JURISDICTION: CORONER'S COURT OF WESTERN AUSTRALIA

ACT : CORONERS ACT 1996

CORONER : SARAH HELEN LINTON, DEPUTY STATE

CORONER

HEARD : 1 FEBRUARY 2024 & 28 MARCH 2024

DELIVERED : 13 NOVEMBER 2024

FILE NO/S : CORC 1122 of 2020

DECEASED : TUPPER, CHLOE GRACE

Catchwords:

Nil

Legislation:

Nil

Counsel Appearing:

Ms S Markham assisted the Coroner.

Ms R Hartley (SSO) appeared on behalf of the East Metropolitan Health Service, the North Metropolitan Health Service and the Department of Health.

Ms C Elphick (Dominion Legal) appeared for Dr Colin Singam.

Mr M Williams (MDA National Insurance) appeared for Dr Ross Haston.

Case(s) referred to in decision(s):

Nil

Coroners Act 1996 (Section 26(1))

RECORD OF INVESTIGATION INTO DEATH

I, Sarah Helen Linton, Deputy State Coroner, having investigated the death of Chloe Grace TUPPER with an inquest held at the Perth Coroner's Court, Court 85, CLC Building, 501 Hay Street, Perth on 1 February 2024 and 28 March 2024, find that the identity of the deceased person was Chloe Grace TUPPER and that death occurred on 9 June 2020 at Joondalup Health Campus, Grand Blvd & Shenton Ave, Joondalup, from organ failure due to anorexia nervosa in the following circumstances:

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INTRODUCTION

- 1. Chloe Tupper was the middle daughter in a family of three sisters, Holly, Chloe and Rosie, along with their father Dave and mother Naomi. Chloe was described as "like a delicate flower," as she was such a sweet, kind and sensitive person. Chloe was also a gifted painter, who had successfully completed a Bachelor of Fine Arts degree and exhibited, and won awards for, her paintings. All of these things were an important part of who Chloe was as a person and how she will be remembered by those who knew and loved her.
- 2. Unfortunately, along with all of these things, Chloe was also a young woman with severe and enduring anorexia nervosa. She had a long and painful journey with her illness, which started when she was 14 years old and only ended with her death in June 2020, at the young age of 31 years. She remained almost child-like through that long period of time, never going through puberty and never breaking away from home and family to forge an independent life as an adult. Chloe was happiest when safe at home with her family who loved her, making her art.²
- 3. Chloe's family, who had been supporting her throughout this difficult journey, came to understand that Chloe did not want to accept the kind of treatment that was being offered to her. They understood that Chloe had chosen to die rather than undergo active re-feeding treatment and she wanted to spend the remainder of her life at home, rather than in hospital. Chloe's family had come to terms with that decision and decided to support her and respect her wishes. I have no doubt that if Chloe's family had felt they could have changed Chloe's mindset, they would have, but after almost 18 years on this journey, they accepted that her mind would not change and that her condition was, in effect, terminal.
- 4. Chloe had been seeing a local general practitioner who was aware of the challenges of Chloe's illness. He knew that Chloe had made previous attempts on her life and that when she had last been treated at Royal Perth Hospital she had been reviewed by psychiatrists and it had been agreed by the treating team that Chloe was no longer for active treatment. Chloe chose to only receive what treatment she could in her own home, and within a scope she was willing to tolerate. Chloe's GP last spoke to her on 29 May 2020. Whilst it was clear Chloe was in declining health, her doctor felt she still had the capacity to choose to decline treatment at that time.
- 5. On 2 June 2020, Chloe collapsed. Chloe's GP was contacted and an ambulance went to her home. Chloe's family advised the attending St John Ambulance (SJA) officers that they understood Chloe was for palliative care only and they did not want her to go to hospital. However, the requisite paperwork was not present to confirm that position. After speaking to Chloe's GP, the SJA officers took Chloe to Joondalup Health Campus (JHC).
- 6. After initial supportive medical treatment at the hospital by general physicians, Chloe was reviewed by a psychiatrist. The psychiatrist had not treated Chloe previously but was informed of Chloe's diagnosis of severe and enduring anorexia

¹ Exhibit 1, Tab 8 [100].

² Exhibit 1, Tab 8.

nervosa and her history of increased risk of suicidality when treated and weight restoration achieved. Chloe and her family's wishes for palliative treatment were noted, but it was felt that there needed to be more consultation before such a significant decision was made. Chloe was made an involuntary patient under the *Mental Health Act 2014* (WA) while more enquiries were made to determine whether active treatment was in Chloe's best interests or likely to be futile. She continued to be given supportive treatment in the interim. This was contrary to the wishes of Chloe and her family, but the doctors were mindful of their duty of care to a young woman whose life might be able to be saved.

- 7. After a lot of consultation and consideration, the medical team eventually agreed it was in Chloe's best interests to cease all active treatment. This decision was made after taking into account how far her illness had progressed and the advice from specialists that her cardiac function was unlikely to improve, even with active treatment.
- 8. On 9 June 2020, parenteral nutrition ceased and Chloe died at 7.45 pm on 9 June 2020 in the company of members of her family. At that time, Chloe weighed only 34 kg with very little body fat or musculature. A forensic pathologist determined she had died from organ failure due to anorexia nervosa.
- **9.** As Chloe was still an involuntary patient at the time of her death, she came within the definition of a "person held in care" under the *Coroners Act 1996* (WA) and an inquest into her death was mandatory. I held an inquest on 1 February 2024 and 28 March 2024.
- 10. Pursuant to the *Coroners Act*, as Chloe's death was a death in care, I am now required to comment on the quality of Chloe's treatment, supervision and care prior to her death.³ I make those required comments at the end of this finding. At this stage it is sufficient to note that I make no specific criticism of any health practitioner involved in Chloe's care, nor of any other person who was significantly involved in Chloe's life and premature death.
- 11. It is, however, important to recognise that Chloe's story is a poignant example of the complexities that surround the treatment of eating disorders, particularly for young women, in Australia. Chloe's experience of severe and enduring anorexia nervosa, despite early diagnosis and treatment, raises questions as to whether her untimely death might have been prevented if other treatment options had been available at an earlier stage. Sadly, eating disorders are far more common than many people in the community might think, and it is an area that has been significantly lacking in coordinated, disease specific, public health treatment in this State. This is despite various funding commitments being publicised by the State and Federal governments in more recent years.
- 12. Accordingly, during the inquest, evidence was sought from not only the North Metropolitan Health Service, where Chloe received much of her treatment during her life, but also the East Metropolitan Health Service and Department of Health in

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³ Sections 3, 22(1)(a) and 25(3) of the *Coroners Act 1996* (WA).

relation to what plans are being made to improve the treatment options available to other patients like Chloe in the future as part of my power to comment on any matter connected with the death and public health.⁴ It is heartening to hear that there have been some significant new developments in this area, which I canvas at the end of this finding.

13. Chloe's family had not sought an inquest and would have preferred not to have her death investigated in such a public way. However, they were understanding of the requirement for such a hearing to be held and were supportive of the focus of the inquest on learning from Chloe's experience in order to create positive change in the future for other patients like Chloe. Chloe's family provided additional evidence for my consideration and their own suggestions for recommendations based upon their lived experience with Chloe and their knowledge gained from talking to other people living with eating disorders. I have given careful attention to their comments and suggestions.

BACKGROUND

- 14. Following the birth of her first daughter, Holly, Chloe's mother suffered a couple of threatened miscarriages during her pregnancy with Chloe. She had to spend time in hospital as a result. After her birth, Chloe had a period of time as a baby where she did not gain any weight. Her mother took Chloe to the doctor, who diagnosed her as having low iron. After receiving an iron supplement, Chloe improved, but she was always quite fussy with her food and was a slim child. Chloe's mother took her to the doctor around the time she started primary school, as she was worried that Chloe remained so thin. The doctor reassured her that as long as Chloe had plenty of energy, her mother did not have to worry.⁵
- 15. Chloe was always happy and active as a child, so her mother was reassured. She did ballet lessons with her sister and participated well at school, achieving very good results with her schoolwork. However, towards the end of primary school and starting high school, Chloe contracted a gastrointestinal illness and lost some weight. Her mother recalled that Chloe "went from being slim to quite skinny." She was referred to a specialist at JHC, who gave her some medication because Chloe was suffering from pain. The medication improved her pain but Chloe never really regained the weight that she had lost.
- 16. During her first year of high school, when she was 13 years old, Chloe started to lose even more weight. By the end of Year 9, Chloe was very underweight, and her mother could not identify a cause. She thought Chloe might have a gluten intolerance, or something wrong with her physically, but it did not occur to Chloe's mother at that stage that she could have anorexia nervosa, as her understanding of this disease was limited. Chloe's mother eventually realised that Chloe was not eating all her dinner, so she took her to the doctor, who advised on an eating plan.

⁴ Section 25(2) of the Coroners Act 1996 (WA).

⁵ Exhibit 1, Tab 8.

⁶ Exhibit 1, Tab 8 [15].

⁷ Exhibit 1, Tab 8.

Her family tried to help Chloe follow the eating plan, but when they returned to the doctor for a follow up visit, Chloe had not improved. The doctor told Chloe's mother to take her straight to Princess Margaret Hospital for Children (PMH), which she did.⁸

- 17. Chloe had just turned 14 years' old when she was first diagnosed at PMH with an eating disorder (type not specified). This was later revised to anorexia nervosa.
- 18. Anorexia nervosa is a psychiatric disorder characterised by patients restricting energy intake to the point that their body weight falls to a dangerously low level and results in impairment of their functioning. It takes different forms for different people, but some common features are:⁹
 - Significantly low body weight for age, height, gender and developmental status;
 - Extreme fear of gaining weight; and
 - Disturbed perception of body weight or shape, overvalued influence of body weight or shape on self-worth, or persistent lack of recognition of the seriousness of the current low body weight.
- 19. While the exact causes of anorexia nervosa are not well established, there are many social, genetic, biological, environmental and psychological risk factors and there can be many different triggers or drivers that might set a vulnerable person down this path of restricted eating behaviours. The 'eating disorder cognitions' that prevent the person from eating may be centred around a sense of control over food or can involve emotional regulation related to starvation, but can also be centred around other very personal and very unique reasoning for the individual. It is very rarely related just to a person wanting to fit into a bikini to go to the beach, although it can start with a simple goal of being more healthy and losing weight, but then slip into starvation in some people.¹⁰
- 20. In this case, Chloe's mother, Naomi Tupper, noticed Chloe had been very sensitive to the changing group dynamics at high school and she believes Chloe developed anorexia as "a coping mechanism and a means of control." It was ascertained that Chloe had been pretending to eat her food, but then concealing it by wrapping it up secretly, thereby restricting her energy intake and leading to significant weight loss.
- 21. Anorexia nervosa is associated with high morbidity and mortality, so this diagnosis for Chloe was a very significant and serious one, with a potentially poor prognosis even with treatment. It is classified as a mental disorder, but it has significant physical sequelae as a result of the starvation, which can impact every part of the body, including the brain and the heart. 12
- 22. Treatment involves a multidisciplinary team of practitioners, often including GP's, psychiatrists, psychologists and dieticians. Although it is a mental disorder, the first

¹⁰ T 12 (1.2.24).

⁸ Exhibit 1, Tab 8.

⁹ T 11 (1.2.24).

¹¹ Exhibit 1, Tab 8 [27].

¹² T 11 (1.2.24).

line of treatment for anorexia nervosa commonly involves restoration of body weight. The need to prioritise weight gain first is because starvation negatively affects the brain and results in impaired insight and decision-making. In effect, the brain can't function properly until it is properly nourished. There are also serious physical health issues associated with starvation, including severe cardiac, metabolic, endocrine and bone-related disease, that may lead to acute life-threatening risks and long-term damage to organ systems. It is, therefore, generally accepted that weight restoration must occur prior to initiating other therapies, such as counselling, to treat the mental disorder.

- 23. Initial weight restoration is often done in a hospital setting, particularly if the person's calculated BMI (Body Mass Index) is very low, because the introduction of nutrition to a malnourished person can be dangerous due to shifts in fluids and electrolytes in the body. This can lead to a potentially fatal condition called 'refeeding syndrome'. The person's nutritional needs need to be carefully monitored and calculated by a dietitian. The refeeding may also initially be done by way of a nasogastric tube rather than orally and the patient sometimes need to be monitored to prevent excessive physical exercise initiated by the person to counteract the increased nutrition.
- 24. Once the patient's weight is restored to what is considered a relatively safe level the treatment is then directed to assisting the person to develop a healthy relationship with food and eating. This is a complex process and will vary for different people and will usually take a considerable length of time. This was true for Chloe. Her treatment involved many different practitioners and health facilities over many years, as set out below.
- 25. I note at this early stage that when Chloe was first treated in the early years of her illness, she did not reach full weight restoration before being discharged home. Since that time, it has been recognised that early intervention is key and sending a person home before they are fully nourished can set the person on a cycle of relapse, as they quickly lose any weight gained. This can embed a sense of hopelessness and a belief that full recovery is no longer a possibility for them.¹³ That certainly became the case for Chloe.¹⁴

PMH EATING DISORDER PROGRAM

26. The medical records show Chloe was referred to the Eating Disorder Program at PMH by her GP in November 2002 and she was seen for assessment in December 2002. Chloe was admitted to a medical ward immediately following her assessment due to her low body weight and poor growth. Over a seven week in-patient admission, Chloe received a combination of oral and nasogastric nutrition. This was the first time Chloe was fed via a nasogastric tube, but it was to be repeated many times over the years as part of the treatment to try to get Chloe to increase her weight.

¹³ T 11 – 14; Exhibit 1, Tab 25.

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¹⁵ Exhibit 1, Tab 10.

- 27. When Chloe eventually went home, she was discharged with plans for ongoing individual psychological therapy, parental psychoeducation and family therapy sessions, which had already begun during the admission. These appointments were complemented by regular physical health reviews by a paediatrician, dietician support and psychiatry review. The therapy sessions continued weekly. 16
- 28. From that first time when she attended PMH, Chloe was in and out of hospital over the following years. Medical records indicate Chloe had a total of six inpatient admissions under the care of paediatricians during her time with the PMH Eating Disorder Program. The last lengthy admission was from 2 September to 18 October 2004 and there was a final shorter admission from 6 to 13 January 2005. Her last documented therapy session was 20 November 2005 and she was discharged from the paediatric outpatient clinic in October 2006, with a note that she had shown stability in her weight since late 2005.¹⁷
- 29. Despite some weight gains when in hospital, Chloe's mother recalled Chloe showed no consistent improvement in her illness after her initial diagnosis. She would gain weight through refeeding via the nasogastric tube, but always lost weight again when discharged home, usually very quickly. Chloe's doctors performed investigations to see if there was any underlying medical reason for her weight loss, but did not identify anything. It appeared to be purely a psychiatric cause, although there were obvious physical consequences that flowed. Chloe was treated by psychiatrists and engaged with psychologists and family group counsellors, but Chloe's mother felt Chloe did not respond to any of the treatment. 18
- 30. During these early years, Chloe still managed to complete high school, attending a regular high school supplemented by the school program at PMH. She successfully finished Year 12 and then took a year off before she enrolled in her Fine Arts degree. At the time she turned 18 years old and officially became an adult, Chloe still had anorexia nervosa despite four years of treatment. She continued to see a psychiatrist while studying at university, but declined to seek any other form of medical treatment, despite encouragement from her family. By the time she finished her degree, Chloe's mother observed that Chloe was very weak. Naomi accompanied Chloe to her end of year exhibition as she was afraid Chloe might faint given her frail state. Nevertheless, Chloe had succeeded in completing school and continued to pursue her artistic goals from that time.¹⁹

HOLLYWOOD EATING DISORDERS PROGRAM

31. In 2010, when Chloe was about 21 years old, she began engaging with the Eating Disorders Program at Hollywood Clinic (Hollywood). Chloe was admitted to a ward on 25 August 2010, with an admission weight of 39.06 kg. A nasogastric tube was initially used to feed her and the treating team then encouraged Chloe to eat regular

¹⁷ Exhibit 1, Tab 10.

¹⁶ Exhibit 1, Tab 10.

¹⁸ Exhibit 1, Tab 8.

