Coroners Act, 1996
[Section 26(1)]

Western Australia

RECORD OF INVESTIGATION INTO DEATH

Ref No: 35/16

I, Evelyn Felicia Vicker, Deputy State Coroner, having investigated the death of ***Leslie Troy OVENS*** *with an Inquest held at Perth Coroners Court, Court 51, Central Law Courts, 501 Hay Street, Perth, on 21-23 September & 6 October 2016 find the identity of the deceased was* ***Leslie Troy OVENS*** *and that death occurred on 24 July 2013 at 67 Rocklea Crescent, Ellenbrook, and was consistent with asphyxia in a man with Friedreich's Ataxia in the following circumstances:-*

Counsel Appearing:

Mr T Bishop assisted the Deputy State Coroner

Ms R Hill (State Solicitors Office) appeared on behalf of the Disability Services Commission (Ms R Hartley on 23 September 2016)
Ms W Gillan (Norton Rose Fulbright) appeared on behalf of Cam Can & Associates

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INTRODUCTION

Leslie Troy Ovens (the deceased) suffered from Friedreich's Ataxia, a progressive disease of the nerves leading to a loss of coordination and so muscle deterioration. He was registered with the Disability Services Commission (DSC) and was wheelchair bound.

The deceased lived independently, but required help with physical aspects of daily living which were provided by carers, employed through a service provider, Cam Can & Associates (Cam Can) funded by DSC.

On the evening of 24 July 2013 a carer did not attend at the deceased's address to assist him to bed. When his morning carer attended on 25 July 2013 to assist him in getting ready for the day she located him deceased, with his upper body suspended from his wheelchair onto the floor. His mobile phone was on the floor, out of reach.

The deceased was 32 years of age.

This inquest into the death of the deceased was held pursuant to section 22 (2) of the *Coroners Act 1996* (WA) as a discretionary inquest to consider systemic issues relevant to the care provided to the deceased as a person with a disability living in the community.

BACKGROUND

The Deceased

The deceased was born on 13 October 1980 in Melbourne. His biological mother and father separated when he was quite young and his mother remarried to the deceased's step father. At some point the family moved to Western Australia. The deceased had five siblings overall, and his biological father remained in contact with him until he was approximately nine years of age.

The deceased's disability was first noticed at school by one of his teachers. He was sent for review to a specialist who diagnosed Friedreich's Ataxia when he was nine years old.

As the deceased grew older he became unsteady on his feet and lacked coordination. He was also diagnosed with degenerative curvature of the spine for which he had a back operation, when he was 13 years old. This placed rods and pins in his spine to help him support the weight of his frame on his internal organs, especially his heart and lungs.

By the age of 15 the deceased had lost much of his mobility and required an electric wheelchair for movement. As his strength diminished so he required additional supports by way of a lap belt to prevent him from slipping or falling from his wheelchair, and a hoist was needed to lift him in and out of his chair and into bed. By the time the deceased required an electric wheelchair he also had eating

difficulties and difficulty with his speech, especially when unwell or first thing in the morning. He also suffered shortness of breath and hearing loss, and suffered extreme coughing fits which considerably disabled him until he had recovered his oxygen levels.

Mentally the deceased was very alert and completed high school, but did not continue with studies due to the fact he would never be able to work.[1]

Once in his wheelchair the deceased was reasonably independent with the assistance of a number of devices, modified for his use, and once they were all activated he could entertain himself for the day, either by staying at home or going out.

By the time of his death the deceased lived in a house purpose built for him and his disability to allow him to live independently, with care funded through DSC. Originally the deceased's care was provided directly by DSC through carers and contracted services organisations such as Silver Chain.

The deceased was quite exacting in the care he wished from carers and this frequently led to difficulties if the deceased perceived a carer was not performing in accordance with his

[1] Ex 1, tab 9

wishes. This was part of his need for independence and some control over his life.

Those carers with whom the deceased formed a very good relationship tended to be long term people with whom he had a good rapport. Even then there were times when the deceased felt his disability did not accord him the independence and respect he warranted as an individual.[2]

The impression is the deceased was popular with those carers he considers his friends, such as Tony McCabe, and became used to carers such as Clare Allen, but was considered extremely difficult by others not used to that level of control by the person they were supporting.

The deceased's condition was progressive and as time went by he required more assistance as his coordination and dexterity decreased. He had originally been resistant to the concept of the provision of additional care, but by the time of his death he had an application in to DSC for additional care funding.[3]

The deceased's medical practitioner advised the court that aside from Friedreich's Ataxia, the deceased suffered from heart failure and atrial fibrillation, hypothyroidism and

[2] t 22.09.16, p129
[3] Ex 2, Ex 1, tab 25, attach 5

depression for which he was medicated. He was under the care of both a neurologist and cardiologist.[4]

In June 2013 the deceased became very unwell and was hospitalised for two weeks due to the extremely high level of care he required when unwell. On his return home the deceased was weaker than he had been previously and his carers were conscious his physical abilities needed to be re-evaluated.[5] While his strength gradually improved on his return home from hospital it was apparent he was not going to return to his previous level of independence.[6]

