, medical, psychological, cultural, social, environmental and wellness dimensions;*
- *Provide short-term linking assistance or care coordination to vulnerable clients to address barriers that affect their access to aged care services;*

were there deficiencies or other limitations in the training and education and support available to health professionals in their assessment, care, and treatment of, and decision making in relation to, [EW]?

6. Whether it is necessary or desirable for the Coroner to make **recommendations** pursuant to section 82 of the *Coroners Act 2009* (NSW) in relation to any matter connected with the death of [EW].

Evidence

117. In order to consider the issues, as set out above, and make the findings required under the Act, before the Court is an eleven volume Brief. The Officer in Charge (**OIC**) of the matter has been Detective Senior Constable Corina Winbank, who was on leave at the time of the hearing. The OIC position was then filled by Detective Senior Constable Luke Briggs. The Brief was prepared with the assistance of the Detective Senior Constables, together with the Inquests, Inquiries and Representation legal team of the Department of Communities and Justice.
118. The Brief includes autopsy and neuropathological reports which have already referred to, as well as statements from a number of health professionals from the Community and Aged Care Services of the Greater Newcastle Sector (**CACS-GNS**), within the LHD.¹⁵³ The General Manager of that Sector, being Ms Louise Lazic, also provided statements,¹⁵⁴ as did Dr Nicholas Hartland, a representative of the Department.¹⁵⁵
119. Also included in the Brief are numerous guideline and policy and procedure documents, from both MAC (the Department) and from the LHD, which have been considered relevant to the issues to be considered in this Inquest, including documents in force at September 2018 and July 2019, as well as the version of those documents in force at the time of the hearing.

¹⁵³ Exhibit 1: Tab 20A at [4], [9], [33].

¹⁵⁴ Exhibit 1: Tabs 20A, 20B.

¹⁵⁵ Exhibit 1: Tabs 112 & 135.

120. In addition to the written statements, and other documentary evidence, the Court heard oral evidence from a number of witnesses. These witnesses include:

Ms Laura Lubinski	2018 RAS assessor and Home Support Worker
Ms Maryanne Matthews	2018 ACAT assessor and Registered Nurse
Ms Deborah Tillitzki	2019 ACAT assessor and Registered Nurse
Ms Katie Cook	Community Occupational Therapist
Mr Chris Baker	Community Physiotherapist
Ms Rachel Merten	Social Worker, ACAT Delegate of the Secretary, Department
Ms Louise Lazic	General Manager, CACS-GNS
Ms Kim Broadhurst	Social Worker, ACAT Delegate of the Secretary, Department; ACAT assessor; ACAT Education Officer

121. The Court also had before it reports containing expert opinions from Associate Professor Christopher Ryan and Conjoint Professor Matthew Large (Psychiatrists) and Dr Susan Arnold (Occupational Therapist). No expert assessed or otherwise consulted EW during her lifetime (or MW during his lifetime), but rather, reviewed documents contained in the Brief and provided retrospective opinions based on that evidence.
122. Both Associate Professor Ryan and Conjoint Professor Large also gave oral evidence. Due to illness, Dr Arnold was unable to attend the hearing and give oral evidence. Notwithstanding this, the report of Dr Arnold was tendered into evidence, without objection.
123. Each expert provided the Court with a copy of their Curriculum Vitae, and Professors Ryan and Large each orally provided descriptions of their areas of training, study, experience and expertise. It is submitted and accepted by me that the experts were well qualified to provide the opinions they considered themselves able to, and that the Court ought to give each of the expert's opinions significant weight.

Findings

124. Counsel Assisting submitted that for the Court to consider the issues raised by Inquest it would be required to make "anterior findings" in relation to whether EW was suffering from dementia in 2018 and 2019 and whether she would likely have had the mental capacity to make the decisions she was called upon to make at those times. Counsel for the LHD submitted that it was not clear why this was the case. I resolve the issue by finding that it is relevant to make a finding on this aspect. As I understood the expression "anterior", it meant "coming before in time". Here in this matter it provides context. Importantly LHD staff who saw EW could not provide a medical diagnosis of dementia. They were not qualified to do so. The staff considered she required a formal diagnosis from a medical health practitioner and as they understood it without a formal diagnosis of dementia, EW could not be referred for other dementia care or support services that she may have needed. Yet EW and MW had no contact with a GP. In contrast to the evidence of the health professionals and

LHD, Dr Hartland, on behalf of the Department, gave evidence that a lack of a formal diagnosis of dementia in MAC clients was not a barrier to access dementia care services in September 2018, July 2019 and nor is it currently.¹⁵⁶ Therefore, this dilemma where there is mutually conflicting or dependent conditions must be explored, and recommendations made to try and avoid the issue occurring again.