¹⁹ Exhibit 1, Tab 8.

meals and snacks until she reached a goal weight. Chloe's mother recalls that Chloe started "really rebelling against the treatment around that time." Naomi recalls Chloe would hide food and empty the nasogastric tube. Chloe said she hated being in the hospital because she felt like she was having to be deceitful all the time. The discharge summary indicates Chloe showed an improvement during admission and a reduction in symptoms and she was discharged home at a weight of 53.30 kg, which was a very significant change.²¹

- **32.** Unfortunately, although Chloe did manage to reach her set 'goal' weight a few times, her mother reported that she would not maintain that weight once she went home. Naomi recalls Chloe took to doing acts like drinking excessive water and putting weights in her clothing to try to artificially increase her checked weight in hospital, in order to circumvent the process and ensure she had less weight to lose after discharge.²²
- 33. In October 2011, Chloe had another admission to Hollywood Clinic, with a note that her weight was 45 kg on admission but she had been water loading. This resulted in an admission to JHC for two weeks' prior with hyponatremia (an electrolyte abnormality with low sodium levels). Chloe was admitted into the closed Eating Disorders Program and was reported to have progressed well. Chloe was reviewed by an endocrinologist as part of her treatment, before being discharged home a month later with a weight on discharge of 50.5 kg. This was less than her previous discharge weight, but still significantly higher than Chloe felt comfortable maintaining.²³
- Eventually, Chloe started absconding when she knew she had an upcoming clinic appointment. She appeared terrified of attending, so Chloe's mother would have to sleep in her bedroom with her the night before her appointments to make sure she did not run off in the night. It was around this time that Chloe began saying out loud, "I can't live in this world. I can't do what they are telling me to do. It's too much."²⁴
- **35.** Chloe had another admission to Hollywood Clinic in August 2012, with an inpatient stay of two months. Prior to admission, she had taken a deliberate paracetamol overdose and her weight had dropped to 41.40 kg. Chloe's weight gain was poor and she was noted to be water loading on the ward, so they had to limit her access to the bathroom and move to nasogastric feeding. Chloe's weight eventually increased to 47.25 kg and she requested to be discharged after a meeting with her psychiatrist. Both Chloe and her mother supported her discharge from hospital, so she was discharged home on 12 October 2012 with planned community follow up.²⁵
- **36.** Chloe continued to struggle with engaging in treatment in the community. On several occasions, Chloe's family had to call the police when she absconded. She also became suicidal and on more than one occasion after absconding Chloe took an overdose of her prescription medications. She apparently would stockpile medication

²⁰ Exhibit 1, Tab 8 [40].

²¹ Exhibit 1, Tab 17. ²² Exhibit 1, Tab 8.

²³ Exhibit 1, Tab 17.

²⁴ Exhibit 1, Tab 8 [48].

²⁵ Exhibit 1, Tab 17.

in secret by filling a prescription before the other was finished, which gave her access to a sufficient number of tablets to harm herself.

- 37. On the last occasion that Chloe was admitted to Hollywood Clinic, in June 2013, she had reportedly earlier absconded from Hollywood hospital while an inpatient and gone missing for three days before she returned home in a weak and severely dehydrated state. Chloe said she had spent most of the time travelling back and forth on the train, with increasing suicidal ideation. Chloe was placed on forms under the *Mental Health Act* and sent to Graylands Hospital for psychiatric assessment before being transferred to Hollywood. Chloe was put on a 1:1 nursing special with supervised meals and fluid balance chart to monitor for water loading. She was initially on strict bedrest before introducing short walks. Physically and mentally, Chloe was in poor condition, with a BMI of 10.5, but she gradually improved over a few weeks. During the last week of her admission, the nurse special was ceased and Chloe was able to have her meals at the table.²⁶
- 38. Unfortunately, Chloe's mood deteriorated as her BMI began to increase (up to the only slightly higher level of 12) and she absconded from Hollywood Clinic on 31 July 2013. Chloe was found at Leederville Train Station by her family and was then transferred to Graylands Hospital for admission as an involuntary patient under the *Mental Health Act*. After that, Chloe's mother said Hollywood would no longer accept Chloe back into their program for safety reasons.²⁷

JHC IN-PATIENT AND OUT-PATIENT PROGRAMME

- 39. Chloe was transferred from Graylands Hospital to JHC on 19 August 2013 as she became medically compromised and lost weight during the admission at Graylands and required physical medical care. She was treated as an involuntary patient under the *Mental Health Act*. Before her discharge, Chloe's mother voiced her concerns that Chloe would often rapidly deteriorate following discharge. She was discharged on a community treatment order (CTO) to ensure engagement with her treating psychiatrists and adherence to her treatment in the community.²⁸
- 40. Chloe had further admissions to JHC after this time. There was no specialist eating disorder program at JHC though, so she was primarily treated as a psychiatric patient. Chloe's mother recalled that the primary focus of Chloe's treatment at this stage was simply to refeed her and get her weight up, but this would make Chloe suicidal and lead her to try to abscond.²⁹ At the inquest, one witness observed that Chloe was never successfully renourished to a BMI of 18 or over at any stage, which current management suggests is necessary to allow the recovery of brain functioning to a level that can then engage in the psychological therapy that is necessary for recovery. She was discharged home at the end of this admission at a BMI of 12,

²⁶ Exhibit 1, Tab 8 and Tab 17.

²⁷ Exhibit 1, Tab 8 and Tab 17.

²⁸ Exhibit 3.

²⁹ E 1 1 1 1 T 1

inevitably then heading back on the cycle of rapid weight lost as soon as she went home, reinforcing her belief that she could not be treated.³⁰

- 41. Chloe eventually transferred to an outpatient program run by JHC again. She was visited at home weekly by a psychiatrist and a mental health nurse; they would also sometimes take her out for the day.³¹ Chloe continued to lose weight and her treating team discussed re-admitting her to JHC as an inpatient. However, Chloe was adamant that she would do anything not to go back and from that time she disengaged from the service, not attending further appointments. As a result, she was discharged from the community health team in early 2017.³²
- 42. In the discharge letter to her GP on 16 January 2017, it was noted that Chloe's last suicide attempt had been in March 2014 and since that time she had been maintaining her weight at 36 kg (BMI 12) even though she expressed the belief her ideal weight was 32 kg. She had shown greater emotional stability, despite refusing to see a psychologist. While she remained in this relatively stable place, albeit still chronically unwell, the Joondalup Community Mental Health team had concluded that coercive treatment and active refeeding was unlikely to be beneficial when balanced against the very high chance of suicide. In that letter, the Head of Service emphasised to her treating GP, Dr Ross Haston, that if and when there were acute concerns for Chloe's physical health, she should be admitted to hospital for further care.³³

<u>GP CARE – 2017 ONWARDS</u>

- 43. Chloe had begun attending the Sonic HealthPlus Medical Centre in Joondalup Drive in March 2010, when she was 21 years old. She continued to attend the medical centre as a patient until her death just over ten years later. Chloe's mother would drive her to the appointments but did not go into the appointments with her. Chloe attended a Medical Centre in Joondalup and saw various GP's at the practice. Chloe would always attend willingly and Naomi understood that Chloe made it clear to her doctor that she did not want active treatment and this was respected.³⁴
- 44. Chloe's diagnoses were recorded as long standing anorexia nervosa and major depressive disorder with previous suicide attempts. She was prescribed an antidepressant, Mirtazapine, and an antipsychotic, Olanzapine. It was noted that Chloe was under the care of Psychiatrist Dr Anne Warcholak, as well as a dietician and psychologist when she first started attending the medical centre, although this changed over time to predominantly just GP care.³⁵
- **45.** Chloe would generally be reviewed by a GP every one to two months over the following years, depending on her care needs. Towards the end, Dr Ross Haston was Chloe's regular GP. In his report to the Court, Dr Haston indicated he was aware of

³⁰ Exhibit 1, Tab 25.

³¹ Exhibit 1, Tab 8.

³² Exhibit 3.

³³ Exhibit 3.

³⁴ Exhibit 1, Tab 8 and Tab 11.

³⁵ Exhibit 1, Tab 11.

Chloe's long history of anorexia nervosa and depression and her medication overdoses in 2012, 2013 and 2014. He started seeing Chloe regularly from mid-2013, Dr Haston gave evidence he was aware that Chloe was "fearful of health professionals and of interventions,"36 so he worked hard to engage with her and try to build a relationship. He believes they developed a good doctor-patient relationship that encouraged Chloe to engage with him and voluntarily go back to see him.³⁷

- Chloe remained under the care of the JHC public mental health team outpatient program until January 2017, with Psychiatrist Dr Raj Tanner as her treating psychiatrist. During that period Dr Tanner made decisions about medications and level of intervention. However, that ended when Chloe was discharged from the service. Dr Haston understood that the decision to discharge Chloe from the community mental health service was based upon an understanding that Chloe did not want to engage in treatment with the service and it was decided that further hospital admission or coercive treatment, with force feeding, would not be of benefit.38
- 47. From 2017, Chloe's care was no longer under the management of a psychiatrist and Dr Haston provided the only regular medical treatment Chloe was willing to accept. Dr Haston would see Chloe approximately every 4 to 6 weeks for review of her condition and to assess her weight and blood pressure. She usually came into the appointments on her own, which he believed was part of giving Chloe some independence in her healthcare choices.³⁹
- 48. Once the decision was made for Chloe to leave the JHC outpatient program, Chloe's mother had made sure she was at home to support Chloe, but she did not try to get her to eat or seek treatment other than seeing her GP. She just allowed Chloe to enjoy her time at home. Chloe's mother observed that Chloe was not eating much but she would eat as long as there was someone to support her while she ate. By that time, Chloe's daily diet consisted of:
 - a cup of weak black tea for breakfast;
 - a diet chocolate mousse and a cup of cordial for lunch;
 - a can of Pepsi Max for afternoon tea;
 - a frozen yoghurt popsicle at 4.30 pm; and
 - a frozen yoghurt popsicle at 7.30 pm.

This was, by her own choice, Chloe's diet for the last few years of her life. She would also take laxatives in large amounts and more than the recommended dosage.40

Chloe's mother had stopped questioning Chloe about her eating habits as it made Chloe feel guilty and worsened her mental health. Instead, Chloe's mother and other family members supported Chloe as best they could to be happy, which generally

³⁶ T 125 (1.2.24).

³⁷ T 124 – 125 (1.2.24); Exhibit 1, Tab 11.

³⁸ T 124 – 126 (1.2.24); Exhibit 1, Tab 11.

³⁹ T 124 (1.2.24).

⁴⁰ Exhibit 1, Tab 8.

involved Chloe spending her time at home painting her artworks. Chloe was receiving a disability pension by this stage and she used the money to pay for her medication, and whatever was left to buy her art supplies.⁴¹

- **50.** Throughout this period, Chloe's weight would generally sit at 36 – 37 kg, with a BMI between 12 and 12.5.⁴² This was well below her accepted healthy weight range and consistent with her diagnosis of longstanding anorexia nervosa. Although she remained very underweight, Dr Haston recalled this was a period of relative stability, both in terms of Chloe's weight and in terms of her function. Dr Haston gave evidence there were levels of care he would have liked to have given her during this time, but he felt he had to be very mindful of Chloe's wishes and respect her choices in order to get the balance that ensured she continued to engage. He recalled she was still agreeable to being actively treated to a level, including sometimes permitting blood investigations for monitoring and also taking some prescribed medications, but he believed if he had pushed her to see a dietician and try to return to a normal weight, "she would just have not come back." ⁴³ Dr Haston gave evidence he did still try to be clear about what he thought was appropriate management, and Chloe would then express her own opinions and ideas before they would negotiate to some sort of middle position.44
- 51. Chloe continued on in this way for a number of years without absconding or being hospitalised again. However, it was apparent that the years of malnutrition had caused damage to her brain, which appeared to heighten her mental health issues, and her physical health continued to slowly decline.⁴⁵ Dr Haston had fairly regular discussions with Chloe about the risk her low weight posed to her future health and what gains could be made from increasing her nutrition, but with an understanding that there were limits to what he could push her to accept in terms of interventions.⁴⁶

<u>ADMISSION TO RPH – OCTOBER 2019</u>

52. On 15 October 2019, Chloe went missing for the first time in a number of years. Chloe later told her mother that she had run away because there was swelling in her legs and all she could see was that her legs were fat. The sight tortured her and she wanted to end her life as a result. This kind of swelling/oedema is not unusual in patients with anorexia nervosa, both as a side effect of starvation and sometimes in response to treatment, and is generally an indication that the heart is not functioning.⁴⁷ For someone like Chloe, even though on some level she would have understood that the swelling was not due to gaining weight but rather a medical condition, the visual effect of the swelling was inevitably very distressing.⁴⁸ Other records show there may also have been an argument about whether Chloe needed to

⁴¹ Exhibit 1, Tab 8.

⁴² Exhibit 1, Tab 11.

⁴³ T 127 (1.2.24).

⁴⁴ T 128 (1.2.24).

⁴⁵ Exhibit 1, Tab 8.

⁴⁶ T 128 (1.2.24).

⁴⁷ T 13 (1.2.24).

⁴⁸ T 13 (1.2.24).

- go and see her GP due to her leg swelling and the home environment was unsettled due to family visiting.⁴⁹
- 53. After she had run away, Chloe intentionally took a large quantity of her prescription medications. She called her mother as she was lapsing into unconsciousness. Chloe lost consciousness while still on the phone. Chloe's sister Holly contacted police for help. Chloe was found at a train station by St John Ambulance officers and taken by ambulance to Royal Perth Hospital (RPH), where she was placed on life support. It was established Chloe had overdosed on her prescription medications. She was found to be suffering seizures, delirium and sedation in the context of drug toxicity. She was given nutrition via a nasogastric tube as part of the early treatment.⁵⁰
- 54. Chloe's medical records show she was admitted to the RPH Intensive Care Unit. At the time of the admission, her weight had dropped to 30 kg, with a BMI of below 10.⁵¹ This later became the baseline weight Chloe chose to remain at for the rest of her life.
- 55. When Chloe's level of consciousness and general condition had improved, a psychiatrist spoke to Chloe. Chloe told the psychiatrist she had planned her overdose for over one week. Chloe also told the doctor she was 'terrified of swallowing food' and admitted to persistent laxative use as she still feels 'fat', despite her low weight and BMI. Chloe's mother was also consulted and she gave her opinion that Chloe would not get better and if she was re-fed she would become suicidal again. Chloe was identified as a severe refeeding risk and it was documented there was a high risk of suicide if she was made to increase her intake. She was placed under the *Mental Health Act*, requiring review by a consultant psychiatrist.⁵²
- 56. Given the complexity of her case, Chloe was reviewed by Consultant Psychiatrist Dr Alexandra Welborn and her colleague Consultant Psychiatrist Dr Nigel Armstrong on the afternoon of 17 October 2019. Dr Welborn is employed as a Medico-Legal Adviser as well as a Consultant Psychiatrist, so she was well positioned to consider the medico-legal framework of Chloe's case. 53
- 57. Dr Welborn recalled that at the time she reviewed Chloe with Dr Armstrong, Chloe was confused and inattentive and insightless with impaired judgment.⁵⁴ Chloe's father, mother and sister were present and they assisted with providing Chloe's background history. It was noted Chloe had not been to hospital for about five years, but her previous presentations in the past were almost identical to the current presentation. She had only been receiving GP care in the intervening years, but Chloe described her GP as "wonderful." It was noted Chloe's father and sisters now lived in NSW and Chloe usually lived with her mother in Perth. One of her sisters had been recently visiting and it seems her routine at home had been disrupted. Chloe's

⁴⁹ Exhibit 1, Tab 15.

⁵⁰ Exhibit 1, Tab 8, Tab 15 and Tab 25.

⁵¹ Exhibit 1, Tab 11 and Tab 25.

⁵² Exhibit 1, Tab 15 and Tab 25.

⁵³ T 4 (28.3.24); Exhibit 1, Tab 25.

⁵⁴ T 5 (28.3.24).