The deceased's care was provided by carers rostered to his home twice a day through the service provider Cam Can. The carers were employed by the deceased through Cam Can. The time periods for which the deceased was funded for carers at the time of his death were between 8.30 to 10.30 am to assist in him getting out of bed, showering and started for the day, settled in the wheelchair. Following that carer leaving the deceased was independent to do as he wished. Another carer would attend in the evening to put him to bed. This was usually sometime between 8-9 pm, daily, although there was some variation in times depending on agreements with the deceased and his carers.[7] In addition there was the provision for extra time on a

[4] Ex 1, tab 23
[5] t 22.09.16, p133
[6] t 21.09.16, p15
[7] t 21.09.16, p66

Thursday to allow for shopping and meal preparation for the deceased.[8]

Disability Services Commission (DSC)

The DSC aims to advance opportunities, community participation and quality of life for all Western Australian's with a disability registered with their commission.[9] The deceased was registered with the DSC and as such received an invalid pension from them to assist him in his living requirements.

While the deceased's care had been originally provided directly through DSC with the assistance of carers and service organisations, in September 2011 the deceased entered into a service agreement with an independent service provider Cam Can. It was a three way service agreement between the deceased, Cam Can and the DSC.[10]

Cam Can & Associates (Cam Can)

Cam Can is a non-government care provider which was formulated in September 2011 to coordinate carers for those funded with a disability through DSC, but providing independent care controlled by the person with the disability. The intention was to provide carers to persons registered (members) with the DSC to enable them to have control over their care as funded through the DSC.

[8] Ex 1, tab 28 & t 21.09.16, p14
[9] Ex 1, tab 25 & 26
[10] Ex 1, tab 25, Attach 1, 3, 4

Cam Can's purpose statement is as follows:

> *"Cam Can assists people with disabilities and their families to create innovative, personalised, flexible and sustainable arrangements that maximise their control over available resources, decision making and choice."*

This would appear to have been a perfect match to an individual such as the deceased who was strongly independent and wished as much control over his life as was possible given his need for physical assistance. It allowed him to make the decisions with respect to his care and carers, to ensure he was physically cared for in the way he believed to be most appropriate for himself. Cam Can's Chief Executive Officer, Marc Lema, originally worked directly for the DSC, but as the DSC moved to a model of allowing their members to have control over the funding for their care, so he and his wife set up as an independent care organisation with their knowledge of the DSC.

Cam Can began coordinating carers through a service agreement with the deceased and DSC from 19 September 2011.[11] In the case of the deceased his carers were more support workers because the deceased was able to direct his requirements for care, and needed people prepared to physically do as he directed.[12]

[11] Ex 1, tab 15 & 16
[12] t 21.09.16, p87, 93

The deceased was able to articulate clear instructions with respect to his choices over his support delivery and what he expected from his support workers. This was in line with government legislation and regulation which requires that *"people with disabilities have a right to determine how the individuals' services are delivered where they are appropriately able to make such determination with respect to their wellbeing".*

Originally Cam Can controlled its carers/support workers for its various members directly, but as the organisation grew in line with the regulatory requirements of government, so they discovered it was necessary that groups of carers/support workers have a service coordinator responsible for a group of members. Those care coordinators became responsible for coordinating the carers/support workers for a group of members and were often carers themselves involved in the care of some of those members.

Cam Can's reputation with the DSC was good.[13] Cam Can went to great lengths to individualise the care of their members according to their wishes. At the time of the inquest the representative from DSC did voice a concern Cam Can, as an organisation, probably grew too quickly to appropriately accommodate the wishes of their various members. Due to various factors there was a difficulty in

[13] Ex 2, t 21.09.16, p92

providing carers at the rate needed for a growing organisation and developing new ways of allowing individuality in people with a range of disabilities.

Where a member, such as the deceased, had high expectations of their support workers it was occasionally difficult to resource people with the appropriate qualities. The deceased preferred his family not to be involved in his care, preferring he handle any difficulties personally with the support workers/carers involved and Cam Can. The deceased's determination to maintain his independence by way of his choice and control over his support, within his own home, did cause problems when he quite vocally resisted a particular support worker if they did not function as he wished them to function. It was known for the deceased to dismiss people with whom he did not engage, on the spot, which left Cam Can or his care coordinator in a difficult position when attempting to maintain a viable roster for the deceased's care.

Aside from the deceased's high expectations from his support workers, there was the additional difficulty for his care coordinator as to his location, which by the time of his death was Ellenbrook. This restricted the ability of some carers to attend for the relatively short periods of time required by the deceased.

Over his two and a half years with Cam Can as his service provided, the deceased needed different care coordinators to control his roster, frequently as the result of his interaction with individuals. At stable times, when there wasn't a difficulty with carers for the deceased, he was cared for by a group of consistent carers who communicated between themselves and the deceased as to their roster times and this was not a problem.[14] However, when carers needed to change their days or rosters, depending on their personal circumstances, and there was a need to appoint new carers for the roster, or use an agency, there were sometimes difficulties in ensuring the deceased had carers with whom he would engage.