125. From the post-mortem examination of EW at the time of her death I find she was suffering from severe Lewy body disease and intermediate Alzheimer's dementia.

Presence of dementia in September 2018

126. There is evidence previously referred to in this decision where health professionals have recorded reports of and observations of cognitive impairment in EW. I accept that the health professionals who made these observations were not qualified to do so.
127. Associate Professor Ryan who gave evidence considered that it was more likely than not that EW was suffering from dementia at that time. That was stated in his written report and again in his evidence at the Inquest. Conjoint Professor Large stated in his evidence he didn't really have a different view. He further elaborated that he suspected there may have been some underscoring of the MMSE. He thought she would have early dementia.
128. The evidence of the neuropathologist at paragraph 108 of this decision noted "*severe Lewy body pathology present*" and the signs and symptoms of that type of dementia as set out in that paragraph including fluctuating attention, possible slowed movement, rigid muscles, memory loss were all present in 2018. I am comfortable on balance in making a finding that dementia was present at this time.

Presence of dementia in July 2019

129. Again, there is evidence from health professionals, family members, and the neuropathologist opinion that all lend weight to observations of cognitive impairment as at this time.
130. The evidence of Associate Professor Ryan and Conjoint Professor Large were in agreement. Both were of the opinion that EW had cognitive impairment arising from dementia and to a more significant extent. I am again comfortable on balance in making a finding that dementia was present at this time.
131. The opinion evidence of the psychiatrists was based on the whole of the documentary evidence and their specialist training as psychiatrists. I note there was no contrary submissions made by any party.

¹⁵⁶ Exhibit 1: Tab 135 at [82].

Decision making Capacity

Expert Opinion as at 2018

132. Associate Professor Ryan stated in his report that he was “*fairly confident that [EW] lacked decision-making [capacity] for complicated decisions from as far back as September 2018*”. Both experts gave evidence that they considered the decision to consent to an ACAT assessment was at the simple end of the decision-making spectrum, as was the decision to consent to an OT assessment, if even simpler. A RAS assessment was down the simpler end of the decision-making spectrum as well.
133. In their oral evidence the professors were asked to consider EW’s decision making capacity, specifically in relation to capacity to consent to or reject seeing a doctor. Associate Professor Ryan said this:

“I’m not sure that I know about that, I doubt – I mean my feeling is it’s more likely than not that she didn’t and the reason I say that is because I think the primary important – most important issue here was that she had- there was a concern that she might have a dementia, so she would have to make an informed decision, she’d have to have an understanding that it was felt that she might have a dementia and the ramifications of that at least in broad terms.

And then she would have to use and weigh that piece of information against, for example, the fact that she has got these religious beliefs. She may well then – she may well make a competent decision not to see the doctor under those circumstances definitely. But she- to make a competent decision she would have to understand that and then decide to use and weigh it to override that and I think on the balance of probabilities she didn’t, but my caveat before about this early time still stands and I’m not – I think it’s more likely than not but not necessarily much more likely than not.”

134. Conjoint Professor Large did not have a dissimilar opinion.

Expert Opinion as at 2019

135. Associate Professor Ryan in his oral evidence said it was clearer that she lacked decision making capacity as at this time. Conjoint Professor Large said “*I’d think it was fairly obvious by this stage that she didn’t have the capacity so much that it might have been a bit pointless trying to give her that information almost*”.
136. I accept their evidence.

Issue No.1 – September 2018

Laura Lubinski

137. Evidence in relation to the assessment and care and treatment of and decision making in relation to EW, provided by Ms Lubinski is summarised above at paragraphs 51 to 56. Ultimately Associate Professor Ryan in his report provided the opinion that Ms Lubinski’s 5 September 2018 assessment “*conformed to the policies and procedures, manuals and guideline documents which were in force to guide the health professionals at that time, bearing in mind the limitations of these.*” There was no contrary evidence.