⁵⁵ Exhibit 1, Tab 15 and Tab 25.

feet then swelled up and her mother suggested a GP visit, following which she absconded and overdosed.⁵⁶

- 58. Chloe's long history of severe and enduring anorexia nervosa was documented, as well as her high index of failure of treatment and high risk of suicide. The psychiatric review noted the very high psychological distress being experienced by Chloe and her family. Chloe's family understood that she would eventually die from her illness without treatment, but they just wanted Chloe to be happy. At the end of the review, the Form 1A under the *Mental Health Act* was rescinded as it was thought the risks and benefits of treating Chloe as an involuntary patient were not clear. The plan was made to care for her with a 1:1 nursing special until her delirium settled, but then the doctors would be willing to abide by Chloe's wishes and the wishes of her next of kin and let her go home. However, Dr Welborn observed that the "stakes in ... this case were exceptionally high" and it was necessary to discuss the matter further with the executive before the decision to discharge was made as the decision had medico-legal implications, and there was a duty of care to treat Chloe in the meantime to keep her stable. 58
- 59. Chloe was well enough to be transferred from ICU to the ward later on the afternoon of 17 October 2019. It was recorded in the medical notes for 18 October 2019 that Chloe had indicated she wanted to go home and wanted her nasogastric tube removed. Dr Welborn saw Chloe again that day and discussed Chloe's case with other experts and her colleagues, who were supportive of the plan. A dietitian reviewed Chloe later that day and expressed concern that the plan for Chloe's discharge had been made without dietitian input. The dietitian highly recommended that Chloe remain an inpatient for nutritional restoration given her severe malnutrition and BMI of only 9.7 at that time. The dietitian believed there was a duty of care to continue to treat Chloe, despite her expressed desire to go home.
- 60. The dietitian consulted Dr Lisa Miller at the North Metropolitan Health Service WA Eating Disorders Outreach & Consultation Service (WAEDOCS). A note was then made that dietetics proposed to withdraw from Chloe's care based on their disagreement with the current plan for Chloe's management, as it was felt there was an inability for them to provide adequate care for Chloe. The dietitian recommended that Chloe continue with the nasogastric refeeding at a reduced rate but otherwise withdrew from Chloe's patient care. It was noted that if a decision was made to nutritionally restore Chloe, a dietitian should be contacted. The Director of Clinical Services was also consulted before the final decision was made.
- 61. On 21 October 2019, a meeting was arranged with Dr Armstrong and a general medical registrar, Dr Fernandez, together with Chloe, her mother and her sister Holly. Dr Armstrong and Dr Fernandez explained that Chloe's low BMI put her at risk of electrolyte derangements and could lead to cardiac arrest. However, if the

⁵⁶ Exhibit 1, Tab 15 and Tab 25.

⁵⁷ T 7 (28.3.24).

⁵⁸ T 7 (28.3.24); Exhibit 1, Tab 15 and Tab 25.

⁵⁹ Exhibit 1, Tab 15 and Tab 25.

⁶⁰ Exhibit 1, Tab 15, RPH Inpatient Case Notes, 18.10.2019, 17:00, Dietetics.

⁶¹ Exhibit 1, Tab 15, RPH Inpatient Case Notes, 20.10.2019, 10:25, Psychiatry.

family accepted the risk, the nasogastric tube would be removed and Chloe could be discharged home. Chloe's mother indicated that they had been dealing with Chloe's illness for 17 years, they understood the risks and they were still choosing to take Chloe home, where she would be comfortable. Dr Armstrong explained the current management strategies for anorexia nervosa so that all family members were aware of what was currently available as an alternative to simply ceasing treatment. However, Chloe chose to be discharged, with her family's support. Dr Armstrong emphasised that Chloe could change her mind and choose to become a patient at the eating disorder unit at Sir Charles Gairdner Hospital at any time. A note was made that all of Chloe's family, including her father and her sister in NSW, had been consulted and agreed with the plan.

- **62.** Chloe's mother recalled being told by the doctors at RPH that Chloe's anorexia was terminal. The doctors told them that if they were going to treat her, they would, in effect, have to "tie her to the bed for a year and force feed her." 64 Chloe's mother recalled the doctors said that when she was discharged, Chloe could pass away at any time. The RPH discharge summary indicates Chloe's family were aware of the "terminal nature of Chloe's health condition" but the family did not wish for her to remain in hospital for prolonged treatment. Chloe's mother stated that, as a mother, "it was the hardest thing to hear but I had to support my daughter." 66 Chloe told her family and close friends that she was "at peace with the idea of going to sleep and not waking up one day."67 Chloe made it very clear that her choice was to refuse invasive and restrictive treatment. Dr Welborn accepted that given her level of malnutrition, her cognitive ability was likely still impaired, but she was able to unequivocally convey her love of painting, her house, her sunny room and her family, as well as her heartfelt wish to go home, which was supported by her family.⁶⁸
- 63. Dr Welborn gave evidence that the only way they could have treated Chloe was involuntarily as she was unwilling to accept treatment. She and the rest of the treating team involved were well aware from past experience of the strength of will exerted by patients to escape the hospital and avoid re-feeding treatment, and they could see a tableau of restraints, sedation and all the attendant risks that go with that, as well as the "dreadful restriction of liberties," it would require to treat Chloe against her will. Noting the plan would be to try to get her to a BMI of around 20 from her BMI of 8/9, it would have required months and even years of inpatient treatment while Chloe would likely have done everything she could to thwart treatment. Having taken steps to be satisfied that Chloe and her family understood the choice that they were making, that choice was accepted by her treating team in

⁶² Exhibit 1, Tab 15; RPH Inpatient Case Notes, 21.10.2019 and Tab 25.

⁶³ Exhibit 1, Tab 15, RPH Inpatient Case Notes, 20.10.2019, 10:25, Psychiatry.

⁶⁴ Exhibit 1, Tab 8 [78] and Tab 25.

⁶⁵ Exhibit 1, Tab 15, RPH Discharge Summary 6.11.2019.

⁶⁶ Exhibit 1, Tab 8 [80].

⁶⁷ Exhibit 1, Tab 8 [81].

⁶⁸ T 8 (28.3.24).

⁶⁹ T 9 (28.3.24).

⁷⁰ Exhibit 1, Tab 25.

the context of the chronicity of her illness and her high risk of suicide if involuntary treatment was attempted.⁷¹

- 64. Unfortunately, at the inquest it became apparent that the Medical Centre only received some of the pages of the discharge summary. It seems likely this occurred as a result of an administrative error, when the two-sided pages of the document was sent (or received) as single-sided, so the second and fourth page of the discharge summary were not transmitted. The missing third and fourth pages included key information about the discussions with Chloe and her family and the anticipated future for Chloe, were omitted.⁷²
- 65. Specifically, the discharge summary recorded that if Chloe were placed under the *Mental Health Act*, the risks/benefits were not clear. Her family were aware of the terminal nature of Chloe's health condition, they did not wish her to remain in hospital for prolonged treatment and her happiness was their priority. The Director of Medical Services at RPH had been consulted and supported the decision to allow Chloe to go home. She was advised to go and see her GP when she felt comfortable and he was encouraged to provide Chloe and her family with continued support through this difficult time. Some of this information was later communicated to her GP by Chloe and her mother, but it would have been beneficial for Dr Haston to have had all the relevant information from a medical point of view. No formal referral for consultation about palliative care was sent to her GP at that time and a palliative care service was not engaged once she had returned home.

CHLOE'S DECLINE - LATE 2019 TO JUNE 2020

- October 2019 in company with her mother. Dr Haston gave evidence he noticed there had been a huge, dramatic jump down in Chloe's weight after this hospital admission. The Haston had a long discussion with Chloe and her mother and confirmed there had been a discussion about putting Chloe on forms under the Mental Health Act and force feeding her, but her mother believed that would likely cause Chloe to harm herself and end her life. They discussed her recent weight loss of 6kg after going home from hospital, and her dangerously low current BMI of 10. Dr Haston discussed the dangers of this and her reduced life expectancy. They had a long discussion regarding her goals for the future. Chloe had put on a small amount of weight by her next doctor's visit, but admitted she continued to restrict her diet and was fearful of another bout of ankle oedema.
- 67. In a record of his consultation with Chloe on 2 January 2020, Dr Haston noted he was very concerned that Chloe was "slowly declining." She reported only being up for three to four hours a day, she had no energy to walk and was spending less time painting. She continued to lose weight and Dr Haston discussed the dangers of

⁷¹ T 9 – 11 (28.3.24).

⁷² T 133 (1.2.24); Exhibit 1, Tab 15; Exhibit 3.

⁷³ Exhibit 1, Tab 15.

⁷⁴ T 129 (1.2.24).

⁷⁵ T 129 – 130 (1.2.24); Exhibit 1, Tab 20.

⁷⁶ Exhibit 1, Tab 20.

sudden death as a result. Chloe indicated she was "at peace" with this and said she believed a further hospital admission would also kill her. Chloe appeared coherent and to have capacity to make decisions around her care, although her weight was only 29.5 kg at this time. She told Dr Haston that mentally she felt 'comfortable' at a weight of 30 kgs, and was fully aware of the dangers this posed to her physical health.⁷⁷ Although Chloe had previously been more stable at a (still very low) weight of 36 kg, she was no longer willing to regain weight back to that level.⁷⁸

- 68. Dr Haston gave evidence at the inquest that he was in a difficult position as by the time Chloe had first presented to him as a patient, "she felt she had exhausted all her possibilities" in terms of treatment options and nothing had made her significantly better, so she had already come to terms with her low weight and what that meant for her life expectancy. She had been maintaining a weight of around 36 kg for some time under his care, but had in the past indicated her preferred ideal weight was more like 32 kg. Accordingly, once she dropped to 30 kg, he understood that his attempts to push her to accept 36 kg again as a target were unlikely to be successful. Nevertheless, he encouraged her to set 36 kg as her goal weight, although in Chloe's mind it became clear she felt that was unacceptable. Dr Haston explained his concerns that any forcefulness on his part might drive Chloe away or increase her risk of suicide, so he was limited in the options available to him.⁸⁰
- 69. However, Dr Haston also indicated he did not consider transitioning to palliative care at that time. Dr Haston explained that usually with patients requiring terminal palliative care he would expect the referral to palliative care to be arranged in hospital before the patient's discharge, but this was not done in Chloe's case. He accepted in evidence that he knew Chloe was gravely unwell but he had no discussions with the hospital staff, Chloe's family or Chloe herself about instigating a palliative care plan and he agreed he would have found starting such a conversation difficult, given her young age and the nature of her illness. In Dr Haston's experience, there would have been a "huge barrier" to referring Chloe to Silverchain palliative care as there would have been a perception that she was a young woman who had a reversible or treatable illness. 82
- 70. It also became clear at the inquest that Dr Haston's Medical Centre only received some of the pages of the RPH Discharge Summary, potentially due to a double-sided document being incorrectly interpreted as a single-sided document at one end or the other. This meant that Dr Haston did not see some of the comments entered by the RPH treating team in relation to discussions with Chloe's family that they were aware of the terminal nature of her illness and they were aware she would eventually die from her illness and their priority was to ensure her happiness until that time. If Dr Haston had seen those comments, it might have prompted him to have discussed

⁷⁷ Exhibit 1, Tab 20.

⁷⁸ Exhibit 1, Tab 11.

⁷⁹ T 132 (1.2.24).

⁸⁰ T 131 – 133 (1.2.24).

⁸¹ T 135 (1.2.24).

⁸² T 134 – 135 (1.2.24).

palliative care options with either the doctors at RPH or Chloe and her family, but as he didn't see them, that did not occur. 83

- 71. From February 2020 onwards, COVID-19 began to impact on health services and vulnerable patients like Chloe were advised not to leave home. From that point, Dr Haston's consultations with Chloe moved to telephone consultations, which made it more difficult for him to monitor her wellbeing as he did not physically see her and the opportunity to weigh her regularly was gone. Dr Haston continued to prescribe Chloe her antidepressant medications, that had been recommenced while she was in hospital, and he had hoped that her medications might have stimulated her appetite, but this does not seem to have occurred.⁸⁴
- 72. In late May of 2020, Chloe's legs started to swell again. She spoke to Dr Haston, who advised her to take a multivitamin. Unlike the previous time when her legs swelled, Chloe was not in a position to abscond this time as she had no access to a car and she was too weak to flee on foot, but it was accepted it would cause her mental distress.⁸⁵
- 73. By now, Chloe's health was in significant decline. Dr Haston had a long discussion with Chloe, her mother and her sister Holly on 29 May 2020 by telehealth. Dr Haston discussed attending in person for an examination, which Chloe declined, and he believed she had the mental capacity to do so. They also discussed hospital admission and Chloe's family indicated they had grave concerns that another hospital admission would be detrimental to Chloe's mental health, given she had previously made serious attempts on her life as an inpatient. Chloe indicated she might agree to some blood tests being done at home and it was arranged that Dr Haston would call her again in four days' time.
- 74. Dr Haston gave evidence that "at no point did we discuss end of life care" although they had previously discussed that Chloe's prognosis would be poor at 30 kg as it would be difficult to imagine her sustaining that weight and surviving for a prolonged period. 87
- 75. Three days later, on 2 June 2020, Chloe had a fall at home and was unable to get up because she was too weak. Her sister had to help her into bed. Chloe's friend Laura, who is a dietician and psychologist, came to visit and they also called Chloe's regular GP practice. Dr Haston was not at work so one of his colleagues, Dr Andrew O'Shea, was consulted. The medical records indicate Chloe's family were asking if a palliative care plan could be put in place. Dr O'Shea spoke to Chloe's mother, sister and friend. They advised Chloe had significantly deteriorated and was now bedbound, breathing slowly and appeared to be dying. The family's wish was not for Chloe to go to hospital as she did not want active treatment. Dr O'Shea agreed to

⁸³ T 139 – 140 (1.2.24).

⁸⁴ T 128 – 129, 135 – 136 (1.2.24).

⁸⁵ T 133; Exhibit 1, Tab 8.

⁸⁶ T 130 (1.2.24).

⁸⁷ T 130 (1.2.24).

- speak to Dr Haston. After Dr O'Shea spoke to Dr Haston, Dr Haston then contacted Chloe's family directly.⁸⁸
- 76. Dr Haston reported that he spoke to Chloe's mother and sister on 2 June 2020 as they were concerned about Chloe's wellbeing. He then arranged Chloe's admission to hospital via ambulance with the assistance of Dr O'Shea. PDr Haston gave evidence that it sounded like Chloe was "in so much distress and discomfort at that time that it would have been cruel for her not to receive any medical attention." She was hypothermic and dehydrated, so he expected she would receive supportive and comfort care initially and then the treating doctors would consult with Chloe and her family and decide on an appropriate care plan.
- 77. Dr Haston did observe in his report to the Court the chronic nature of Chloe's condition, noting that Chloe had "a longstanding treatment resistant eating disorder and had multiple attempts at treatment via both the public and private system" before this last admission, as well as a major depressive disorder for which she had been prescribed antidepressant medication for many years, but had still had multiple suicide attempts in the form of overdoses.
- 78. Dr Haston was consulted by a psychiatrist from JHC after her admission, and he provided her history of a lengthy and severe illness with a recent drop in condition since the end of 2019, but he explained it was very difficult for him to comment on her recent physical condition as he hadn't seen her in person for some time and it was a matter for the treating physicians at JHC as to what should happen next. 93

FINAL ADMISSION TO JHC – 2 JUNE 2020

- 79. The SJA Patient Care Record indicates the ambulance crew were informed of Chloe's long history of anorexia and she was recorded as having a weight of 28 kgs and was gaunt, pale and cold. Chloe's mother advised the crew that Chloe had been talking and mobile that morning but had become unresponsive at approximately 11.00 am. The ambulance had been requested to attend at 1.36 pm and they had arrived at the scene at 2.08 pm. At the time of their assessment, Chloe's eyes were open but she was unresponsive.⁹⁴
- 80. It was noted that Chloe's family advised the SJA crew that Chloe was palliative but this was not documented anywhere. She was observed to be peripherally shut down and had observable bed sores and burn scars from using hot water bottles to regulate her temperature. SJA officers spoke to Chloe's GP who stated that Chloe was expected by JHC Consultant Dr Sarah Carter. The crew then spoke to Dr Carter, who was happy for Chloe to be given intravenous fluids and glucose. She was warmed

⁸⁸ T 137 (1.2.24).

⁸⁹ Exhibit 1, Tab 11 and Tab 20.

⁹⁰ T 137 (1.2.24).

⁹¹ Tm 137 – 138 (1.2.24).

⁹² Exhibit 1, Tab 11, p. 3.

⁹³ T 138 (1.2.24).