Many of the deceased's preferred carers also worked for other care organisations and only worked for Cam Can for the purposes of caring for the deceased. This meant a number of his carers had other organisations and individuals dependent upon them for care and would be unable to alter their rostered times for caring for the deceased due to other commitments.

Evidence from the deceased's various support workers indicated that, while they were aware of their own rostered commitments towards the deceased, they were largely unaware of other rostered support workers. Communication appears to have been mainly by email or

[14] t 21.09.16, p16

text message and although the CEO indicated there were regular workshops where support workers/carers and coordinators discussed procedures surrounding changing rosters, these did not appear to be well followed or documented.[15]

At the time of the deceased's death his care coordinator was Clare Allen. She had only very recently taken over coordinating for the deceased. While Ms Allen had been a care coordinator for the deceased in the past, that had ended badly when the deceased believed Ms Allen to be performing some of her coordination duties, at the time she was supposed to be caring for him.[16] As a result the deceased had said he did not wish Ms Allen to be his care coordinator. In return Ms Allen declined to be rostered to care for the deceased. It was issues such as these in the past which made the deceased's need for independence around his support workers difficult for care coordinators and Cam Can to accommodate.[17]

The deceased communicated by using a mobile phone which he usually had on a lanyard around his neck or looped to his bed rail. He found texting easier than talking due to his disability although he could access a computer. He did not

[15] t 21.09.16, p18 & 23
[16] t 22.09.16, p125
[17] t 22.09.16, p129

have a personal alarm, considering his phone to be sufficient.[18]

Ms Allen's evidence, largely agreed with by Mr McCabe, was that when Ms Allen had been the deceased's care coordinator sometime before his hospitalisation in June 2013 she believed he was relatively healthy.[19] They had a good relationship though, with respect to the work aspect, it could be volatile.

Following Ms Allen declining to work at all for the deceased following their disagreement she remained working for Cam Can as a coordinator for a number of other members.

In the period between Ms Allen's times as coordinator for the deceased, he had various coordinators, including Mr Anthony (Polly) Coufos. There is no doubt in my mind the deceased could be perceived as difficult,[20] however, understand that for someone who is so dependent on others for physical assistance, the need to retain control over his environment as far as possible must be a significant concern.[21] On Ms Allen's return as the deceased's coordinator, partially at his request, she was horrified by his changed appearance. Ms Allen described the deceased as no longer being able to hold his cigarettes, dropping his dinner, being more difficult to understand, partly due to his

[18] t 21.09.16, p31
[19] t 22.09.16, p131
[20] t 06.10.16, p245
[21] t 22.09.16, p129

deteriorating muscle control,[22] and that he appeared to be very tired, cold and unwell.

On one occasion the deceased had fallen out of his wheelchair when trying to pick up his cigarettes and Ms Allen had been concerned he needed more strapping in his wheelchair to enable him to remain properly upright and place less stress on his internal organs. While the deceased was resistant to this Ms Allen made an appointment for him to be assessed for additional support while in his chair.[23] Ms Allen noted that on the occasion of his falling from his wheelchair he was unable to right himself and coughed severely.[24]

The evidence is fairly consistent through the carers that the deceased had very debilitating coughing fits which rendered him breathless and extremely agitated. It was at this time, shortly after Ms Allen's return as his coordinator, the deceased was hospitalised.

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On the deceased's discharge from hospital Ms Allen was close to an intended leave date. She had two weeks in which to organise the deceased's carers before she went on leave. The deceased had lost a number of carers with whom he had not established a reasonable relationship.[25]

[22] t 22.09.16, p131
[23] t 22.09.16, p136
[24] t 22.09.16, p133
[25] t 22.06.16, p152

The deceased was still having serious coughing fits which rendered him almost helpless and would be of serious alarm and concern, especially if occurring when there was no one else present and the deceased disabled himself in some way.[26] As Mr McCabe confirmed, the deceased was extremely unwell when he came out of hospital and although recovering and improving, was definitely not as well as he had been prior to his illness requiring hospital admission.

During Ms Allen's leave Cam Can allocated her coordinator position for the deceased to Mr Coufos because he had prior knowledge of the deceased. Ms Allen prepared a two week roster for the deceased, and to ensure cover for the times where he had lost carers/support workers, or they had changed their days, she had to add four new carers to the deceased's roster. The roster for Wednesday evenings was not fixed, but she had filled those positions, temporarily while she was away.[27]

I find Ms Allen produced a two week roster to cover the period she was on leave from 8-21 July 2013. In her absence Mr Coufos was the deceased's care coordinator and the expectation was that on her return to work on 22 July 2013 there would be a draft schedule for that week proposed for the deceased.[28]

[26] t 22.09.16, p133 / t 21.09.16, p54
[27] t 22.09.16, p154
[28] t 22.09.16, p155

Following Ms Allen's going on leave the problems for Mr Coufos started on Sunday 7 July 2013 with alterations to the roster Ms Allen had prepared, which Mr Coufos had to accommodate.[29] These were communicated by text. Those texts reflect the extent of the changes Mr Coufos needed to make in order to maintain cover for the deceased during that two week period, despite Ms Allen's roster.