138. Counsel Assisting in her submissions submitted that the evidence, including the expert evidence, supports a finding that Ms Lubinski's assessment and care and treatment of, and decision making in relation to EW was "adequate" in the circumstances. It was submitted by Counsel for LHD staff that the evidence supports a finding the staff acted "appropriately and reasonably". Other synonyms of "adequate" are "competent, enough, and sufficient". I will adopt the expression "appropriately and reasonably". I will give a more detailed reason later in this decision.
139. It is intended due to the unusual circumstances (the Christian Scientist beliefs) and complex nature of the issues that recommendations will follow that would assist health professionals in future for training, education and guidance. The recommendations that are detailed below in this decision follow from all of the evidence and not just from, or arising from, this witness.

Maryanne Matthews

140. Evidence in relation to the assessment and care and treatment of, and decision making in relation to EW, provided by RN Matthews is summarised above at paragraphs 57 to 68.
141. Counsel Assisting submitted that the evidence including the expert evidence supported a finding that RN Matthews' assessment and care and treatment of, and decision making in relation to EW, was adequate in the circumstances. Again, I will adopt the expression "appropriate and reasonable" and make a finding to that effect.

Rachel Merten

142. Evidence in relation to the assessment and care and treatment of, and decision making in relation to EW, provided by Ms Merten is summarised above at paragraphs 70 to 72.
143. It is accepted that in her role as ACAT delegate, Ms Merten did not actually assess EW personally but rather reviewed documents available from the ACAT assessment that had been undertaken by another person.
144. Counsel Assisting submitted that the evidence, including the expert evidence, supports a finding that Ms Merten's assessment and care and treatment of, and decision making in relation to EW was adequate in the circumstances. I make a finding that it was "appropriate and reasonable" in the circumstances.

Issue No.2 – Community Health Professionals (2018 – 2019)

145. This issue addresses the evidence of Ms Cook and Mr Baker, the Community OT and Physiotherapist respectively.

Katie Cook

146. Evidence in relation to the assessment and care and treatment of and decision making in relation to EW, provided by Ms Cook is summarised above at paragraphs 73 to 80.

147. Associate Professor Ryan in his written report made a number of assumptions about the context of Ms Cook's assessment and care. The Professor was critical that as EW was suffering significant cognitive impairment from November 2018, she failed to consult others who might have had expertise in that area.
148. Conjoint Professor Large reviewed the assessment and ongoing intervention undertaken by Ms Cook and disagreed with Associate Professor Ryan's opinion.
149. The Court was also assisted by the provision of expert OT opinion in the form of a report provided by Dr Susan Arnold dated 7 July 2022. In her report, Dr Arnold addressed a number of issues including the role of an OT working in the community.
150. Specifically in relation to Ms Cook, Dr Arnold was not critical that a geriatrician was not consulted, nor was she critical that steps were not taken to consult with a clinician with experience in dementia. Overall, Dr Arnold concluded that she was of the opinion that Ms Cook took all reasonable and necessary steps to assist EW and MW to manage on a day-to-day basis at home. Further I accept the submission by Counsel for the LHD that neither Ms Cook or Mr Baker were qualified to diagnose dementia.
151. There was some limitations of information available to Associate Professor Ryan when he wrote his written report. It is accepted that he did make some incorrect assumptions however on further information being provided in oral evidence from Ms Cook the Professor was asked in in his oral evidence to rethink his opinion. The Associate Professor stated that with the further evidence provided at Court he did not maintain the opinion that he had previously stated in his report.
152. Counsel Assisting submitted that the evidence, including all of the expert evidence supports a finding that Ms Cook's assessment and care and treatment of, and decision making in relation to EW was adequate in the circumstances. I make a finding that it was "appropriate and reasonable" in the circumstances.

Chris Baker

153. Evidence in relation to the assessment and care and treatment of, and decision making in relation to EW, provided by Mr Baker is summarised above at paragraphs 77 to 80.
154. It was accepted by the experts that physiotherapists would not in general terms have any particular special training nor any better understanding of cognitive deterioration and dementia. Accordingly, neither of the experts were critical of Mr Baker and I am able to accept the submission that Mr Baker's assessment and care and treatment of and decision making in relation to EW was "appropriate and reasonable" in the circumstances.