⁹⁴ Exhibit 1, Tab 9.

with a heater and space blanket but the IV access was unsuccessful. Chloe was then taken by ambulance to JHC, with care transferred to hospital staff at 3.08 pm. ⁹⁵

- **81.** On arrival, Chloe was severely unwell with hypothermia (low temperature), hypoglycaemia (low blood sugar), low blood pressure and pulse, low sodium and a possible infection. She was commenced on antibiotics, intravenous fluids, rewarming, thiamine replacement and admitted to the High Dependency Ward. Chloe spent the last week of her life as a patient at JHC. ⁹⁶
- **82.** In the early part of her admission, there was some conflict between her family's desire to respect Chloe's wishes and provide Chloe only with comfort care, compared to the medical view that active treatment options might still be available for Chloe. Chloe was referred for psychiatric review on 3 June 2020 after discussions with her family about the risk that Chloe would attempt suicide if she was forced to receive treatment.⁹⁷
- Consultant Psychiatrist Dr Colin Singam reviewed Chloe for the first time on 3 June 83. 2020. Dr Singam recalled that he received a specific request to first speak to Chloe's sister Holly, before seeing Chloe, which he did. He recalled that Holly conveyed a lot of information about Chloe's history and Chloe and her family's acceptance that her health was poor and her condition untreatable, so they had come to hospital seeking palliative care for her. 98 Dr Singam also looked at Chloe's previous JHC medical records and the records of her RPH admission the previous year and spoke with Chloe's GP, Dr Haston, who confirmed Chloe's condition was chronic and that she had indicated her wish for non-invasive management, which he had respected. Dr Singam understood from his conversation with Dr Haston that in the most immediate period before her hospital presentation, Dr Haston had been trying to support Chloe by prioritising her comfort and quality of care only. His management plan did not include a plan to intervene in Chloe's malnutrition even if her death was likely, which was supported by her family. Chloe's increased risk of suicidality with weight restoration and her failure to maintain her weight after treatment in the past was also noted.99
- 84. When Dr Singam spoke directly to Chloe, he noted she was very unwell and appeared fatigued, which limited their ability to have a lengthy conversation. However, he was able to speak to her in order to establish that she did not want to be refed and understood that without being refed, she would die. Chloe emphasised that she did not want any treatment and said she did not believe that any treatment for her anorexia nervosa would work. Chloe denied any disordered thinking or perceptual abnormalities but she did tell Dr Singam she believed she was fat, although this was demonstrably not the case. Chloe said she knew she would probably die from complications of her illness but felt this was preferable to weight gain. Chloe said she

⁹⁶ Exhibit 1, Tab 16.

⁹⁵ Exhibit 1, Tab 9.

⁹⁷ Exhibit 1, Tab 16.

⁹⁸ T 59 (1.2.24).

⁹⁹ T 59 (1.2.24); Exhibit 1, Tabs 16, 18, 20 and 24.

- would resist any attempt to refeed her. ¹⁰⁰ Specifically, Chloe said "she would kill herself if she was refed." ¹⁰¹
- At this early stage, Dr Singam felt that Chloe's diagnosis of severe anorexia nervosa **85.** was clear but in terms of formulating a plan moving forward, he was faced with "a very complicated scenario and the stakes were very high, life or death." He was conscious of trying to balance his clinical obligations to do what was right by Chloe and her family with his ethical obligations to 'first do no harm', his legal obligations under the Mental Health Act and his obligations to the hospital and its staff. 103 Dr Singam understood on face value that Chloe, her family and several clinicians had all come to a consensus not to try to reverse her anorexia nervosa, but as a clinician he felt an obligation to gather more information to reach his own informed opinion as to the best course to adopt. He had formed the view that Chloe's decision-making capacity that day was impaired, so her views expressed on that day had to be considered in that context. 104 At that early stage, Dr Singam's opinion was that the severity of Chloe's illness and attendant risks was sufficient for her to be detained under the Mental Health Act, although it was not clear to Dr Singam if enforced treatment would ultimately be in Chloe's best interests, or likely to be futile. 105
- **86.** Dr Singam arranged for the following actions to be undertaken: ¹⁰⁶
 - A family meeting was scheduled (noting he had only spoken to Holly and Chloe);
 - Additional collateral information from medical records was sought; and
 - A second psychiatric opinion was requested.
- 87. Chloe remained admitted under the care of a consultant physician in the High Dependency Unit in the meantime and supportive medical treatment continued to be provided, but re-feeding was not initiated. It was noted that her oedema was probably masking her actual weight at that time, and her 'dry weight' BMI was estimated as less than 10. This information was later passed on to Dr Singam.¹⁰⁷

INVOLUNTARY PATIENT ORDER?

88. On 4 June 2020, a second psychiatric opinion was obtained from Professor Hans Stampfer in relation to Chloe's capacity and management plan. Professor Stampfer believed Chloe was in a 'psychotic' state of denial about the seriousness of her eating disorder and the medical complications that had arisen. In his opinion, her judgment was impaired and she did not have the capacity to engage in rational discourse about her illness, nor to make rational decisions about treatment. Professor Stampfer endorsed involuntary treatment and suggested that a hearing date before the Mental

¹⁰⁰ T 62 (1.2.24); Exhibit 1, Tab 24.

¹⁰¹ T 60 (1.2.24).

¹⁰² T 60 (1.2.24).

¹⁰³ T 60 – 61 (1.2.24).

¹⁰⁴ T 62 (1.2.24).

¹⁰⁵ T 65 (1.2.24); Exhibit 1, Tab 24.

¹⁰⁶ Exhibit 1, Tab 24.

¹⁰⁷ Exhibit 1, Tab 18.

Health Tribunal hearing should be obtained as soon as possible. Dr Stampfer also indicated his view was that active treatment should be commenced, contrary to Chloe's wishes, with the treatment aiming for Chloe to achieve a weight that was likely to restore her capacity so that she could then make treatment decisions. ¹⁰⁸

- 89. A family meeting was held on 5 June 2020 between Dr Singam and Chloe's parents and her sister Holly. Also in attendance were an ICU nurse, other doctors and a consumer liaison support person. Dr Singam discussed Chloe's medical state and Professor Stampfer's second opinion with her family, which recommended full active treatment until Chloe reached a stage where she had the capacity to make informed decisions about her care. Dr Singam also discussed the alternative approach, which was to make the determination that forceful re-feeding was futile and allow Chloe to return home and probably die. Dr Singam advised them that there would need to be a legal framework around the second option, which was not yet in place. 109
- 90. Chloe's mother, Naomi, explained that in the wake of Chloe's recent health deterioration, she had called Dr Haston with the expectation that they could receive support at home to assist Chloe to have a peaceful death. Naomi and Holly were both horrified by the lack of community supports and the fact they were now back in hospital and facing the prospect of Chloe being forcibly re-fed once again. Chloe's family expressed their belief that Chloe had received no benefit from previous interventions and that she was happiest after 2017 when she was discharged from mental health services and remained at home. It was documented that Chloe had not been able to be re-fed to a weight above the low 40kgs in all the years of her illness. 111
- 91. Dr Singam told Chloe's family his plan was to make Chloe an involuntary patient in the short term while the treating doctors worked together to determine the appropriate course of treatment. At the inquest, he explained he had made this decision after giving due weight to Professor Stampfer's opinion. Dr Singam also advised them that he had sought a specialist opinion from Dr Lisa Miller, the Head of Service of the WA Eating Disorders Outreach & Consultation Service (WAEDOCS), with the understanding that she might be available to review Chloe on 16 June 2020 (her earliest availability). 112
- 92. Dr Singam said that after the family meeting, his inclination was to allow Chloe to be discharged home as he felt it was likely she would die from complications of anorexia nervosa irrespective of treatment. However, given the complexity of her case and the difference of opinion, he felt it was appropriate to take further steps to determine the proper course and ensure all relevant matters had been considered. Therefore, it was decided by Chloe's treating team after the family meeting that Chloe should be made an involuntary patient under the *Mental Health Act*, which would trigger a Mental Health Tribunal hearing. Chloe's family would have the

¹⁰⁸ Exhibit 1, Tab 24.

¹⁰⁹ Exhibit 1, Tab 24.

¹¹⁰ Exhibit 1, Tab 24.

¹¹¹ T 60 (1.2.24).

¹¹² T 65 (1.2.24); Exhibit 1, Tab 24.

opportunity to express their wishes to the Mental Health Tribunal. If the Mental Health Tribunal supported the family and other clinician's views that Chloe's illness was irreversible and treatment was futile, then it would likely lead to a decision for the involuntary patient order to be revoked and Chloe could be discharged home with possible palliative care involvement. Dr Singam acknowledged that Chloe's family were upset by this decision, given their understanding from her RPH discharge that she would be made palliative. ¹¹³

- 93. Dr Singam signed a Form 6B Inpatient Treatment Order and Chloe was made an involuntary patient under the *Mental Health Act* at 2.36 pm on 5 June 2020. The order was set to expire on 26 June 2020 unless revoked earlier. The plan at that stage was "to continue treatment to prevent imminent death, but not with the goal of weight restoration." This included trying to correct her electrolyte status and treat her low blood pressure. Dr Singam discussed with Chloe his plan. He recalled that "Chloe acknowledged that her health problems at that time were too severe for her to feasibly go home, which was her hope." 115
- 94. On the same day, Dr Singam reviewed Chloe's medical records from her previous RPH admission. He noted there was reference to Chloe being 'terminal', which was consistent with the family's understanding and explained Naomi's expectation that Dr Haston would arrange palliation when Chloe needed it. However, Dr Singam also observed that the notes from RPH did not refer to a plan for palliation or what to do when Chloe became severely unwell due to inadequate nutrition, which explained Dr Haston's position.¹¹⁶
- 95. An urgent request was made for a hearing with the Mental Health Tribunal, where the views of Chloe and her family and her medical team could be aired and a decision made as to the best path forward. Dr Singam let Dr Haston know in case he also wished to be a part of the process. The potential for a SAT application for guardianship was also raised. In the end, no tribunal hearing eventuated as Chloe's health deteriorated rapidly before a hearing could be convened. 117
- 96. Dr Singam also sought advice from the Chief Psychiatrist, Dr Nathan Gibson. Dr Gibson noted that Chloe's case was extremely complex and likely to divide clinical opinion, with no obvious single correct approach. Dr Gibson commented that any long term plan to treat Chloe at that stage would likely have required keeping her in hospital for several months under highly restrictive conditions to "try to treat her incapacitous starvation cognition," with the inherent risks of suicide and foreseeable potentially significant conflict among family, [Chloe] and staff during that time," with the understanding the treatment would probably be unsuccessful given the effects of her longstanding starvation. The other option was to essentially inevitably let her die. Dr Gibson agreed that Dr Singam's approach, in making Chloe an

¹¹³ T 66 (1.2.24); Exhibit 1, Tab 16 and Tab 24.

¹¹⁴ Exhibit 1, Tab 24 [32].

¹¹⁵ Exhibit 1, Tab 24 [33].

¹¹⁶ Exhibit 1, Tab 24.

¹¹⁷ Exhibit 1, Tab 24.

¹¹⁸ Exhibit 1, Tab 18, p. 1.

- involuntary patient for a short period and supporting her without forcing her to eat, were important acts of due diligence to allow him to formulate a plan. 119
- 97. Dr Miller was included in some of the exchanges with Dr Gibson at this time as it was hoped she might be able to review Chloe and provide expert input. Unfortunately, Dr Miller was on a rare period of leave at that time and then had other commitments, so she could not immediately assist. Dr Miller has no leave cover in her role, so there was no one to replace her in the meantime. Dr Miller explained in an email that the first time she would be able to review Chloe was on 19 June 2020. Given the urgency of the situation, Dr Miller offered some alternative private practitioners who might be able to assist within a more rapid timeframe. However, matters progressed very quickly and it seems there was no opportunity for further input from an eating disorders specialist. Dr Miller was involved as an expert at the inquest, and I discuss her evidence later in this finding.
- **98.** While all of this was taking place, peripheral parenteral nutrition via vascular access was commenced for Chloe, as Chloe refused oral or nasogastric feeding. It was hoped this would keep her stable until a clearer path of action had been formulated, understanding that a lot hinged on her physical prognosis as there was no purpose in curative treatment for her mental illness under the *Mental Health Act* if she was not going to recover. ¹²²

DECISION TO PROVIDE COMFORT CARE

- 99. Chloe required treatment for low sodium and developed renal failure and signs of pulmonary oedema (fluid on the lungs) over the weekend. On 6 June 2020 she was noted to be intermittently confused and hypothermic. A family meeting with the HDU doctors was held to discuss her clinical deterioration. While noting it was difficult to anticipate her ongoing progress, the doctors indicated that Chloe might not get well enough to be able to go home. ¹²³ Chloe continued to appear drowsy on 7 June 2020, although she remained stable and was able to engage with treating staff. ¹²⁴
- 100. By 8 June 2020, Chloe's condition was obviously deteriorating further. A diagnosis of Beri Beri, a condition caused by B12 deficiency, was made. Chloe's blood counts were low due to bone marrow failure, she had kidney failure and her liver was not functioning properly. She remained hypothermic and hypoglycaemic. An echocardiogram showed she had severe cardiomyopathy. A HDU doctor reviewed Chloe at 5.00 pm that day and noted their significant concerns that Chloe had reached end-stage disease, with severe organ dysfunction without chance of significant recovery. Dr Singam then reviewed Chloe and noted she was less able to converse due to tiredness. He had been advised of her less optimistic outlook for physical recovery and made a note that if the concerns crystallised into an opinion

¹¹⁹ Exhibit 1, Tab 18.

¹²⁰ T 101 (1.2.24).

¹²¹ Exhibit 1, Tab 19.

¹²² T 67 (1.2.24).

¹²³ Exhibit 1, Tab 16, Integrated Progress Notes, 6.6.2020, 14:40.

¹²⁴ Exhibit 1, Tab 16.

that physical recovery was unlikely, then he would be included to stop the involuntary treatment order, but for now he was still pursuing an urgent Mental Health Tribunal hearing. A cardiology opinion was sought by the HDU intensivists who were caring for Chloe and she was reviewed by the cardiology team that evening, after Dr Singam. The cardiology team concluded that due to the severity of her heart failure, Chloe's prognosis was very poor. 125

- 101. On 9 June 2020, before the Mental Health Tribunal hearing meeting could be convened, another meeting was held between Chloe's treating team and Chloe's family. Chloe's family requested palliative care service involvement. The attending medical team agreed that there was medical consensus that Chloe was in the end stage of her illness and Chloe's condition had deteriorated to the point where comfort care was in Chloe's best interest. Chloe was barely rousable by this stage. Morphine and midazolam were given and parenteral nutrition was ceased. Chloe died at 7.45 pm that evening in the company of her parents. 126
- 102. Dr Singam advised that he was not working at JHC on the day of Chloe's death. He was not updated in relation to her condition and the decision to transition her to comfort care, until after her death that evening. Dr Singam gave evidence he had made an entry note in Chloe's medical records about his planning and had handed over his impression of what was happening with Chloe's care to other psychiatrists on shift, but it doesn't appear they were consulted prior to her death, so it seems there was no opportunity to rescind the order. 127
- 103. An initial entry in the medical records made that evening incorrectly recorded that the involuntary patient order had been revoked and Chloe's death was not reportable to the coroner. The error was corrected the next morning, once it was recognised the Form 6B had not been revoked, and Chloe's death was reported to the coroner. 128
- 104. Chloe's mother described the final week of Chloe's life in JHC as "heart-breaking for us as a family." She explained that it was not what Chloe wanted and it was really hard for her undergoing the treatment they provide. Chloe's mother noted that Chloe was an adult and she could no longer force Chloe to seek treatment, even though she wanted to do so. Chloe's family had tried for many, many years to try to get Chloe to want to accept help and be saved, but they had reached the point where they understood that Chloe was happiest and safest at home and what she really wanted was her family to simply support her as a daughter and a sister and respect her decisions. 130
- 105. Chloe's mother also observed that over the 18 years or so that Chloe had suffered with the illness, the treatment methods had never changed and nothing had worked to shift Chloe's brain pattern and make her want the help and accept the treatment. Chloe never went through puberty because of her anorexia and, like her body, her

¹²⁶ Exhibit 1, Tab 16.

¹²⁵ Exhibit 1, Tab 16.

¹²⁷ T 68 – 69 (1.2.24); Exhibit 1, Tab 24.

¹²⁸ Exhibit 1, Tab 16.

¹²⁹ Exhibit 1, Tab 8 [94].

¹³⁰ Exhibit 1, Tab 8.

mind also remained quite young and immature for her age. In many ways, she remained as innocent as a child in her desire to stay at home and simply create beautiful art, without any wish to go out and socialise and drink or smoke or do any of the other things young people do as they reach adulthood. Chloe was part of a close and loving family and they had been there with her throughout the years as she suffered with her illness, during which time they had come to understand she was fixed in her position. They were willing to make the difficult decision to let her go, if that is what she wanted.

106. It was, understandably, more difficult for the doctors treating Chloe to accept that this was the right decision for Chloe, given her young age, the fact that her physical condition affected her brain's capacity to make rational decisions and there was a possibility she could still be successfully treated. However, once it became clear there was no prospect Chloe could be saved, given how far her disease had progressed, the decision was made, in consultation with her family, to cease all treatment. I recognise how hard that last period would have been for Chloe and her family, but I also recognise that her treating doctors were in a difficult, and unusual, situation that required them to consider all options and ensure they had a good medical and legal foundation for ceasing treatment.