Mr Coufos notified Ms Allen of some of those difficulties by email on 19 July 2013.[30] At the end of that email to Ms Allen, Mr Coufos said the following:

> *"I have not made up the schedule for next week. One thing you need note is that Ruth is not working Tuesday night (her man is back from the bush) and Emma is going to cover for her. I don't remember if I've sent last week's schedule through. If not it is attached.*
>
> *I think that's all. If there's anything else I'll let you know."*

From that email it is not unreasonable, without knowledge of all the preceding texts that Mr Coufos had received, to believe the intended schedule/draft roster for the week commencing 22 July 2013 would be the same as the one for the previous week, with the alteration made by Mr Coufos in the quoted part of the email. There is nothing else in the

[29] Ex 3, attachment PC3
[30] Ex 3, attachment PC4

email to indicate Ms Allen could not rely on the prior week's roster as the intended draft roster for the week in which she returned, with the alterations stated.

I accept the rosters Ms Allen had prepared for her absence did not work smoothly, and Mr Coufos had to spend more time as care coordinator for the deceased than he expected. This was exacerbated by the deceased's sacking one support worker and refusing to have her assist him, and the fact some carers the deceased preferred, had other commitments or day jobs and could not cover gaps in the roster, although they would try if at all reasonable.[31]

Following Mr Coufos's email to Ms Allen on 19 July 2013, he received a text from Ruth Gregory, one of the carers, on the Sunday night (21st) reminding him she was not able to work on either the Tuesday or the Wednesday night, and stating she could not open the attachment which she believed would be the draft roster for the coming week which she could not access. That would seem to imply the support workers believed they had a draft roster for the week of Ms Allen's return, but Ms Gregory was reminding Mr Coufos, without seeing the roster, that she would not be working on the Tuesday or Wednesday.[32]

The fact of cover for the Tuesday was noted in the email sent to Ms Allen on 19 July 2013, however, the fact the

[31] t 21.09.16, p13
[32] t 21.09.16, p77

Wednesday remained uncovered, without Ms Allen's access to that text message of the Sunday night, meant Ms Allen had no way of knowing there was no cover for the Wednesday afternoon without some indication from Mr Coufos. She needed to be alert to the fact Ms Gregory remained unavailable. While Ms Allen knew Ms Gregory had recently changed her days due to personal commitments, there was nothing to indicate Wednesday had not been accommodated in some way during her leave, for the coming week.

Ms Allen returned to work on Monday 22 July 2013 relying on the information from 19 July 2013. There was a later telephone conversation between Ms Allen and Mr Coufos on either the Monday or Tuesday, in which neither Ms Allen nor Mr Coufos indicated there was a problem for the deceased's roster on Wednesday 24 July. While it is not clear whether this conversation took place on the Monday or the Tuesday, both Ms Allen and Mr Coufos confirmed in evidence, cover for the deceased for the Wednesday 24 July was not discussed.

In addition to the difficulties Mr Coufos experienced in filling the changes in the deceased's rosters while Ms Allen was away, the evidence of all carers was that the hand over process for leave to relief coordinator, and relief coordinator back to the permanent coordinator, was not as rigid as it should be. The expectation was there would be a draft

roster prepared and sent out to the relevant support workers the preceding week. This expectation is supported by the fact Ms Gregory texted Mr Coufos with a concern she could not open the roster and reminding him she had changed her days.[33]

Ms Allen assumed the arrangements for the week of her return would mirror those of her last week of leave, with the alteration made by Mr Coufos for the Tuesday. Mr Coufos believed Ms Allen would understand he had not finalised the roster due to his email of 19 July 2013, but did not draw her attention to the Wednesday afternoon cover, for which he had not provided a carer.

The evidence does not support there was a dedicated hand back procedure from relief coordinator to permanent coordinator, and while I accept that would not usually be a problem with an established roster and carers, it was clear the roster for the deceased would be difficult due to changes that had needed to be made to provide cover while Ms Allen was away.[34]

Ms Allen's evidence was she made Mr Coufos aware of those at a fortnightly meeting, and asked him to organise a draft roster for her return, just for one week, with the people on her schedules or alternatives where necessary. Ms Allen's evidence was Mr Coufos was surprised she had been able to

[33] t 21.09.16, p72
[34] t 22.09.16, p150, p152

arrange a two weekly roster and that he would arrange things for the week of her return.[35]

Unfortunately, Mr Coufos was unable to provide a draft roster for the week commencing 22 July 2013. This meant that where the roster consisted of established, known carers for particular time periods there was not an issue. However, over areas which were to have been covered by temporary carers, or changes in the roster, a draft roster had not been prepared indicating those areas of problem. Wednesday was one of those days.