Issue No.3 – July 2019

Deborah Tillitzki

155. Evidence in relation to the assessment and care and treatment of and decision making in relation to EW provided by RN Tillitzki is summarised above at paragraphs 86 to 92.

156. Both experts came to the conclusion that no criticism could be made of RN Tillitzki's assessment care and decision making in relation to EW. Put appropriately by Conjoint Professor Large:

"85. Any failure of RN Tillitzki to organise a multidisciplinary review of [EW's] case after her assessment must be strongly tempered by the short timeframes involved.

86. More importantly, RN Tillitzki could have reasonably expected that her recommendation for an increased priority for the home care package would have rapidly brought about changes that would have relieved the situation she perceived in [EW's and MW's] household. In this event a multidisciplinary meeting might not have been needed.

87. It might also have taken a considerable time to convene and organise a multidisciplinary meeting and still longer to enact any recommendations....In the normal course of events, timely and consensual provision of services was a more simple strategy that was very likely to be effective."

157. The issue previously referred to which I described as a dilemma is highlighted from the evidence of this witness. In her supplementary statement, RN Tillitzki added that she was of the view that EW "required a medical review to investigate the underlying cause" of her "physical and cognitive issues", but neither EW nor MW would consent to such a review.

158. Asked for her consideration and/or assessment of whether EW required referral to any dementia care and support services she responded: "a referral to dementia and support services was not available as [MW] and [EW] declined health service referrals, and [EW] did not have a diagnosis of dementia."¹⁵⁷

159. Ms Tillitzki appears to explain in her supplementary statement that, as a carer, MW was only able to access dementia support services if EW had been diagnosed with dementia. It was apparently for this reason that she did not refer MW to dementia care and support services."

160. It was submitted by Counsel Assisting that the evidence, including the expert evidence, supports a finding that RN Tillitzki's assessment and care and treatment of, and decision making in relation to EW, was adequate in the circumstances. Whilst Associate Professor Ryan was critical of this witness for not invoking "linking support" the evidence suggests that the deficiency may be related to some ambiguity in the Manual or because of deficiencies in the education and training provided to RN Tillitzki (which had only recently been undertaken).

161. The submission made by Counsel for the LHD for its staff members included the following:

"69. As to the assessments undertaken, the decisions made by the RAS and ACAT assessors about [EW] and [MW]'s eligibility for care services, the treatment provided by Mr Baker and the OT services provided by Ms Cook demonstrates that there was an appropriate recognition of the fact that, although [MW] was providing [EW] with exemplary and devoted care, the arrangement was not sustainable and that [EW] was eligible for a range of services that would relieve [MW]'s burden. As a result of the RAS assessment, [MW] and [EW] were given access to a range of Commonwealth funded services. This was followed, soon afterwards, by an approval of the highest level of home care package. Ms Cook immediately recognised that [MW]'s approach to bed transfers represented a significant risk to the [sic] safety and she used her knowledge and experience as an OT to find a safe solution to this problem. Mr Baker used his professional skills as a physiotherapist to assist her in this endeavour. Ms Tillitzki, noting that [EW] and [MW] had not accessed services that had been

¹⁵⁷ Exhibit 1: Tab 3A at p.81-82.

approved the previous year, recommended that the priority of their home care package be increased to the highest level.”