CAUSE AND MANNER OF DEATH

- 107. Forensic Pathologist Dr Clive Cooke conducted an external post mortem examination, including CT scan, and reviewed some of Chloe's medical records. Dr Cooke observed changes of recent medical care and noted Chloe had a low body weight (34 kg), with apparently spare body subcutaneous fat and musculature and mild oedema. Biochemical testing showed the sugar level to be not raised, with possible mild impairment of kidney function. Toxicology analysis showed the presence of medications consistent with terminal medical care. At the conclusion of the limited investigations, Dr Cooke formed the opinion the cause of death was organ failure due to anorexia nervosa. Dr Cooke expressed the opinion the death was due to natural causes. ¹³¹ I accept and adopt Dr Cooke's opinions as to the cause and manner of death.
- **108.** For the sake of Chloe's family, as I know this was a matter of great concern for them, I reiterate that Dr Cooke did not perform an internal examination and dissection as this was not necessary in order to form an opinion as to her cause of death.

INDEPENDENT EXPERT REVIEW

- **109.** Counsel Assisting posed a number of questions for my consideration at the conclusion of the inquest:
 - was the supervision, treatment and care provided to Chloe while she was a person held in care appropriate?

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¹³¹ Exhibit 1, Tab 5 and Tab 6.

- was the decision to make Chloe an involuntary patient under the Mental Health Act an appropriate one?
- what is the current state of public health services for adults who are diagnosed with severe eating disorders in Western Australia and is it sufficient to provide appropriate care for a person like Chloe?
- 110. In order to assist me in considering these questions, Consultant Psychiatrist and Adjunct Professor Rebecca Anglin was requested by the Court to review Chloe's case and provide an independent expert opinion on Chloe's medical management. Professor Anglin gave particular attention to the quality of the supervision, treatment and care Chloe received immediately prior to her death, as this was the primary focus of the inquest.
- 111. Professor Anglin qualified and practised in Canada, before moving to practise in Australia in 2018. Professor Anglin currently works as a consultant psychiatrist in the Consultation-Liaison service at Sir Charles Gairdner Hospital and is an Adjunct Professor at Notre Dame University. There was no dispute at the inquest as to her relevant expertise to provide this opinion, although I note that Chloe's family did raise some concerns in written material about connections between Professor Anglin and other medical witnesses. In an isolated place like Western Australia, and in such a specialised area of care, connections are inevitable and it was with great difficulty that the Court was able to find any expert who was not intimately involved in Chloe's direct care. Accordingly, while I can appreciate the Tupper family's concerns, I emphasise that I found Professor Anglin to be an appropriately independent expert, who took great care to consider this case with objectivity and offer helpful comment and constructive criticism. I note Chloe's family were supportive of Professor Anglin's evidence, despite their early misgivings. 132 However, I take on board their suggestion that, if a similar case were to arise in the future, it might be wise to try to identify an interstate or overseas expert, with specific SE-AN (Severe Enduring Anorexia Nervosa) expertise. 133
- 112. Professor Anglin reviewed a large number of relevant medical documents, the WA Police coronial investigation reports and a comprehensive statement from Chloe's mother to assist her in forming her opinion. Professor Anglin was only given limited information about Chloe's care and treatment in the early years of her illness, as the primary focus of her opinion was on the final period leading to her death. Professor Anglin did, however, comment on some aspects of her early care as they were relevant to Chloe's diagnosis of severe and enduring anorexia nervosa later in her life.
- 113. Professor Anglin acknowledged Chloe's family's frustration and sadness on their part watching Chloe cycle in those early years through being refed in hospital and then coming out of hospital and quickly losing weight again. Professor Anglin observed that this experience is unfortunately not uncommon and often occurs when the intensity of the stepdown to outpatient treatment is missing. Professor Anglin noted that the goal of refeeding to reverse the starvation processes and associated

¹³² Exhibit 1, Tab 22.2

¹³³ Exhibit 1, Tab 21 and Tab 22.1.

eating disorder cognitions was very appropriate early in Chloe's illness, but it was apparent that she had not recovered after a number of years of treatment when she became an adult.¹³⁴

- 114. Professor Anglin commented that it was unclear whether there was a proper transition between Chloe's care as a child across to adult services when she turned 18 years old, noting that there is very little information about her care around this time. It seemed clear that Chloe had not recovered from her eating disorder at this time, but there was no documented close handover of her care despite the change in services available to her. Professor Anglin commented that there is unfortunately a common gap in care in Western Australia when patients become an adult, as we do not have a comprehensive adult outpatient eating disorder treatment program in the public system in this state. Therefore, there are no established processes for transitioning adolescents to adult care.¹³⁵
- 115. As Professor Anglin suspected, the evidence shows that Chloe did not have a coordinated transition across from child to adult care. Chloe's mother advised that when Chloe turned 18 years old and commenced her university studies, she disengaged from treatment for a few years. She did not recommence formal treatment until she turned 21 years old, when she became a private patient with Hollywood Clinic. Professor Anglin did not have access to information about Chloe's treatment at Hollywood although she noted that they are not an authorised setting so there are limitations on the care that can be provided within that setting for patients who are not willing to voluntarily receive treatment. Chloe's extreme distress and associated risk of self-harm was very real, which seems to have pushed her into the public system. 136
- 116. In 2013, after absconding from Hollywood Hospital and her treatment moved into the public health system again, Chloe became a patient of the JHC Community mental health team. Professor Anglin observed that in the absence of a comprehensive adult outpatient eating disorder program in the public health system in Western Australia, the care for adult patients with eating disorders predominantly falls to community mental health teams (unless patients seek private care). It was, therefore, normal for Chloe to be managed by a community mental health team. However, with her understanding of what is required for treating such a complex illness, Professor Anglin noted that such a team may not have had the resources or expertise to treat Chloe's eating disorder, which might have reduced the standard of care she was able to be provided. Nevertheless, overall Professor Anglin noted Chloe had been receiving appropriate multi-disciplinary care while engaged with this outpatient service. 137
- 117. Professor Anglin commented that looking back over Chloe's history to this time, there was a lot of bouncing back and forth between the public and private health systems and inpatient and outpatient care, "without a really consistent clear plan and step-up/step-down within the system in a team that [knew] Chloe and [knew] her

¹³⁴ T 16 – 18 (1.2.24).

¹³⁵ Exhibit 1, Tab 21.

¹³⁶ T 19 (1.2.24).

¹³⁷ Exhibit 1, Tab 21.

family well"¹³⁸ so that they could tailor her treatment. Professor Anglin observed that one problem with these multiple transitions would be that Chloe and her family would be telling their story to a new person all the time; a problem that became very apparent at the end, noting the different approaches between RPH and JHC staff.

- 118. The next significant change was when Chloe made the decision to be discharged from the JHC outpatient program in early 2017. From that time, she began to see solely her GP for her ongoing medical management. Based on the materials that was provided, Professor Anglin felt Chloe's discharge from the JHC community mental health service to her GP appears to have been "a critical juncture in her care." Professor Anglin noted it was a significant change in management, with an apparent decision to cease all active eating disorder treatment.
- 119. By this time, it would seem that Chloe fell into the subtype of eating disorders referred to as severe and enduring anorexia nervosa. Professor Anglin gave evidence at the inquest that severe and enduring anorexia nervosa is not a diagnosis but is a commonly used label in clinical practice. It generally refers to a patient who:¹⁴¹
 - has had anorexia nervosa for a period of time, but usually more than five years;
 - has not recovered despite having adequate evidence-based treatment, which would usually be adequate refeeding; and
 - there is significant impairment in their quality of life as a result of the anorexia nervosa.
- 120. Professor Anglin indicated that cases of severe and enduring anorexia are not completely uncommon or rare in the healthcare system, but there is very little good data on its incidence and there isn't complete agreement on what is the optimal treatment for people who fall into this category. Professor Anglin observed that information on treatment of severe and enduring anorexia nervosa tends to come from observational studies and programs internationally, rather than from within Australia. Often the focus of these programs is on creating a supportive environment to ensure quality of life and removing the burden of distress caused by active treatment focussed on weight restoration. This is done through providing supportive psychotherapy and monitoring of their physical condition to assist with maintenance of weight within a BMI band where they have enough energy to still engage in activities that improve their quality of life.
- 121. It is clear that this was the approach taken by Chloe and her family in the later years of her illness and Professor Anglin noted that for a very long time Chloe maintained her weight at 36 kg, or a BMI of 12, with supportive monitoring by Dr Haston, and during that time she was incredibly productive in her art and maintained meaningful relationships. 142

¹³⁹ Exhibit 1, Tab 21 [8].

¹³⁸ T 19 (1.2.24).

¹⁴⁰ Exhibit 1, Tab 21.

¹⁴¹ T 13 (1.2.24).

¹⁴² T 13 – 15, 22 (1.2.24).

- 122. Professor Anglin acknowledged that there is another school of thought in the literature around patients who can recover from severe and enduring anorexia nervosa. However, Professor Anglin commented that like with any medical treatment, the evidence base has to be interpreted for that patient in that family and then work collaboratively together to achieve an outcome. It is clear in this case, that the concept of a supportive treatment plan for Chloe, acknowledging the length and severity of her illness and her resistance to re-engaging with traditional treatment, resonated with Chloe's family.
- 123. In terms of Dr Haston's more supportive monitoring approach, that appeared to align with the wishes of Chloe and her family, Professor Anglin's primary concern was around the lack of monitoring and planning for when Chloe's condition eventually deteriorated further. Professor Anglin acknowledged that Dr Haston was placed in a difficult position as Chloe put significant limits on the care she was willing to receive, but if it had been possible then Professor Anglin suggested some monitoring to identify critical shifts in her trajectory could then have hopefully led to discussions around encouraging her to regain enough weight to get her back to some kind of equilibrium. Alternatively, it would have allowed for advance planning around palliative care and other end of life options. 143
- 124. Returning to the earlier discussions about treatment options for patients with severe and enduring anorexia nervosa, Professor Anglin noted that the period around her admission to RPH in 2019 at a low weight of 30 kg was another critical juncture. Professor Anglin explained that even with a patient with severe and enduring anorexia nervosa, a drop in weight like this from Chloe's earlier base weight of 36 kg was an appropriate juncture to try to negotiate with Chloe to refeed to at least the previous weight at which she had been able to function. Professor Anglin acknowledged that for Chloe the thought of refeeding at that stage may have felt insurmountable but ideally a few weeks as an inpatient to give her medical treatment and stability in the people working with her might have been beneficial and assisted Chloe to return to a weight where she might have been able to function for several more years. Professor Anglin accepted that these kinds of discussions may have been had with Chloe while she was at RPH, but if they were, they were not documented. 144
- 125. Professor Anglin observed that from the notes there appeared to be some disagreement within the RPH treating team about what was the optimal approach for treating Chloe. Professor Anglin thought this was reasonable, and reflected the fact that there isn't a really clear-cut course for treating a patient like Chloe with severe and enduring anorexia nervosa; as indicated above, there is a school of thought that the aim should still be refeeding and recovery versus those who would focus on quality of life. 145
- 126. It was apparent that during her admission to RPH in 2019 some detailed conversations were had with Chloe and her family about the risks of her weight remaining at the new low of 30kg, which was not life-sustaining, and the decision

¹⁴³ T 24 – 25 (1.2.24).

¹⁴⁴ T 26 (1.2.24).

¹⁴⁵ T 26 (1.2.24).

had eventually been made to allow her to go home to her family at that time. Unfortunately the information about the final discussions between RPH staff and the family that was included in the discharge summary did not make its way to Dr Haston and Professor Anglin commented that there did not appear to be "a really comprehensive discussion with the GP around where to from here." Professor Anglin suggested that what would have been ideal was to provide advice to the GP about who he could involve for help, such as the WA Eating Disorders Outreach Consultation Service, or linking them in with palliative care services, as Dr Haston may not necessarily have had access to all of those resources.

- 127. In essence, Professor Anglin's comments were that, looking back in hindsight, the period while Chloe was at RPH before then transitioning back to GP care, was the time to either negotiate with Chloe to refeed her back to a BMI where she could function reasonably well again, as she had for some time, or to develop a clear plan for what would happen if things continued to deteriorate, recognising that the actual course of events could be variable.¹⁴⁷
- 128. Instead, there was no planning around end of life care for Chloe and no continuity, so it seems that Chloe and her family had formed a view as to what was going to happen at the end after their discussions with RPH staff, which was different to what Dr Haston understood, and was not documented sufficiently for the medical staff at JHC to be satisfied that a well-informed plan was already in place. 148
- 129. Professor Anglin expressed the view that Dr Singam and his team went to great lengths to try to quickly gather the information needed to understand the complexity of Chloe's case and treat her case individually, rather than simply applying the usual treatment approach. However, Professor Anglin acknowledged this does take time, which was frustrating and distressing for Chloe and her family.¹⁴⁹
- 130. Dr Singam made a very comprehensive record of his clinical reasoning for the decisions he made at different times and in Professor Anglin's opinion those decisions appeared reasonable, even though different clinicians at RPH had taken a different approach. Professor Anglin observed that at the time Chloe presented to JHC, her presentation was significantly worse than when she had presented at RPH, and matters had reached the point where the decision whether or not to treat had become an immediate life-or-death decision due to Chloe's medical instability, which she acknowledged "then requires due diligence in really making sure you're doing the right thing by Chloe and, also, her family." Professor Anglin commented that it was clear Dr Singam showed an intent to work with the family to try and get Chloe home, but he was also trying to follow an appropriate process within a legal framework, and the time this took unfortunately led to Chloe dying in hospital rather than at home with her family, as Chloe would have hoped. Professor Anglin also

¹⁴⁶ T 27 (1.2.24).

¹⁴⁷ T 27 (1.2.24).

¹⁴⁸ T 27 – 28 (1.2.24).

¹⁴⁹ T 28 – 29 (1.2.24).

¹⁵⁰ T 29 (1.2.24).

noted that there appeared to have been an intention to revoke the involuntary patient status before Chloe's death, but for some reason that did not occur. 151

- 131. In terms of more general comments about the care that was available to Chloe, Professor Anglin commented that there were a number of challenges present in the system due to a lack of a continuous eating disorder service that could follow Chloe through her adult phase of her illness. A service that knew her well and could assist in planning and ensuring continuity of service and easy accessibility to records, might have made a difference, at least at the end stages of Chloe's illness. Professor Anglin suggested that, at the very least, better documentation in PSOLIS, which is an electronic database for psychiatric patients generally available in most hospitals, would have provided a framework for the doctors at JHC who were dealing with Chloe during her final presentation.¹⁵²
- 132. Professor Anglin advised at the time of her evidence at the inquest in February 2024 that there have been some very recent improvements within the public health system in terms of the development of a north metropolitan, east metropolitan and south metropolitan outpatient service that can provide a more intensive, step-down, outpatient service as a patient with an eating disorder transitions from inpatient to going home. Professor Anglin described this as a new and really positive development, noting that "early intervention is the cornerstone of care of patients with eating disorders."¹⁵³
- 133. However, it still does not provide the continuity of care involving a "robust step-up, step down comprehensive system of eating disorders treatment that ...we find in other states or internationally." ¹⁵⁴ Professor Anglin explained that the problem is that patients are still treated either on the general medical ward with psychiatry input or as an inpatient in a psychiatry ward, and there are limits on beds available for eating disorder patients as they require a lot of active involvement and treatment, which can be frustrating for patients and their families. There are also very few experts in Western Australia treating eating disorders, so it is left to general medical practitioners and psychiatrists in the main. 155 Nevertheless, while there is still a lot of space for improvement in the resourcing, Professor Anglin considered the recent developments to be very promising in terms of improving care for patients with eating disorders in this State. 156
- 134. In terms of looking forward, Professor Anglin commented that "we're talking about a disorder with the highest mortality of any mental illness that affects young women at the height of their life and can result in atrophy of their brain if not treated in a timely fashion." 157 She observed that the account of Chloe as a person was not atypical of a person with anorexia nervosa, noting they "are some of the best people. Creative. Smart. Bright. Driven." The illness often occurs in really high-achieving

¹⁵¹ T 30 – 31 (1.2.24).

¹⁵² T 33 (1.2.24).

¹⁵³ T 36 (1.2.24).

¹⁵⁴ T 35 (1.2.24).

¹⁵⁵ T 35 (1.2.24). ¹⁵⁶ T 36 (1.2.24).

¹⁵⁷ T 37 (1.2.24).