Mr Coufos had managed to ensure the deceased had support workers for all of the rostered times during his time as relief manager, but he had not been able to cover gaps in the roster for the return week commencing 22 July 2013. He did not provide Ms Allen with a draft roster indicating the gaps, and in his communication with Ms Allen indicated she need only be concerned with a Sunday cover, which Ms Allen was intending to do herself.[36]

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On the morning of Wednesday 24 July 2013 the deceased's regular morning carer at that time, Natasha Walsh, attended as usual and provided him with his morning routine, including medication. She described him as quite weak in the time she had cared for him, especially so in the

[35] t 22.09.16, p154 - 157
[36] t 22.09.16, p157

mornings before he had warmed up.[37] While Ms Walsh had never seen the deceased fall out of his chair she had heard about it and believed that if he had dropped items from his chair he would not be able to retrieve them from the floor, especially if his feet were not on the paddles of his wheelchair which gave him a pushing fulcrum.

Ms Walsh last saw the deceased at about 11am 24 July 2013. She recalled him as having a bad day with his cough being particularly noticeable. Ms Walsh described the deceased's coughs as so violent they could knock him out of his wheelchair, if he was not properly secured by a belt around his waist. Although Ms Walsh had not seen the deceased come out of his wheelchair, she had seen him fall out of his bathroom chair during a coughing fit. Ms Walsh believed the deceased had been noticeably weaker in the last few days in his upper body.[38]

Ms Walsh did not recall very much about the last morning she had seen the deceased, but it was routine. She confirmed that although she recalled receiving rosters as to her times with the deceased, she was not particularly worried about them because she had set times, which she knew, and would not refer to the rosters once confirming her times were as she expected.

We have no evidence as to what the deceased did during the day. There is evidence from Mr McCabe as to the deceased's

[37] t 21.09.16, p51
[38] Ex 1, tab 10

normal routine, and how that fitted with the scene as he saw it on the morning after the deceased's death.

Part of the deceased's routine during the day would be to retrieve clothes from the airer in the lounge, following the morning carer having placed them in the washing machine to be washed and then placed them on the airer. The deceased would take the dry items into his bedroom and place them on his bed, ready for the evening carer to put them away on their attendance that night.[39]

Mr McCabe recalled getting rosters emailed to him weekly,[40] although he had set days and did not retain the rosters. None of the carers appeared to have specific recall of any need to refer to rosters, if they were carers with long term set times. They just knew their times. Mr McCabe confirmed that on occasions no one turned up and the deceased would call him to help him to bed.[41]

At approximately 5.00 pm on the afternoon 24 July 2013 Mr McCabe arrived at the deceased's home, not as part of his roster, to give the deceased some drinking straws.

Mr McCabe's evidence was he lived close to the deceased, and although he had a regular day job, he would frequently

[39] t 21.09.16, p28
[40] t 21.09.16, p17, p23
[41] t 21.09.16, p26

call into the deceased's home on his own way home to help the deceased out with odd chores.[42]

Mr McCabe said he was only with the deceased for about 15 minutes during which time he microwaved a meal for the deceased, and placed it ready for him to eat, and opened a can of Pepsi which he left on the kitchen bench for the deceased to drink.[43] At the time Mr McCabe left the deceased was unsure of whom his carer was to be that evening, and Mr McCabe believed someone would turn up as they usually did, according to their set times. On the occasions upon which no carer had turned up for the deceased, the deceased had contacted Mr McCabe via text, his preferred method of communicating, and Mr McCabe had gone over to assist in the absence of a carer. This had not happened frequently but it had happened.[44]

When Mr McCabe left the deceased that evening the deceased was fine, in his wheelchair, and about to eat his evening meal.

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Ms Walsh again attended at the deceased's home on the morning of 25 July 2013 and located the deceased.

[42] t 21.09.16, p25
[43] t 21.09.16, p28
[44] t 21.09.16, p27

It is obvious from Ms Walsh's description the deceased had not been to bed the previous night. The house sliding door was open, the curtains were open and the lights were on. The bed was as she had left it the previous morning.[45] Had a carer attended the door would have been closed with the curtains drawn and the lights off. The deceased would have been in bed.

Ms Walsh went into the house and had a quick look around the kitchen. She noticed everything was extremely quiet. She walked down the hallway towards the deceased's bedroom and noticed his wheelchair on her left as she passed the television room. This was where she expected it to be overnight because the deceased's wheelchair stayed in the television room to be charged. In the bedroom Ms Walsh noticed his bed had not been slept in. She returned through the house and went to the television room.

It was as Ms Walsh went into the television room she realised the deceased's wheelchair was not empty and being charged, but that his feet were actually at the bottom of the wheelchair although not on the paddles.[46] He appeared to have fallen sideways out of his wheelchair under the arm rest and his head and arms were on the floor. The airer had fallen over onto him.

[45] t 21.09.16, p62
[46] t 21.09.16, p52

Ms Walsh checked the deceased and noticed he had what appeared to be vomit around his head, which was on the floor. She checked for vital signs but could not find any and was satisfied the deceased was not breathing and dead. She had by this time called 000 and called for an ambulance to attend at the address.

The ambulance arrived and Ms Walsh let them in to examine the deceased. She then called Ms Allen who attended with the police.