162. I accept that LHD staff members acted appropriately and reasonably, having regard to the roles that each of them was performing at the time, the information available to them, their qualifications and experience and the issues identified in their assessments. I thought it important to reflect on the benefit of hindsight and specific roles that assessors are tasked with. In addition, I have accepted that there is a primary role in the assessment process and a specific purpose as set out in the following paragraph.
163. Counsel for LHD submitted that it was important to understand that an ACAT assessment is conducted for a specific purpose. Before financial services can be provided the recipient of care must, in most cases, be approved in respect of the type of aged care provided.¹⁵⁸ In this particular case, that power is delegated to a senior ACAT assessor such as Ms Merten. Before approval is granted that senior assessor must ensure that the care needs of the person have been assessed. This is the function that is being performed by ACAT assessors, in particular. The obligation of an ACAT assessor is to undertake an assessment of a client’s care needs, for the purpose of determining their eligibility for Commonwealth funded aged care services. Consistent with the legislation and the documents admitted into evidence Ms Merten said, in her evidence, that the purpose of the assessment is to obtain and assess information as to the client’s functionality and care needs by reference to legislation and eligibility principles. An ACAT assessor does not provide care or treatment to clients, and an ACAT assessment is not undertaken for the purpose of determining whether a client, generally, is in need of medical treatment.
164. Similarly, the function of a RAS assessor is to determine a client’s eligibility to receive CHSP services. It is not to provide care or treatment to determine whether they are in need of medical care. It is not expected that they provide ongoing case management services either. I accept the submission.
165. That last sentence has relevance to a further submission made by Counsel for the LHD:
- “82. In 2018, [EW] had been assessed as eligible for a range of services. There is no evidence that there had not been an “effective referral” of [EW] to those services. There is no evidence that the RAS or ACAT assessor who assessed [EW] in September 2018 had any expectation or belief that [EW] or [MW] would not access the services to which they had been referred. In July 2019, the ACAT assessor realised that [EW] and [MW] had not accessed those services. She recommended that the priority of [EW]’s home care package be increased to the highest level.
83. There is thus no basis in the evidence for a finding that any of the LHD staff who undertook a RAS or ACAT assessments, failed to take any step that was expected by them by reference to the “linking support/care coordination” section of the MAC Manual.”
166. It was accepted by Counsel for the LHD that there is a degree of ambiguity in the Manual as to what precisely is required of assessors in this regard, and she considered that this is appropriately addressed in a proposed recommendation directed to the Department.

¹⁵⁸ Paragraphs 72 to 79.

Issue No. 4, 5 and 6 – Recommendations

167. We heard from each of the professors that in their opinion, more probably than not, in September 2018 and July 2019, EW was suffering from dementia. Each of the professors also opined in respect of both of these dates they were of the view that EW likely lacked the decision making capacity to refuse to consent to consult a doctor. I accept that each of the LHD staff in the situation they met were dealing with complex and troubling issues.
168. The health professionals assessing and caring for EW considered EW would benefit from seeing a doctor, and that her refusal to consult with one was valid. As was described by Counsel Assisting, this situation resulted in what was often referred to during the hearing as a “*catch 22*”, being that if EW did not attend a doctor and receive a formal diagnosis of dementia, then she could not be referred to dementia care services and EW could not be referred to dementia related services.
169. In contrast to the understanding of the LHD and health professionals, Dr Hartland of the Department stated in his recent statement dated 31 August 2022 that:
- “[82] In short, in September 2018, July 2019 and currently, My Aged Care did not, and does not currently require a formal diagnosis of dementia before a client or their carer may be referred to any dementia care and support services.”
170. Importantly, Dr Hartland also stated:
- “[88] For current and future arrangements, the My Aged Care contact centre staff will now ask clients that mention a dementia diagnosis or memory concerns if they would like their contact details provided to Dementia Australia. Dementia Australia will then proactively get in contact and discuss the range of services and supports that may be of assistance. This functionality is part of the expansion of the National Dementia Support Program in response to the Aged Care Royal Commission recommendations and it is expected to commence from September 2022”.
171. Counsel Assisting considered this action is indicative of positive progress. I wholeheartedly agree.
172. Counsel for the LHD submitted that it would be appropriate for any further LHD education and training on issues such as assessments of cognitive impairment, mental capacity and what is expected operationally, by way of the provision of linking support, occur after any update in the policies and procedures by the Department as proposed in the first proposed recommendation directed to the First Assistant Secretary. This would ensure that any training and education was appropriately tailored to the functions that RAS and ACAT assessors are required to perform. That is a sensible and pragmatic suggestion which I adopt.

Section 81 Findings

173. It was submitted by Counsel Assisting (no other competing submission made) there is a sound documentary basis for the Court to make the following findings in relation to EW's death. I make the following findings:¹⁵⁹

Identity: EW (a pseudonym).

Date of death: Between 11 July 2019 and 12 July 2019.