¹⁵⁸ T 37 (1.2.24).

professional people, so we are losing an immense amount of talent and potential when the lives of these wonderful young people are cut short by an illness that, if caught early, can be treatable. In Professor Anglin's opinion, we should be "offering the very best of robust, wrap-around care," which also needs to reflect the continuum where patients with severe and enduring anorexia nervosa, like Chloe, who don't have the ideal trajectory, might need to have a shifting focus on quality of life when evidence-based treatment has not achieved its aim.¹⁵⁹

135. Professor Anglin also suggested that there would likely be financial benefits in a more focussed eating disorder treatment service, rather than the current piecemeal approach with patients dotted around the general medical wards in this State, in addition to improving the experience for patients and their families. ¹⁶⁰ It is also relevant in this context that national data and international data reveals an exponential increase in diagnoses of patients with eating disorders since the COVID-19 pandemic, for various reasons. Early and effective treatment for these patients is essential, as "[t]hat first presentation of a patient with an eating disorder is the most critical time to really try to achieve recovery during that episode of care with then ... ongoing follow-up"¹⁶¹ to maintain that stability after discharge. Professor Anglin observed that this also requires support to be available for the family, not just the person diagnosed with the eating disorder. ¹⁶²

OTHER MEDICAL EVIDENCE

Dr Haston

- 136. Chloe's family expressed their gratitude to Dr Haston for his considerate care of Chloe in the years prior to her death. It was acknowledged that he was placed in a difficult position when he took over her care, given she was many years into her illness and felt she had already exhausted the treatment options available to her. Dr Haston demonstrated a willingness to listen to Chloe and her family and try to work within the boundaries of the care she would accept to keep her as well as possible for as long as possible.
- 137. Dr Haston gave evidence at the inquest that he found it difficult to manage Chloe's care as there was no obvious service in the public system to refer her to, where he could feel confident she would be seen and managed in a timely manner. He commented that "there were so many different points in her care before [he] looked after her and after that [where] she didn't fit this criteria or this box," so he didn't really know where to turn for help. He was generally aware of WAEDOCS as a service but it was not something he used while caring for Chloe. In hindsight, he agreed that knowing he could call them up for reassurance or more guidance, would have been helpful. Chloe's family also commented that there was nowhere that Chloe

¹⁵⁹ T 37 (1.2.24).

¹⁶⁰ T 38 (1.2.24).

¹⁶¹ T 39 (1.2.24).

¹⁶² T 43 (1.2.24).

¹⁶³ T 142 (1.2.24).

seemed to fit at the time within the services available, which left them having to rely heavily on Dr Haston. 164

Dr Singam

- 138. Chloe's family posed a number of questions to Dr Singam about his care of Chloe, in her final days, which he answered both in writing and in his evidence at the inquest. Dr Singam indicated he had treated previous patients suffering with anorexia nervosa in his capacity as a consultant psychiatrist, but he acknowledged he had never met a patient as unwell as Chloe until he first met her at JHC. He was guided by the HDU intensivists in relation to Chloe's physical care at that time, and his focus was on her mental state and capacity to accept and decline treatment. Dr Singam found that Chloe's decision-making capacity was impaired when he met her and there was no Advanced Health Directive¹⁶⁵ or formal guardianship orders in place, which meant that he had to turn to the informal substitute decision makers, which in this case was Chloe's parents and, to a lesser degree, her sisters. However, under the *Mental Health Act*, Dr Singam had the right to override the other decision makers where involuntary mental health treatment was warranted, which in his view was necessary, at least in the early stages of her treatment while they were still gathering information. ¹⁶⁶
- 139. Dr Singam acknowledged that the existence of this power of substitute decisionmaking by a consultant psychiatrist did not prevent every effort being made to involve the patient, Chloe, and her significant others in the decision-making process and to pay due respect to their wishes. Dr Singam submitted that he made his best efforts to do so in this case and he was hoping that a rapidly convened Mental Health Tribunal hearing would allow this to be formally done in a structured way. Dr Singam acknowledged that the process heightened Chloe and her family's distress while they waited for a decision to be made. He indicated if it had been possible for a well-documented plan to be presented to him when he first took over Chloe's care, this might have changed her pathway at an earlier stage, but contrary to the understanding of Chloe and her family, this had not been done. In any event, Dr Singam gave evidence that he would still need to have been satisfied that at an earlier time when Chloe was making decisions about her care, she had been at a weight where she might have the appropriate decision-making capacity. Dr Singam believed he took the most cautious path, which was to attempt to stabilise Chloe but not attempt to re-feed her, while a medical consensus/legal framework was able to be achieved.167
- 140. Dr Singam also emphasised in his evidence the challenge highlighted by Professor Anglin by the diametrically opposed opinions in the literature on treatment for a person with severe and enduring, treatment resistant, anorexia nervosa and the concept that they are effectively terminal versus whether they may be curable. Dr

¹⁶⁴ T 143 – 144 (1.2.24).

¹⁶⁵ Noting that an Advanced Health Directive may still not be determinative for a psychiatric patient – see Dr Singam: T 77 – 78 (1.2.24).

¹⁶⁶ T 63, 71 (1.2.24); Exhibit 1, Tab 24.

¹⁶⁷ T 78; Exhibit 1, Tab 24.

Singam noted that on a very basic level, if someone is malnourished, there is an obvious treatment path of re-feeding them and they will no longer be malnourished. However, he acknowledged that this can be a gross simplification of the issues in a case like Chloe's, where her history of illness is lengthy and she has expressed significant suicidality around treatment. Dr Singam understood that at the time he was brought in to perform a psychiatric review, the intensivists still thought there was a possibility that physical treatment might be successful or else there was no role for a psychiatrist to review Chloe. In his mind at that time, his task was to assess her capacity and then balance the prospect of physical recovery with treatment (that was still a possibility at that time) against the likelihood that it might lead to worsening of her psychiatric condition. While Dr Singam understood her family's view was that any treatment would be futile, he understood they were expressing that opinion based on their knowledge of Chloe's long history of anorexia nervosa, whereas without that prior knowledge, he required more time and information to reach an informed opinion himself in this complicated context. 168 Dr Singam also noted, as demonstrated by Professor Stampfer's opinion and the evidence of Professor Anglin, it's quite likely you would not get "a uniformity of opinion from psychiatrists or physical medicine doctors regarding Chloe's state." ¹⁶⁹

141. Chloe's family posed the question to Dr Singam, "What have you learnt from Chloe's case and how will it inform future practice at JHC?" Dr Singam acknowledged, firstly, the stress and distress that Chloe and her caring family experienced in her last days alive and emphasised that it was never his intention for his actions to add to their pain. 170 Whilst he no longer works at JHC, Dr Singam acknowledged it was an important question to consider how the lessons learnt in Chloe's case may alter the course of a patient in another case. Dr Singam said he has reflected a lot on Chloe's case over the years since her death. He does not believe there will be a 'next Chloe' as every person is unique, and suggested that the most important thing will be in each case to try to understand the specific circumstances as thoroughly as possible and respond appropriately, as he believes he did in Chloe's case. However, Dr Singam expressed his hope that the chances of the next patient having to face the difficult situation that Chloe and her family faced may be reduced by improved services that encourage a person in Chloe's position to still engage with health professionals through better continuity and support, so that even if the outcome is the same, the trajectory of her health journey would be better.¹⁷¹ Dr Singam also gave evidence that from a personal perspective, Chloe's case will remain "an important experience" for him to consider if he was faced with a similar situation in the future.

Dr Miller

142. Although she never got an opportunity to review Chloe, like Professor Anglin, Dr Miller reviewed Chloe's medical records and gave evidence at the inquest as an

¹⁶⁸ T 71 – 75 (1.2.24).

¹⁶⁹ T 75 (1.2.24).

¹⁷⁰ T 76 (1.2.24).

¹⁷¹ T 76 – 77 (1.2.24); Exhibit 1, Tab 24.

¹⁷² T 80 (1.2.24).

expert on eating disorder treatment in Western Australia. Following the inquest, Dr Miller also prepared submissions on behalf of the North Metropolitan Health Service (NMHS).

- 143. Dr Miller is a consultant psychiatrist and also a Fellow of the Australasian Chapter of Palliative Medicine and a past Fellow of the Australasian College of General Practitioners. Dr Miller indicated that she had done a dual fellowship in palliative medicine and psychiatry as she has a particular interest around the care of people at the interface of physical and mental health. This interest has ultimately led to her specialty in the treatment of eating disorders.¹⁷³
- 144. As noted above, she is the current Head of Service of WAEDOCS. Dr Miller explained at the inquest that while working as a consultant liaison psychiatrist at Sir Charles Gairdner Hospital in 2011, she saw her first severely malnourished patient with anorexia nervosa and after reaching out to colleagues for advice, she realised that there was very limited expertise in Western Australia for the care of youth and adults with eating disorders at that time, with the bulk of experience predominantly based at the private Hollywood Hospital. As a result of her experience with that first patient, Dr Miller raised by email the need for a more specialised service within the public health service for eating disorder patients. At the same time, Dr Miller and a colleague took steps to better educate themselves around this complex area. Within a short time, Dr Miller received a response to her email, in the form of being given a position as head of the newly created WAEDOCS, despite only having treated one patient for a prolonged admission. In that sense, Dr Miller sought to counter the notion of being an expert in this treatment area, at least at that time. However, since 2011, Dr Miller has, in her role with WAEDOCS, been involved in the treatment of many other persons who are severely unwell with eating disorders, so she has developed her expertise over time and certainly is a colleague whose experience is sought by other psychiatrists when they have a complex patient like Chloe. 174
- 145. The funding for WAEDOCS was initially only 2.4 clinical FTE. That has not increased in the more than 10 years that have since passed, which allows effectively four sessions of Dr Miller per week, a full-time nurse, a part-time dietitian and some part-time psychology staff. With such limited staffing, it is not possible for WAEDOCS to provide full service eating disorder treatment to patients. Instead, the WAEDOCS staff provide a consultation service for other practitioners, helping to build capacity to treat eating disorder patients with health professionals across the state. This can include a GP, a country health service, a large tertiary hospital, a junior nurse or a peer support worker at a community centre. Dr Miller indicated that any of them can pick up the phone and speak to a WAEDOCS team member to get advice on a particular patient or to seek further education or training. WAEDOCS also acts as a "contact point for further advocacy and try to provide some form of leadership for system reform." 175
- 146. Dr Miller explained that it is very challenging to look after people who are severely unwell with eating disorders, noting it is very resource intensive, although in her

¹⁷³ T 81 – 82 (1.2.24).

¹⁷⁴ T 83 (1.2.24).

¹⁷⁵ T 84 (1.2.24).

opinion it does not require any specific technical prowess per se.¹⁷⁶ Dr Miller commented that learning more about Chloe's case, and particularly reading Chloe's family's comments about their experience, highlighted for her "that it has taken so long to get any funding for investment in a continuum of care," which was something that may have helped Chloe earlier if the capacity had existed within the health system.

- 147. Dr Miller acknowledged the evidence disclosed in relation to Chloe's death made it clear there is a need for "an individualised and person-centred approach to balancing all relevant risks" when managing a person with an eating disorder, particularly when severely malnourished. Dr Miller explained that one of the challenges in eating disorders is that "although officially they come under the definition of a mental illness, they are inherently a brain illness and a body illness. So both the body and the brain are trapped in a state of starvation." 179 Dr Miller described it as "a body that's trying to adapt to the famine that it thinks exists around it," 180 noting there are evolutionary adaptations our body will make in times of food shortage, such as a drop in the basal metabolic requirement, that in the past allowed our ancestors to cope with famine and drought. In a person with an eating disorder, who is deliberately restricting their calorie intake, the response of the body will be the same. At the same time, the lack of nourishment can cause actual changes of atrophy in the brain, and with that brain atrophy comes high states of dysregulation, disinhibition, irritability and other mood disorders, which can make the person very difficult to engage in care as they lack insight.¹⁸¹
- 148. In terms of Dr Singam's evidence, Dr Miller agreed with his approach in trying to establish whether Chloe had had access to evidence-based treatment whilst fully-nourished "because we know that's critical in terms of the neuroplasticity of the brain, the brain's ability to actually benefit from those treatments." Dr Miller observed that the acute phase of anorexia nervosa is in the first two to three years of the illness, and if they are able to intervene early with full nutrition, many people will manage to recover from that point. However, in a case of chronic and severe illness, with a phase of chronicity lasting 20 years or more, full recovery may be challenging and it is difficult then to work out "the degree of reversibility back to a life that is meaningful and purposeful for them versus someone who is moving into a phase which is actually a terminal phase where the accrued complications within the body to many organs as a result of chronic severe malnutrition mean that that is less likely to be feasible." Dr Miller explained that the impact of the brain in staying in such a chronically malnourished state for such a long period of time means that the likelihood of reversibility has diminished significantly as well. 184

¹⁷⁶ T 83 (1.2.24).

¹⁷⁷ T 84 (1.2.24).

¹⁷⁸ Submissions filed on behalf of NMHS by email dated 15 May 2024.

¹⁷⁹ T 85 – 86 (1.2.24).

¹⁸⁰ T 86 (1.2.24).

¹⁸¹ T 86 (1.2.24).

¹⁸² T 85 (1.2.24).

¹⁸³ T 85 (1.2.24).

¹⁸⁴ T 85 (1.2.24).

- 149. Dr Miller commented that there is often a reluctance for health professionals and health services to want to care for patients with severe eating disorders as they are highly resource intensive to manage. Also, in a siloed health system such as ours, where traditionally physical health issues are dealt with by one group of practitioners and mental health issues are dealt with by another group of practitioners, there is a mismatch in resourcing and a lack of coordination between the two types of care required that leads to a disconnect about who is responsible for the care of people with eating disorders. Dr Miller observed that this can result in lack of recognition of the magnitude of the problem and a lack of leadership around the investment in the services that are required. As a result, "the burden of unmet need is ... high." 185
- **150.** Dr Miller advocates for funding of a service that provides a continuum of care, noting that whilst there will always be people who require an acute medical admission or acute mental health admission, there needs to be less restrictive forms of care available when that assertive form of in-hospital care is not, or no longer, required. Dr Miller ¹⁸⁶explained that a residential care setting would be one component of a continuum, but it would also provide 'step up' and 'step down' services to manage people on their ongoing journey, as anorexia nervosa is often a cycle due to the nature of the brain illness. ¹⁸⁷
- **151.** When considering the current lack of services available, Dr Miller offered the comparison of a patient with heart disease or cancer, who is told that the likelihood of a cure or recovery is fundamentally impacted by how early intervention can be started, but they will have to wait six to eight months to commence treatment. This is what many eating disorder patients are told about the waitlist for an appointment with a clinical psychology standalone service. ¹⁸⁸
- 152. Dr Miller gave evidence that she has "sent thousands of emails and gone to hundreds of meetings" in order to reach the very early stages of the services that are now being put in place this year in Western Australia. Dr Miller observed that one of the issues has been the difficulty in categorising the treatment into either mental health or general health in terms of resourcing, which has meant that adequate resourcing has been difficult to obtain. As a result, treatment has often "relied on essentially the altruism of a handful of health professionals," with a lot of the general care falling onto GP's without a broader supportive framework to help them to manage the patient's care. Chloe's case is a prime example of this occurring.

COMMENTS ON TREATMENT SUPERVISION AND CARE

153. On behalf of Chloe and her family, Naomi Tupper provided a detailed chronology of their experience with the health system over the many years of Chloe's illness. I recognise and acknowledge the deep distress and frustration Chloe's family have experienced witnessing Chloe's long journey through various attempts at treatment

¹⁸⁵ T 86 (1.2.24).

¹⁸⁶ T 88 (1.2.24).

¹⁸⁷ T 86 – 87 (1.2.24).

¹⁸⁸ T 88 (1.2.24).

¹⁸⁹ T 88 (1.2.24).