In evidence Ms Walsh described that on her arrival at the house on the morning of 25 July there was an open can of Pepsi on the bench which she did not believe he could have opened himself. She did not at that time understand Mr McCabe had called in at approximately 5.00 pm to assist the deceased.

From the photographs taken by police on 25 July 2013, it is clear the deceased had fallen sideways out of his chair, under one of the arm rests. There are clothes on the floor and the deceased is partially entangled with the clothes airer. Mr McCabe attended on the morning of 25th to assist the police, Ms Allen and Ms Walsh. He examined the area and noted the deceased had not finished the meal he had heated for him the previous afternoon. It was only three

quarters consumed. Also there was still some Pepsi in the can he had opened for him.[47]

The phone the deceased usually wore on a lanyard around his neck was on the floor, along with his cigarette lighter, usually between his legs on the wheelchair. The phone was clearly out of reach of the deceased once on the floor and it is not clear if he had dropped his phone prior to the incident, or as Ms Allen considered, had fallen with it around his neck, but due to his position had not been able to use it. She was concerned he had removed it from his neck in an attempt to use it, but then dropped it and it fell out of his reach.[48]

Mr McCabe noted the deceased had already put some clothes on his bed and it looked like what ever had happened had happened while the deceased was preparing for the evening carer to arrive. Usually the deceased would have removed clothes from the airer to his bedroom by the time of the evening carer's arrival. It looked as though the deceased was in the process of doing that chore at the time of the incident.

The deceased looked, to untrained observers, as though he had been bashed because it was believed he had serious bruising around his head. Mr McCabe initially thought the deceased had been attacked. He was concerned it was

[47] t 21.09.16, p28
[48] t 22.09.16, p140

obvious no evening carer had arrived at the home to put the deceased to bed.

Had a carer arrived at around about 8 o'clock Mr McCabe believed there may have been some opportunity to assist the deceased, depending on how long he had been in the position in which Ms Walsh located him on the morning of 25 July 2013.

POST MORTEM REPORT

The post mortem examination of the deceased was performed by Dr Clive Cooke, Chief Forensic Pathologist of the PathWest Forensic Laboratory of Medicine in Forensic Pathology.

Dr Cooke examined the deceased on 29 July 2013 and noted reduced musculature in the deceased's legs consistent with his history of Friedreich's Ataxia. While Dr Cooke saw some markings on the skin with the appearance of superficial abrasions in the area of his scalp, on the left side of his face, left shoulder and on the back of his right elbow, and some on his hands, there was no evidence of internal injuries consistent with a bashing.[49]

There was early atherosclerotic hardening of the deceased's arteries, but otherwise no pathology which would account for the death. Microscopy indicated some subtle changes in

[49] t 29.09.16, p215

his heart consistent with a neuromuscular degenerative disorder, while toxicology showed no alcohol or common illicit drugs.[50]

Dr Cooke outlined there was no evidence the deceased had been assaulted and the bruising people believed they had seen was as a result of post mortem lividity. Due to the amount of time the deceased had been in a suspended position, his head and upper torso were particularly badly affected by lividity.

Dr Cooke came to the conclusion the deceased had died primarily from positional asphyxia, due to his inability to recover from the head down position in which he had been located. Dr Cooke gave his opinion the cause of death of the deceased was consistent with asphyxia in a man with Friedreich's Ataxia.

With respect to the timing of the deceased's death, Dr Cooke indicated this was a very difficult estimation, especially with no clear understanding of what exactly had happened. It was clear to Dr Cooke, from the superficial abrasions to the deceased and the photographs of the position in which the deceased was found, that he had been moving around in that position prior to death. This would be consistent with the deceased trying to recover from his head down position. While asphyxia can kill very quickly, the difficulty is

[50] Ex 1, tab 4

estimating the extent of the asphyxia when it is positional and partial, and therefor the potential for the deceased to have survived for longer than a few minutes. In addition is the issue as to how much damage would have been done to the deceased's functionality as he moved toward death, as a result of hypoxic brain injury.

Dr Cooke was unable to help with the time of the deceased's death, other than to say it was long enough after his last meal for most of his stomach contents to have been digested. The deceased had vomited and there was little left in the deceased's stomach, although there was evidence of a meal sometime earlier. With respect to how long it would have taken for the deceased to die in view of his disability Dr Cooke could not give an estimate. He believed it could have been from half to one hour, but it could have been several hours.[51]

CONCLUSION AS TO THE DEATH OF THE DECEASED

I am satisfied the deceased was a 32 year old male suffering from progressive Friedreich's Ataxia.

He was an invalid pensioner registered with the DSC and his care was provided through Cam Can by support workers/carers employed by the deceased through Cam Can, funded by DSC through a service agreement.

[51] t 23.09.16, p226-stomach contents

While the deceased was mentally alert and capable of independent living with the assistance of carers for the physical aspects of his daily life, it is clear he was in June-July 2013 deteriorating physically and it was likely he would be requiring more intensive care shortly.

The deceased was very independent and very anxious about his control over his life. The prospect of having more assistance from carers and so emphasising his declining loss of control over his functionality, was probably a source of distress. Following the deceased's illness in June 2013, his inability to recover his previous level of functioning was probably something about which he was acutely aware.