Place of death: Matrimonial home, Stockton NSW 2295.

Cause of death: Plastic bag asphyxia in the setting of blunt head injury.

Manner of death: Death was caused by actions of a person known with the intention of ending life.

Recommendations

174. Pursuant to s.82 of the Act, Coroners may make recommendations connected with a death.

175. I make the following recommendations:

To the First Assistant Secretary of the Australian Government Department of Health and Aged Care, Home and Residential Division

Recommendation 1

That consideration be given to reviewing and updating its My Aged Care policy and procedure and other related manuals and guideline documents, with a particular focus on the "My Aged Care Assessment Manual: For Regional Assessment Services and Aged Care Assessment Teams" (and associated documents), with a view to providing for guidance in relation to:

- a. knowledge and detection of "possible" cognitive impairment and dementia
- b. assessment of mental capacity to make decisions, including decisions to consent or refuse to consent to further assessment or investigations, including further assessment by a medical practitioner; and
- c. operational expectations of RAS and ACAT assessors in relation to "Delivering Linking Support/Care Coordination to Vulnerable Clients", particularly in relation to:
 - i. clarifying the circumstances when assessors ought to provide Linking Support to clients; and
 - ii. clarifying the operation of Linking Support once implemented, including the ongoing role of the assessor.

¹⁵⁹ In particular, see Autopsy Report: Exhibit 1: Tab 3 at p.44.

Recommendation 2

That consideration be given to reviewing and updating its My Aged Care policy and procedure and other related manuals and guideline documents, with a particular focus on the “My Aged Care Assessment Manual: For Regional Assessment Services and Aged Care Assessment Teams” (and associated documents), with a view to providing for:

- a. the collection of information during ACAT assessments that would allow for the calculation of a “possible” cognitive impairment and dementia variable; and
- b. a pathway by which ACAT assessors and delegates may (if considered appropriate) refer clients, and their carers, to appropriate dementia care and support services for clients and their carers with “possible” cognitive impairment and dementia in circumstances where the client does not have a formal diagnosis of dementia.

Recommendation 3

The Australian Government Department of Health and Aged Care be provided with copies of the following documents (redacted as necessary to enable distribution beyond parties):

- a. Report of Associate Professor Ryan
- b. Report of Conjoint Professor Large
- c. Transcript of 28 July 2022 expert evidence
- d. Supplementary statement of Maryanne Matthews dated 28 July 2022; and
- e. Copy of these findings.

and to consult with the Hunter New England Local Health District on issues of concern raised by the professors and RN Matthews, including whether it is appropriate that both entities agree on whether clients without a formal diagnosis of dementia may be referred to dementia care and support services.

To the Chief Executive of Hunter New England Local Health District

Recommendation 1

That consideration be given to providing RAS and ACAT assessors and delegates with training and education in the following areas:

- a. knowledge and detection of “possible” cognitive impairment and dementia
- b. assessment of mental capacity to make decisions, including decisions to consent or refuse to consent to further assessment or investigations, including further assessment by a medical practitioner;

- c. implications of a finding of a lack of mental capacity in NSW:
 - i. need to obtain consent from substitute decision maker, who will make decisions in assessed persons best interests; and
 - ii. how to identify substitute decision maker via Enduring Guardianship appointment or through application for appointment of Guardian through NCAT or the Supreme Court of NSW, or where relevant, through determination of Person Responsible under NSW Guardianship laws.
- d. operational expectations of RAS and ACAT assessors in relation to “Delivering Linking Support/Care Coordination to Vulnerable Clients”, particularly in relation to:
 - i. clarifying the circumstances when assessors ought to provide Linking Support to clients; and
 - ii. clarifying the operation of Linking Support once implemented, including the ongoing role of the assessor.

The training and education contemplated by Recommendations (1) (a), (b) and (d) should reflect any update(s) in Departmental policy and procedure, and other related manuals and guideline documents as contemplated in Recommendations 1 & 2 directed to the First Assistant Secretary (see above).