¹⁹⁰ T 88 (1.2.24).

that never achieved any lasting improvement in her health and without continuity in terms of the carers involved. Naomi Tupper described a system deprived of resources and lacking answers, that in its failure to treat Chloe often resulted in a sense of blame being pushed onto Chloe and her family. 191

- 154. Although Chloe had periods of treatment as an inpatient and was able to be re-fed to a higher weight, she would quickly lose weight again on discharge. She also learned techniques over time to help her prevent gaining weight by masking her true weight when receiving treatment. It seems clear that whatever physical treatment she received, the treatment never reached the stage of effectively treating the mental element of Chloe's illness. Dr Miller explained that as the body and brain start to come out of the state of starvation, it is a gradual process to recover and the brain can lag behind the body by weeks to months. Therefore, while Chloe showed signs of physical improvement, her psychological treatment was still at an early stage whenever she was sent home from hospital. As her illness worsened, her treatment options reduced because her suicidality around re-feeding increased her level of risk. Dr Miller acknowledged that this sense of being abandoned and rejected is profoundly distressing for individuals and their families, and it is apparent that Chloe and her family struggled with this sense of doors being closed to them over time.
- 155. Dr Welborn noted that she has had many discussions with Dr Miller about Chloe and they reflected on how the management of eating disorders has changed since Chloe's early treatment at the start of her illness. Dr Welborn observed that Chloe was discharged in 2014 with a BMI of 12, which they know today is "not good medicine" because we now know the patient hasn't restored enough nutrition and they will rapidly go back to their former weight. The current management suggests that patients need to achieve a BMI in the 18–20 band. If in the early stages of her illness this had been her treatment plan, Dr Welborn considered it might have changed the trajectory for Chloe. Instead, Chloe's experience was that of a lot of patients of that generation, where they were refed only to BMI 12 and then allowed back into the community with a belief they had been 'treated', only to rapidly return to their pre-admission weight, leading to a false belief they were not treatable. In the community weight, leading to a false belief they were not treatable.
- 156. By the time she was admitted to RPH in late 2019, Dr Welborn felt it was no longer realistic to try to achieve the current treatment focus of a BMI of 20 for Chloe without her cooperation and her family's support, as the treatment journey would have been long and arduous. Knowing what the outcome was for Chloe, Dr Welborn indicated that on balance, she and her colleague Dr Armstrong felt they would make the same decision again. Dr Welborn gave evidence both she and Dr Armstrong used to think about Chloe every single week after she left RPH and wonder how she was

¹⁹¹ Exhibit 1, Tab 22.1.

¹⁹² T 89 (1.2.24).

¹⁹³ T 91 (1.2.24).

¹⁹⁴ T 13 (28.3.24).

¹⁹⁵ Exhibit 1, Tab 25.

¹⁹⁶ T 11, 14 (28.3.24); Exhibit 1, Tab 25.

going, so it was lovely for them to hear that she managed to have nine months of artistic and happy life at home before her death.¹⁹⁷

- 157. The lack of continuity in care also forced Chloe and those who supported her to have to tell her story again and again. This is clearly demonstrated by Chloe's discharge from RPH on 21 October 2019, with an understanding that she was being sent home as a terminal patient, and her re-admission to JHC on 2 June 2020, when the whole process of consultation had to effectively begin again. The distress this fragmentation of care caused to Chloe and her family is undeniable. Dr Welborn gave evidence the implementation of electronic medical records will hopefully alleviate some of this confusion, but she also agreed with Chloe's mother, Naomi Tupper's, suggestion that a person like Chloe with a long history of illness and associated medical care might benefit from carrying a brief summary of their medical care, or even a mental health care plan prepared by a GP, to give to hospital staff when they present for care. ¹⁹⁸
- 158. In relation to Dr Haston, Dr Miller acknowledged in her evidence that "99 out of 100 GP's would have declined to take on Chloe's care." She understood the immense responsibility Dr Haston would have felt as a GP trying to manage such a complex patient with no resources or support and noted that his experience further supports the need for a continuum of care for patients being discharged from hospital, so that their treatment in hospital dovetail in to help that person remain well and get traction with treatment outside in the community. Professor Anglin also acknowledged that Dr Haston was working in a system that left him isolated and unsupported while treating a very complex patient. Nevertheless, he showed an unwavering commitment to his patient and a willingness to be flexible to try to keep her engaged with him.
- 159. Dr Haston did not pursue a palliative care referral, but at that time, and without a fulsome discussion with the RPH staff, that was reasonable. Dr Welborn explained that at the time they discharged Chloe home, her family were not really keen on further involvement with hospital systems and there were fewer referrals going to palliative care for a patient like Chloe. However, a lot has changed since Chloe's death due to the enactment of the voluntary assisted dying laws in Western Australia, and Dr Welborn now believes a palliative care process would be more readily accessible for a patient like Chloe. Dr Welborn gave evidence that she has had other patients in this situation that have been able to go home and be with their family at the end of their life, and she currently has a patient receiving palliative care for an eating disorder, so a lot has changed in the five years since Chloe's death, which is heartening to hear.²⁰¹
- 160. I am satisfied it was appropriate, in the circumstances, for Chloe to be taken by ambulance to hospital on 2 June 2020 and, given it was a new treating team, it was reasonable for Dr Singam in conjunction with the HDU specialists to consider all options for Chloe and consult with their colleagues before making such a significant

¹⁹⁷ T 11 (28.3.24); Exhibit 1, Tab 25.

¹⁹⁸ T 15 – 16 (28.3.24).

¹⁹⁹ T 84 (1.2.24).

²⁰⁰ T 84 (1.2.24).

²⁰¹ T 9 – 11, 18 (28.3.24).

decision in relation to such a young patient. The real question they were trying to establish was whether Chloe had any chance of recovery, which was a complex question. Once it became very clear that she was at the end stage of her illness, care was withdrawn and she was allowed to pass peacefully in the company of her parents. It is regrettable that a psychiatrist was not consulted at that stage to allow the involuntary patient order to be rescinded so that Chloe's death would not have been reportable. It would have saved Chloe's family considerable distress. Nevertheless, it has given this Court an opportunity to learn more about this complex illness and what is planned for the future to help other people like Chloe.

161. Overall, I am satisfied that within the context of the resources that were available at the time, and the limited understanding of eating disorder treatment, all the practitioners involved in Chloe's care behaved reasonably and appropriately. Unfortunately, the system failed Chloe and her family, which brings me to the next part of this finding, which is looking at what is being done to improve care for other people like Chloe who are living with a severe and enduring eating disorder and the families who are trying to support them.

COMMENTS ON PUBLIC HEALTH – EATING DISORDERS IN WA

- 162. Dr Miller acknowledged in the submissions filed on behalf of the NMHS that there is widespread recognition that timely access to evidence-based care for West Australians with eating disorders has been limited for some decades. This has "likely reflected a disconnect between mental and physical health care funding, planning and leadership." The NMHS submits that the answer is not a simple, 'one stop shop' solution. Rather, care for youths and adults with eating disorders needs to be delivered "via an integrated continuum across a range of settings including inpatient, outpatient, primary care and private sector services." Dr Miller described the aim in her evidence is to have a "no wrong door approach to care," recognising that patients may need to step up and down from intensive support more than once and it might take some time. This is consistent with the Commonwealth Government's *National Eating Disorders Strategy 2023 2033* (National Strategy). ²⁰⁵
- 163. The aim of the National Strategy is to improve access to treatment, support, and care for people impacted by eating disorders in Australia. To achieve this aim, a sustainable mechanism for funding care across all these settings is required, which will involve oversight from both the Department of Health and the Mental Health Commission.²⁰⁶
- 164. I am advised the Mental Health Commission facilitates several dedicated eating disorder services and programs in Western Australia, including community-based treatment with outpatient clinics and day programs, consultation liaison and peer support programs. The State Government, with input from the Commission, is now

²⁰² Submissions filed on behalf of NMHS by email dated 15 May 2024, p.1.

²⁰³ Submissions filed on behalf of NMHS by email dated 15 May 2024, p.1.

²⁰⁴ T 93 (1.2.24).

²⁰⁵ Exhibit 2.

²⁰⁶ Submissions filed on behalf of NMHS by email dated 15 May 2024, p.1.

pursuing further initiatives to address eating disorders in Western Australia and has drafted a Western Australian Eating Disorders Framework 2025-2030 (draft Framework), as part of the process. It is due to be released in 2025 and will have an implementation period from 2025 to 2030. I am told that the draft Framework, which is yet to be released, has been informed by national and state consultation that was part of the development of the National Strategy, as well as a review of current WA services and targeted engagement with members of the community, including those with lived experience.²⁰⁷

- 165. Currently, a backbone of specialist outpatient-based services has been established in each area health service via the West Australian Eating Disorders Specialist Services but it is acknowledged there is still likely to be unmet demand, particularly given the many years of under-investment coupled with the post COVID increase in prevalence of eating disorders in the community. Unmet demand will likely result in many individuals living with the chronic effects of eating disorders. Like Chloe, they may not be a good fit for existing treatment options, but they will have serious and often complex illnesses with a high burden of physical and mental suffering. As was seen with Chloe, that burden will often fall on family members and primary care services like GP's, when they don't 'fit in the box'.²⁰⁸
- 166. The NMHS submits that where it is determined that an individual with a severe and enduring illness has received evidence-based treatments and a shift in goals of care is requested by that individual, a process of due diligence should be undertaken by a specialist eating disorder service outside of a crisis setting in conjunction with the person, their next of kin and any other key family stakeholders, in addition to their regular healthcare providers, to collaboratively determine clear guidance for future care. It is, however, suggested that this should only occur while the patient is nutritionally restored, so that their brain is functioning at a level objectively able to make these kinds of decisions.²⁰⁹ In Chloe's case, that would have required getting her weight back up through re-feeding before any discussions about palliative care.
- 167. Dr Miller explained that there needs to be awareness of the impact of brain changes due to starvation on both the severity of body image concerns and the drive to restrict, which can potentially impact on an individual's ability to understand, retain, recall, process or communicate information pertinent to weighing up a range of treatment decisions and to engaging safely with care. Dr Miller expressed the opinion that the biggest challenge with eating disorders is that the effect of the starvation is the brain atrophy, for which the appropriate treatment is nutrition, but the effect of the brain atrophy is to reduce the person's capacity to accept the nutrition. It instead makes the person strongly resist the treatment that will make them better and give them that capacity to choose it. The longer it goes on, the more the brain changes and the more hard wired the belief becomes that treatment won't help.²¹⁰ In the end, Dr

²⁰⁷ Letter to DSC from Dr Shirley Bowen, Director General, Department of Health dated 12 November 2024; Letter to DSC from Commissioner Maureen Lewis, Mental Health Commission dated 13 November 2024.

²⁰⁸ Submissions filed on behalf of NMHS by email dated 15 May 2024, p.1.

²⁰⁹ Submissions filed on behalf of NMHS by email dated 15 May 2024, p.1.

²¹⁰ T 98 – 99 (1.2.24).

Miller accepted that there are some patients with a particularly severe illness and a level of chronicity where the "notion of complete cure has probably eluded us". ²¹¹

- 168. These conversations and goals for future care should then be formally documented and distributed to help guide future treating health professionals to provide safe care to the person within an accepted medico-legal framework. Assuming the robust process has been followed, then a person with a severe and enduring eating disorder who is approaching end of life should then be able to be referred to a palliative care service for the terminal phase. 213
- 169. Dr Miller did acknowledge in her evidence at the inquest that "recovery as a concept is often about people leading a life that is meaningful and purposeful for them." However, Dr Miller pointed to patients who have been severely malnourished but have gone on to be able to recover fully from their illness, as well as studies that showed that people can still fully recover from an eating disorder in their fifties and sixties, even when they have been living with an illness for 30 plus years. She suggested there needs to be a distinction between chronicity and the relatively rare case of a severe and enduring eating disorder, where 'living with' the illness becomes a more achievable option than full recovery. Although she emphasised these cases are rare.
- 170. Dr Miller observed that even in these cases, a brief admission and some attempt to stabilise their acute nutritional state can still be beneficial, recognising the physical burden of suffering that comes from severe malnourishment, including symptoms such as severe constipation, pressure sores and mouth ulcers. In addition, there is mental anguish and potentially co-occurring depression that comes with severe malnourishment, with evidence suggesting the more malnourished the person becomes, the more intense the eating disorder cognitions in keeping with the atrophy in the brain. Even if the specific goal of care is not then to cure their illness, Dr Miller suggests this is a moment to identify where they are in the trajectory and see if they can get them back to their previous level of adequate functioning or if they really are in the end of life terminal care phase.
- 171. Accepting they are in the terminal phase, arranging palliative care for a young patient like Chloe will still meet many challenges, noting that palliating someone who arguably has a reversible illness does not fit within the typical medico-legal framework of palliative care.²²⁰ Dr Miller commented that it is important to ensure that the due diligence has been done about what care has been provided to the person when they have been fully nutritionally restored, and then ensuring that no individual health professional is left in a position of holding all the responsibility for, and risk

²¹¹ T 100 (1.2.24).

²¹² Submissions filed on behalf of NMHS by email dated 15 May 2024.

²¹³ Submissions filed on behalf of NMHS by email dated 15 May 2024.

²¹⁴ T 94 (1.2.24).

²¹⁵ T 94 (1.2.24).

²¹⁶ T 94 (1.2.24).

²¹⁷ T 95 (1.2.24).

²¹⁸ T 95 – 96 (1.2.24).

²¹⁹ T 96 (1.2.24).

²²⁰ T 96 – 97 (1.2.24).

of, that decision.²²¹ Dr Miller noted that this is a huge undertaking to plan for and would need months, if not years, of planning.²²² It also requires work to stabilise the person sufficiently to the point they would be suitable for a community palliative care service.²²³ The appropriate time to commence that planning in Chloe's case would have been when she was still at RPH, before she was discharged back to her GP's care, so that a framework could start to be put into place for this next phase of her illness. However, I accept that back in 2020 that was less common than it would be today, since the introduction of voluntary assisted dying (VAD) into our legislation has led to a greater acceptance of a broader scope of what is terminal, while noting Chloe would not have fallen within the VAD framework.²²⁴

- 172. Dr Miller and NMHS acknowledge that youth with eating disorders are at highest risk of difficulty accessing care due to fragmentation of service delivery, particularly for 16 to 17 year olds. "This key point of transition between child and adolescent and adult physical and mental health services overlaps with the peak age of onset of eating disorders, alongside key phases of brain and body development." I note Chloe dropped out of formalised care for a number of years around this transition stage, only re-engaging around 21 years of age. By then, she was well down the path of her illness, having been living with an eating disorder for many years.
- 173. As noted above, there is evidence that eating disorders have been increasing in prevalence. Post COVID, there has been a recognised further "sharp and significant increase," particularly in children and young adults. Dr Miller described the unmet need of these patients as akin to "standing on the cliff watching the tsunami coming in." 227
- 174. The NMHS submits that there is a need for robust investment to support safe transitions between child/adolescent and adult services and to link young people with other non-eating disorder based services to support them during the transition. It is also noted that at the present time, inpatient care is delivered predominantly in adult general hospitals without funding for specialist expertise, which potentially impacts safety, quality and consistency of care. Dr Miller spoke at the inquest of the "bimodal peak" for anorexia nervosa, with the peak age of onset in the range of 14 to 24 years, but because it takes many years to recover, 85% of people with an eating disorder are over 18 years. How an adolescent might engage with treatment can be different to how a young adult or adult will engage, noting that frontal lobes keep developing until a person is in their mid-twenties, so Dr Miller commented that it is important for services to continue to offer continuous care to these patients as they age into adulthood. Safe

²²¹ T 97 (1.2.24).

²²² T 97 (1.2.24).

²²³ T 100 (1.2.24).

²²⁴ T 97 – 98 (1.2.24).

²²⁵ Submissions filed on behalf of NMHS by email dated 15 May 2024, p.2.

²²⁶ T 92 (1.2.24).

²²⁷ T 92 (1.2.24).

²²⁸ Submissions filed on behalf of NMHS by email dated 15 May 2024, p. 2.

²²⁹ T 93 (1.2.24).

²³⁰ T 93 (1.2.24).

- 175. There have been changes made in more recent times to the services available, although some are still in the early planning change. Currently, the State Government has provided \$31.7 million over five years to fund the establishment of an area based specialist service for north metro and south metro health services, and the Commonwealth Government has contributed some additional funding to allow the east metro health service to establish a level of specialist service. However, it is recognised that, like in all other areas of health, there is a shortage of available specialist expertise, so trying to recruit people to these services will be challenging. This then requires training of less experienced staff to build capacity in the workforce from within, which obviously takes time.²³¹
- 176. Although not an eating disorder specialist, Dr Welborn often treats patients with eating disorders as part of her work as a consultant psychiatrist at RPH. Dr Welborn noted that the psychiatric team has to work very closely with the physicians as the medical status of these patients is often very precarious and needs to be monitored on an hourly basis. Therefore, any inpatient treatment generally requires good cooperation between different disciplines and a lot of specialist input. Therefore, while Dr Welborn supports the option of a centre for excellence that could provide care for the most complex cases, like Chloe, it is noted that it would have to have the capacity to provide a very high level of complex physical care as well as psychiatric care. ²³²
- 177. The Acting Deputy Director of the Department of Health, Robert Anderson, helpfully provided information about the funding arrangements and recent developments for eating disorder treatment in Western Australia. Mr Anderson indicated that the Australian Government provided funding to all states and territories in 2019 for a range of related projects, including \$4 million for the construction of a residential eating disorder treatment centre at the Peel Health Campus. However, the WA Department of Health concluded that the high cost of the inpatient treatment model would limit the number of patients that could be treated and the level of funding offered by the Commonwealth would not be sufficient to build and run such a facility. Further, current best practice recommends eating disorder services are based in the community, as articulated in the National Eating Disorders Strategy.²³³ Therefore, the WA Government sought variation to the funding and received in-principle approval to amend the model of care from residential treatment services to community based out-patient care and away from the hospital campus to a different location in the Peel region. In addition, the WA Government has committed more than \$30 million to establishing a comprehensive state-wide out-patient eating disorder service in line with the WA Mental Health Commission 2021 Model of Service for WA Eating Disorder Specialist Services. 234
- 178. In a report dated 12 March 2024, I was advised that work had commenced to identify an appropriate site or existing facility in the Peel region for the commissioning of the community mental health facility. When giving evidence at the inquest on 28 March 2024, Mr Anderson advised that the facility had been identified and a pre-existing

²³¹ T 104 – 105 (1.2.24).