The fact of the deceased's declining functionality made it imperative there were more checks in place for his wellbeing than were apparent at the time of his death.

I accept the level of care the deceased required, and would accept, were becoming mismatched. However, at the time of his death he was still able to function as he wished, provided he could rely on the regular attendance of carers to assist him with the most difficult physical aspects of his day, getting up, and going to bed. While there was an application in place for additional funding to provide him with a wider range of cover, that had not yet been approved. Realistically it is impossible to say that an accident could not have occurred with the same outcome, even with carers

attending as rostered. However, the lack of attendance of an expected carer would certainly increase the risk of the deceased's exposure to a fatal outcome from any accident.

I am satisfied that for the evening care slot on Wednesday 24 July 2013 there was no rostered carer. It is not the case a rostered carer failed to attend. There was no carer rostered.

While I understand the difficulty for Mr Coufos and Ms Allen, I do not believe this is an individual difficulty, but rather there was no system in place to ensure the lack of attendance of a carer would be detected in a timely manner, if the deceased was incapacitated in some way.

Review of Mr Coufos' email exchanges during the time as relief care coordinator for the deceased make it apparent there were difficulties which were only temporarily alleviated pending a return to stability in the deceased's roster.

However, Ms Allen was not in possession of that chain of emails. It is entirely feasible Mr Coufos, with knowledge of those difficulties, believed Ms Allen would understand the schedule she had outlined had not been maintained and was not properly in place for the following week. However, the only input Ms Allen was aware of was the email of 19 July 2013 which implied the roster for the prior week

would be operative for the week of her return, with the difficulty of which he advised her on the 19th.

Ms Allen was not further reminded of the difficulty communicated by Ms Gregory to Mr Coufos on the Sunday evening (21st), and there is an implication in that text message to Mr Coufos, Ms Gregory believed there was a draft roster, but did not know if the Wednesday evening time had been covered.

I accept there wasn't, however, can understand Ms Allen's difficulty in appreciating there was no cover for the deceased for the evening of 24 July 2013, without a draft roster showing a gap, or being advised of a gap.

This difficulty arose due to the lack of an appropriate and clear system of handover for the communicating of rosters. That communication of rosters should include people in the position of the deceased. The deceased was clearly concerned about his cover for the evening of Wednesday 24 July 2013. If he had a copy of a draft roster he would have been able to see no one was listed. And, in the event no one was listed, he would have known to contact the relevant care coordinator. This implies it was a known occurrence the deceased did not have, or expect, a weekly roster, draft or otherwise.

Lack of adherence to any appropriate handover caused Ms Allen to assume the temporary arrangements for Wednesday evening had been covered, and Mr Coufos did not remind her of the need to consider Wednesday evening in either his email before Ms Gregory's reminder, or the telephone conversation on Monday or Tuesday after he had been reminded. Ms Allen believed she only need be concerned with Sunday.

Even the provision of a draft roster with the gaps clearly shown, or Ms Allen's roster with carers crossed out, would have been an improvement on what occurred. While Cam Can may have considered there was a relief coordinator handover in place, the evidence of carers and coordinators, and the lack of acknowledgement of an established practice indicates it was not adhered to, and there is no documentary evidence it was in place in July 2013.[52]

Having identified the fact that, due to misunderstandings and a misinterpretation, there was no rostered carer for the evening period on 24 July 2013; it is necessary to say that had there been a rostered carer who attended it is impossible to determine whether the deceased's life could have been saved. Depending upon when he fell, and how quickly he died, it may have been impossible to save him, or he may have suffered significant hypoxic injury, reducing his mental function.

[52] t 22.09.16, p146 & p152

I am satisfied the deceased was alive at approximately 5.30 pm on 24 July 2013, shortly after Mr McCabe left. The evidence is clear the deceased had eaten some of his evening meal and drunk some of the can of Pepsi. That is also consistent with the post mortem evidence which indicated the deceased had eaten a meal, sometime before his death, but it was impossible to determine when exactly.

It is not clear from the evidence as to whether the deceased had a coughing fit while attempting to retrieve his clothes, and so fell from his wheelchair, or whether he dropped his phone, or the clothes, and fell to the floor either before or after an attempt to retrieve either the phone or the clothes. It is clear the phone was out of reach, but whether it had fallen there as a result of what happened, or was pushed there when the deceased was attempting to reach for it, is not clear.

What is clear is that the deceased was performing his normal chores of removing clean washing from the airer into his bedroom at the time something occurred which caused him to fall sideways from his wheelchair and, in his weakened state, he was unable to right himself or seek help. Due to the position of the wheelchair, items around the airer, the displacement of the deceased's feet and the position of the airer, the deceased and the arms of the wheelchair, it also seems likely the deceased was struggling to right himself for a time.

It is clear that what ever happened to the deceased probably happened before 8 pm, but how long before is difficult to estimate, and whether he still would have been alive at 8 pm, again is difficult to estimate. Had the incident occurred around 7.30 pm it is possible, but not certain, the deceased may have still been alive at 8 pm, but his ability to recover from whatever state he was in by that time will never be known.