Recommendation 2

That consideration be given to providing education and training to ensure that RAS and ACAT assessors and delegates are aware of, and have access to advice, mentorship and supervision, in the following circumstances:

- a. evidence of “possible” cognitive impairment or dementia (such as reports of decline in cognition or behaviour from the assessed person, their carer and family, or impaired performance on cognitive testing), but there is no formal diagnosis of dementia, and where the assessed person refuses further assessment and investigation to enable diagnosis; exercise of discretion when selecting “appropriate” Supplementary Assessment Tools (SATs) as set out in the relevant guideline documents concerning same i.e. IQCODE/assessment in relation to carer/family member in conjunction with assessment of the client (under the circumstances), as opposed to reliance on “core” SATs
- b. complex and unusual circumstances, such as where a religious or cultural belief appears to be a barrier to acceptance of recommended mainstream aged support or care; and
- c. the breadth of available Linking Support / Care Coordination to vulnerable clients.

The training and education contemplated by Recommendations 2 (a) – (c) should reflect any update(s) in Departmental policy and procedure, and other related manuals and guideline documents as contemplated in Recommendations 1 & 2 directed to the First Assistant Secretary (see above).

Recommendation 3

That consideration be given to making available the education and training recommended for RAS and ACAT assessors and delegates at **Recommendation 1 and 2** to health professionals who work in Community Occupational Therapy and Community Physiotherapy Services who are providing assessment, care and treatment to older clients.

The training and education contemplated by Recommendation 3 should reflect any update(s) in Departmental policy and procedure, and other related manuals and guideline documents as contemplated in Recommendations 1 & 2 directed to the First Assistant Secretary (see above).

Recommendation 4

The LHD be provided with copies of the following documents (redacted as necessary to enable distribution beyond parties):

- a. Report of Associate Professor Ryan
- b. Report of Conjoint Professor Large
- c. Transcript of 28 July 2022 expert evidence
- d. Supplementary statement of Maryanne Matthews dated 28 July 2022; and
- e. Copy of these findings.

and to consult with the Department on issues of concern raised by the professors and RN Matthews, including whether it is appropriate that both entities agree on whether clients without a formal diagnosis of dementia may be referred to dementia care and support services.

Conclusion

176. Rhetorically one could ask whether the outcome would have been any different if we knew what was in MW's mind as things became so challenging and daunting for him. Would the care of EW have been taken out of MW's hands? If so, how would that have been achieved?

177. In a handwritten note on 22 February 2019, MW wrote:

“Logical arguments are one thing, but I am dealing with feelings, not always rational and being supported by less than angelic thoughts including:

– *resistance to change*

– *telling lies*

– *tears*

– *criticism*

[The daughter] who is very logically orientated (and has no children) says [EW] needs to suffer until she aligns with reality – like shutting the nursery down and leaving the baby to cry itself to sleep. I can't do that – is that being soft and manipulated or unconditional love?”

178. MW had unconditional love and feelings – without a shadow of doubt. Certainly, he did not want EW to suffer, and he wanted to try to do his best to abide by EW’s wishes. By doing so, caused him great anguish and while he was obviously a very smart man he could not see, in his mind, any way out. This is one of those matters where there is no clear-cut answer. I am not in any sense condoning his actions, but one can have a significant understanding of why and how this tragedy occurred.
179. Counsel Assisting and her instructing solicitors worked diligently and thoroughly and made great efforts to ensure that this Inquest had all the information that could possibly be obtained. They were compassionate and caring to the children of the deceased and kept them informed of what was happening. I greatly appreciate and thank them for undertaking what has been challenging and in part emotionally troubling. I also thank the OICs for their efforts.
180. As I find, invariably in all Inquests that I preside over, the assistance and help that I gain from other legal representatives of the interested parties is invaluable. This Inquest was no different. My genuine appreciation goes to all.
181. I hope and trust that this Inquest and the preceding recommendations will allow various agencies to at least consider and hopefully implement meaningful change. I completely understand the highly unusual complexity of this matter brought about by a lack of medical intervention because MW and EW had gone through most of their lives without medical assistance by reason of their religious faith.
182. My sincere condolences to the children of MW and EW. I hope the Inquest has helped in understanding the unfortunate circumstances that occurred. I think I can say on behalf of the legal representatives that we hope this helps with closure and aids you both in the grieving process.
183. I close this Inquest.

Magistrate R G Stone
Deputy State Coroner
4 November 2022
Coroner’s Court of New South Wales