²³² T 17 – 18 (28.3.24).

²³³ Exhibit 1, Tab 26.

²³⁴ T 21 (28.3.24); Exhibit 1, Tab 26.

building was to be re-fitted in order to be utilised for a community eating disorders clinic in Peel, providing a 'step up, step down' service that will help maintain a continuum of care for patients.²³⁵ In addition, the WA Government seized on an opportunity that presented itself when a private mental health facility became available. That facility presented the State Government with an opportunity to take on the lease of a newly constructed facility, which had cost and time benefits. After consultation with South Metro Health Service staff, it was concluded that the facility would be well placed to fill a gap in women's mental health services and eating disorders treatment, as well as some other services. The new facility will provide the first dedicated adult eating disorder beds in this State, although the beds will be limited to voluntary adult inpatients.²³⁶ This will add an important link or step in the continuum of service, between hospital care for involuntary patients and high acuity patients, and community outpatient care.²³⁷

- 179. More recently, I have been given updated information that the new stand-alone facility will be managed by Fiona Stanley Hospital (FSH) Cockburn Health and will provide 75 inpatient beds for women requiring treatment for mental health issues, eating disorders and/or requiring behaviour and withdrawal management for alcohol and other drugs. It will not be an Authorised Hospital by the Office of the Chief Psychiatrist, so care will only be provided for voluntary patients at this point in time. The facility will be opening in a staged implementation approach, with regard to opening the beds, in order to allow for review of workflows, procedures and policies at each stage. I am advised the FSH Cockburn Model of Care for Eating Disorders has been finalised as to how it will provide consultation, assessment, clinical intervention, education and support for women with a primary diagnosis of an eating disorder aged 18+ years. Those patients will be able to be admitted from various different services, including emergency departments and community eating disorder services. FSH Cockburn Health is actively working with the potential referrers to identify suitable patients, for when the service is up and running.²³⁸
- **180.** All of these changes are a positive step. However, more can be done. In the submissions prepared by Dr Miller on behalf of the NMHS, it was suggested that I might consider making two recommendations, namely:²³⁹
 - Consideration be given to registering and maintaining eating disorders data collection within the WA Health System Information Register to help inform demand modelling and future state-wide investment and to enable WA to benchmark care of youth and adults with eating disorders against National data collection; and
 - The Mental Health Commission consider developing a working group to explore unmet needs for people with chronic and complex or severe and enduring eating disorders to ensure that evidence-based programs are offered and primary care providers are supported in managing the high level of risk associated with this cohort.

²³⁵ T 22 (28.3.24).

²³⁶ T 23 (28.3.24).

²³⁷ T 26 (28.3.24).

²³⁸ Letter to DSC from Dr Shirley Bowen, Director General, Department of Health, dated 12 November 2024.

²³⁹ Submissions filed on behalf of NMHS by email dated 15 May 2024., p. 2.

- **181.** Dr Miller explained at the inquest that the first recommendation is important as we need a data footprint in both health and mental health, to start to measure demand and service utilisation in order to inform modelling and know where to direct funding. It will allow them to know "where all the gaps are, understand the magnitude of that unmet need, at all stages" so that what service is built in response is a good fit for what's required. The National Eating Disorder Strategy provides a blueprint and the Mental Health Commission has set up a statewide framework but there needs to be an understanding of demand and funding in that framework. ²⁴¹
- **182.** I note the second recommendation is, in part, because there is a need to balance the priority of early intervention for new patients, which can often be provided in an outpatient community based setting and gives the greatest chance of a full recovery, with recognising the high burden of suffering for patients with more severe and enduring chronic illnesses that may require intensive inpatient care and lengthy periods of treatment.²⁴² Dr Miller commented that it is not directed at building separate services, but ensuring there is specialist expertise in both areas.²⁴³ Having said that, Dr Miller emphasised that the high level of demand and the breadth of this State still means that there will be patients across the State's health services, so it is about building expertise in eating disorder treatment across the board. As Dr Miller commented at the inquest, "eating disorders are everybody's business,"244 so every health professional should have confidence to at least identify it and then have somewhere to go for advice and support. Dr Miller emphasised that, in her view, the solution is not to build one statewide in-patient eating disorders unit, but rather to ensure there is a footprint of in-patient beds in every health service area with a continuum of stepping down after in-patient admission to a community based service, with a planned and well-managed transition between the services.²⁴⁵

FAMILY PERSPECTIVE

- 183. Chloe's family, through Naomi Tupper, also provided a very detailed submission with suggestions about possible recommendations, based upon their personal experience trying to navigate the system. They indicate it is their hope that in committing to the inquest process, they "may illuminate opportunities for change, to spare other families from the additional stress, trauma, pain and suffering, especially at the end stages of anorexia nervosa," that they experienced as a family through Chloe's illness and eventual passing.
- **184.** Naomi Tupper commented that what is absent, in many ways, from all of the evidence in this inquest is a real understanding of what is Severe and Enduring Anorexia Nervosa (SE-AN), as distinct from anorexia nervosa. Without that knowledge, it is hard to develop a cure for this dreadful illness. The recovery rates

²⁴⁰ T 112 (1.2.24).

²⁴¹ T 105, 223 (1.2.24).

²⁴² T 104, 108 (1.2.24).

²⁴³ T 106 (1.2.24).

²⁴⁴ T 107 (1.2.24).

²⁴⁵ T 116 – 117 (1.2.24).

²⁴⁶ Exhibit 1, Tab 22.1, p. 1.

for SE-AN are low and there is little hope of this changing in the context of the historical chronic underfunding for research and treatment. Chloe's family saw for themselves that Chloe's treatment needs were different as her illness progressed and the traditional treatments failed her.²⁴⁷

- 185. Chloe's family agree with the evidence of Dr Welborn and the other experts that a significant component of the failure in Chloe's early treatment was the 'crisis care' response of re-feeding in hospital to medical stability followed by quick discharge at a very risky BMI, setting Chloe up for failure. She was never re-nourished to a level that allowed her brain to recover to a level that she would be able to commit to a weight and BMI that matched the goals of care set for her. Naomi commented that she could not get anybody treating Chloe to help her to live with her intractable illness, once it became clear she was in the smaller category of patients with SE-AN. Chloe's family came to understand that the achievable goal for Chloe was quality of life, but they were often told they were "'colluding' with the delusions of her illness." This was despite the fact that Naomi had advocated for treatment to increase Chloe's BMI in the early days and keep her in hospital until she was at a safer weight, but recalls being told "you can't lock her up forever Naomi." 249
- 186. Naomi provided information about her family's personal experience of the gaps in care when transitioning between child and adult care, a feature of some of the evidence in the inquest. Chloe fell ill at an age when she could initially access Princess Margaret Hospital's Eating Disorders Program (as it then was) and they had sufficient time to take out private health insurance to cover Chloe's transition to adult care at Hollywood after she was no longer eligible for PMH due to her age. However, Naomi noted that many private practitioners, including GP's and psychologists, were reluctant to treat Chloe due to her low BMI or due to a lack of understanding of, or empathy for, her illness. Other places and practitioners simply didn't have the resources or expertise to care for her properly.
- 187. This matched information I received from an unnamed GP who commented on the great difficulty in getting eating disorder patients admitted to public hospitals, due to bed shortages, and accessing services in the private sector can be very expensive. Public psychology services won't accept patients if their BMI is below a certain level, so a patient can effectively be deemed too unwell for therapy, but without the option to go to hospital to become well enough to engage in therapy. Much of the care is then left to the GP's. The statement was made that, ²⁵⁰

Managing a patient with an eating disorder in general practice is time consuming, poorly remunerated, and stressful given the high risk nature of the illness, tricky family dynamics, frustration about the nature of the illness and the lack of support.

188. The other issue that Naomi raised, which was not really touched on in the evidence generally, was the issue of 'carer burden' in the face of this crushing lack of resources and expert care. Naomi observed that without any safe place for Chloe to

²⁴⁷ Exhibit 1, Tab 22.1.

²⁴⁸ Exhibit 1, Tab 22.1, p. 4.

²⁴⁹ Exhibit 1, Tab 22.1, p. 5.

²⁵⁰ T 114.

go, the safest place for her was at home, but this limited any opportunity for Naomi to return to any form of paid work or to offer adequate support to her other two daughters and husband, let alone take any time for herself. This toll on the carers, with no offer of respite, is another unacknowledged aspect of SE-AN.²⁵¹

- 189. Chloe's family advocate for a different kind of treatment that would "match with the reality of her chronic, unrelenting, intractable illness."²⁵² A form of care that would allow them to seek help without fear that she would be placed under the *Mental Health Act* and forced fed against her will. Care that could improve Chloe's comfort and quality of life, through a compassionate lens that respects the illness history of the individual and is prepared to listen and adapt. I note that the expert evidence of Professor Anglin was that this is an approach known to be adopted by some practitioners in some cases of SE-AN, and it seems to be an approach supported by Dr Welborn and her colleagues at RPH in particular rare cases. It is not an approach that applies to every practitioner, nor every case of SE-AN, but it seems that there is a developing understanding that in some cases this may be the only realistic option.
- 190. I understand Naomi and the extended family's frustration at the early decisions made at JHC in June 2020, noting their very clear understanding of the path Chloe was on after she was discharged from RPH. In my view, it demonstrates the need for better continuity of services and communication between health practitioners in such a case. Chloe and her family had understood that Chloe had been allowed to leave RPH on ²⁵³the understanding that she would be permitted the dignity of eventually succumbing to her illness at home. Sadly, that was not to be. Chloe's family believe she was denied a peaceful end of life
- 191. I acknowledge that this inquest has added only further pain to Chloe's family and I am grateful to Naomi, Dave, Holly and Rosie and their support network for being willing to still engage with the process and try to find some meaning in it. I accept that there are questions that they have asked that I will not have answered to their satisfaction and that the gains in treatment and resourcing since Chloe's death will seem fairly minimal in the face of the still huge unmet need. However, I hope that they will appreciate that everyone involved in this inquest has attempted to make it a meaningful exercise in understanding how the system failed Chloe, and how it can be improved for others in the future. In terms of recommendations that I can make following this inquest, I take from Naomi's submissions the particular themes of more flexible services for people with eating disorders generally, and more agency for the family of a person suffering with SE-AN, so that they are provided with more information around the options and planning in order to then be able to guide the decision-making in a more informed way.
- 192. I also acknowledge Chloe's family's strong belief that a flexible, person-centred approach needs to be implemented in cases of SE-AN, and that their lived experience with Chloe could have been different if this approach had been taken. In support of

²⁵¹ Exhibit 1, Tab 22.1.

²⁵² Exhibit 1, Tab 22.1, p. 7.

²⁵³ Exhibit 1, Tab 22.1.

this proposition, Naomi Tupper points to the lived experience of Rosiel Elwyn,²⁵⁴ who came to the same crossroads as Chloe in 2017, but somehow has found a path to live with her illness in a way that prioritises her autonomy and quality of life. The Tupper family submits that moving forward, there needs to be a recognition that models of clinical care for people with SE-AN need to be informed by the wisdom gained from the lived experience of people like Chloe and Rosiel, with an emphasis on flexibility and personalised care, to ensure that they do not become isolated, but rather remain engaged and supported by healthcare professionals.²⁵⁵

CONCLUSION

- 193. Chloe Tupper was a bright and talented young woman, beloved by her close and supportive family, but that did not prevent her from developing a fatal eating disorder. Chloe lived by the motto that "in a world where you can be anything be kind," but she could not extend that kindness to herself. She was a perfectionist who put a lot of pressure on herself to do well a common trait in people who develop eating disorders.
- 194. Chloe received medical and psychiatric treatment for her illness from her mid-teens, both in hospital and in the community, but her weight remained extremely low despite treatment and her risk of suicide was often high. She eventually elected to cease engaging in the treatment that she did not find was helping her, and chose to remain at home with her family with limited monitoring by her GP her only form of treatment. Chloe was happiest at a weight that could not sustain her life and was fundamentally opposed to being re-fed. Her family had come to accept the sad truth that the severity of Chloe's illness would lead to her early death. She died at only 31 years of age.
- 195. Some might read this and think that there was a simple solution, but Chloe's family and friends and the many clinicians who work in this complex area will tell you otherwise. However, Chloe's story is also not without hope. The clinicians emphasise that some people do recover with appropriate treatment and Chloe's family note that some people can also learn to live with their illness in a way that ensures they can still live a purposeful life. The point emphasised is that not everyone fits into boxes, and individualised care is needed for anorexia across the spectrum of this serious illness.²⁵⁷
- 196. In the depths of her illness, Chloe created beauty in her art that lives on. Following her death, the Tupper family authorised their close friend, Laura Kiely, to publish a book titled *A Life Within Stillness: Illuminating Severe Enduring Anorexia Nervosa*, that includes a collection of Chloe's exceptional paintings accompanied by her poems and thoughts to both highlight Chloe's immense talent and to "illuminate her poorly understood and stigmatised illness." The book accompanied a posthumous

²⁵⁴ Elwyn, R. *A lived experience response to the proposed diagnosis of terminal anorexia nervosa: learning from iatrogenic harm, ambivalence and enduring hope.* Journal of Eating Disorders (2023) **11**, 2.

²⁵⁵ Exhibit 1, Tab 22.2.

²⁵⁶ Exhibit 1, Tab 22.1, p. 2.

²⁵⁷ Exhibit 1, Tab 22.2.

²⁵⁸ A Life Within Stillness, Laura Kiely, (2021), Foreword - https://www.seeinganorexia.com/buy-the-book.

exhibition of Chloe's paintings. All proceeds from the book are donated to eating disorders research, as part of Chloe's legacy, along with the paintings she has left behind. I understand Chloe personally selected the paintings to be included and interpreted the works in her final months of life, knowing that the book would communicate her experience for others.²⁵⁹ Her art is also held by the Holmes à Court collection, a testament to her talent. With her family's permission, I have included a photograph of Chloe, along with one of her paintings below that is a self-portrait. As Naomi observed, it is difficult to distil the true essence of a person in words, so we are fortunate that Chloe offered a 'painted self' as part of her artistic legacy.²⁶⁰

197. Chloe has left a lasting legacy through her art, but also through the evidence that has been led in this inquest that might lead to change for other people who suffer from the same devastating illness as Chloe. The recommendations I have made below will hopefully lead to change in terms of access to good data that will inform improvement in services and information sharing for other families who are going through the same journey that Chloe and her family travelled. Hopefully, the changes that may come from the recommendations may lead to a different end to that journey for other patients in the future.

RECOMMENDATIONS

Recommendation 1

I recommend that the Department of Health continue to collect hospital-based eating disorders data and the Mental Health Commission undertake demand modelling to support future state-wide investment. Further to this, I recommend the Mental Health Commission undertake regular benchmarking of WA youth and adults with eating disorders against National trends and data.

Recommendation 2

I recommend that the Mental Health Commission consider developing a working group to explore unmet needs for people with chronic and complex or severe and enduring eating disorders to ensure that evidence-based programs are offered and primary care providers are supported in managing the high level of risk associated with this cohort. The working group should give specific consideration to how best to transition care from child specialist services to adult services (recognising crossover of care is likely for patients with severe and enduring eating disorders), in order to ensure good continuity of care.

*I understand the draft Framework is likely to address aspects of this recommendation, and the Commission supports this proposed recommendation.²⁶¹

²⁵⁹ Exhibit 4; Anorexia nervosa through the lens of a severe and enduring experience: 'lost in a big world', Journal of Eating Disorders, Kiely et al. (2024) 12:12, 3.

²⁶⁰ Exhibit 1, Tab 22.1, p. 3.

²⁶¹ Letter to DSC from the Commissioner, Ms Maureen Lewis, Mental Health Commission dated 13 November 2024.

Chloe Grace Tupper (10.9.1988 – 9.6.2020)



Photo from Exhibit 1, Tab 22.



Self-portrait from Exhibit 4, p 11, Image 9.

S H Linton Deputy State Coroner 13 November 2024