It is impossible for me to determine with certainty that a carer attending at 8 pm would have necessarily been able to save the deceased's life.

All I can say with certainty is the deceased would have been discovered earlier, but I suspect the outcome would still have been devastating for all of those who knew, respected, and in their own way, loved the deceased as the strong, independent character he was before the event which led to his death.

It certainly would have been less distressing than the lack of clarity with which we are now confronted.

THE MANNER AND CAUSE OF DEATH

I am satisfied that during the course of the evening, sometime before 8 pm on 24 July 2013, an incident occurred while the deceased was taking dry washing from

the airer in the lounge into his bedroom in preparation for the evening carer's attendance. The incident, possibly a coughing fit, caused the deceased to fall from his wheelchair and then be unable to access his mobile phone.

The difficulty with the angle and configuration of the wheelchair, the state of the airer, the location of the vomit and signs of movement within the vomit indicate the deceased attempted to right himself prior to his death from asphyxia due to his position, and an inability to breathe effectively.

I am satisfied the deceased was deprived of adequate oxygenation for his continued life and died as a result of his inability to correct that situation due to his disability and his condition at the time.

I find death occurred by way of Misadventure.

COMMENTS ON THE DIFFICULTIES FOR THE DECEASED AND THOSE CARING FOR HIM

The death of the deceased emphasises the difficulty for those with progressive physical disabilities who remain of sound mind. The deceased's knowledge of his disability made him very anxious to maintain control over his life in the only ways open to him, by the choice of who and how he had assist him. With the aim of DSC being to provide those with a disability capable of controlling their lives, with the

ability to do so, there also needs to be an understanding by those with the capability to understand, there attaches to their independence some additional risks for their welfare. Indeed, that also applies to those without a disability. The difference is ordinary living may pose a risk for those with a physical disability.

The deceased did not make caring for him easy, and his anxiety to determine his life, put added pressure on those attempting to assist him in achieving that.

This office does not have the capacity to review the relevant legislation or service provider's compliance with service agreements and how that would affect situations like that of the deceased. I also acknowledge there are currently changes in place for the provision of services to those with a disability, not yet settled.

However, I am anxious there be better systems in place for those very vulnerable persons, like the deceased, to ensure they are provided with reviews as to their ongoing physical capacity, and some methodology in place to ensure the services for which they do contract to be provided, are in fact provided.

An external body, presumably the DSC as the funder on behalf of the community, needs to have the ability to ensure the systems in place adequately protect the disabled person

to the extent they are not prepared to take the consequences of their failing functionality.

If a disabled person is capable of stating their intention and they understand the consequences of their decisions and are prepared to stand by them that should be respected. But it is not clear to me the deceased actually understood his deteriorating state and the vulnerability that placed him in, because everybody was too concerned about challenging his personal dignity.[53]

The very least which should have been in place in the case of the deceased was his receipt of a functional roster at a set time each week so he could see if there was an issue before it arose. There also needed to be a system where by carers gave some clear indication of their attendance to the current care coordinator.

In the current case if Ms Allen, as the current care coordinator, had not received notification from a carer by 8.15 pm on 24 July 2013 that a carer was present at the deceased's address, then the relevant care coordinator would know it was necessary for someone to attend to check on a member's wellbeing. I am certain technology is advanced enough for there to be an alert system operated by carers on their attendance at a location to say they have attended or they are leaving. I cannot imagine that

[53] t 6.10.16, p293

someone, even as independent as the deceased, would have objected to such a system. It could be made a condition of any service agreement.

In the current case such a system would have ensured someone had checked on the deceased by 8.30 pm that evening. As mentioned it is impossible to say what his prognosis would have been in that timeframe, but it would ensure some sort of security to those with a disability and dependent on physical assistance, they would not be left in the situation the deceased was left in for Ms Walsh to find on the morning of 25 July 2013.

There needs to be a point at which it is made quite clear to members that continued independence may not protect them from accidental deaths, where they do not have adequate supervision. The lack of 24 hour supervision is entirely their choice, but it needs to be a choice consciously made by someone capable of making it, with the potential consequences clearly in mind.

It is a matter I believe the DSC and its service providers should consciously address in agreements with those being provided with funding on behalf of the community through DSC. I note there was a concern expressed on behalf of DSC[54] that Cam Can did not have in place a process whereby it would be aware of the lack of appropriate safe

[54] t 21.09.16, p91

guards for a member's wellbeing due to the lack of attendance of a carer/support worker. It is a matter DSC needs to address in its independent evaluation of Cam Can specifically, and service providers generally.

This was a terrible death for anyone. And the lack of dignity so important for someone such as the deceased, who valued his independence so much, is magnified by the knowledge he must have been in that position for at least twelve hours. For the short time in which he remained aware of his circumstances, he must have felt truly abandoned by those assigned to care for him.

I am, however, confident that while he may have remained alive for a period of time, he would not have been conscious for all that time.

E F Vicker
Deputy State Coroner
26 April 2017