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IN THE CORONERS COURT FOR NORTHERN IRELAND

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IN THE MATTER OF AN INQUEST INTO THE DEATH OF

Jade Rogan

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Before: Coroner Mr Patrick McGurgan

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[1] The deceased, Jade Rogan, born on 31st July 1990, of 1 Castle Meadow Avenue, Cloughey, died on 5th October 2017.

[2] In her evidence to the Inquest, Mrs Samantha Rogan, mother of the deceased stated that at the time of her death the deceased, who was affectionate and smart, had been residing in Strangford Court Care Home ("the Care Home") , 26 Strangford Road, Downpatrick. The deceased had resided in the Care Home on a respite plan for 5 years and then was residing as a permanent resident from April 2017. Mrs Rogan stated that she was fairly comfortable with the Care Home and would have placed the deceased nowhere else. The deceased had suffered from severe epilepsy and learning difficulties from birth. Her epilepsy was controlled by medication but her difficulties led to her banging her head off any hard surface when angry. The deceased had a care plan, one of the main aspects of which was the deceased having one to one care 24 hours per day. This was because the deceased would exhibit seizure activity throughout the day which in turn would sometimes lead to major seizures lasting around 4-5 minutes. The care plan was drawn up in conjunction with Mrs Rogan. In relation to night time supervision, the deceased initially had a staff member stay in her room all night. According to Mrs Rogan at a care plan meeting with the Care Home manager and others, she proffered that a staff member should stay outside the door of the room and observe from there at night as the presence of a staff member within the room could be a distraction to the deceased and thus disturb her sleep. Mrs Rogan stated that this proposal was refused by the Care Home manager on the basis that the Care Home was receiving funding from the South Eastern Health and Social Care Trust ("SEHSCT") for one to one supervision and therefore that was what the deceased was going to receive. This

meeting occurred sometime in April after the deceased had settled into the Care Home.

[3] An entry in the Care plan dated 24th April 2017 and timed at 18.30 states:
"Spoke to Sam (mum) she advised to tell all 1:1 not to stay inside Jade's room when she is sleeping as it is a distraction for her. They can stay outside bedroom as 1:1 to observe seizure activity. Sam wants staff to practice routine, 8-9 p.m. bedtime, early supper and night medication at 8 p.m. Morning time routine is 9 a.m. or 8.30 up and dress daily. To continue routine at home."

[4] The Inquest subsequently heard that the time of 18.30 represented the time the entry was made in the notes and not the time of the discussion.

[5] Mrs Rogan explained that the deceased would come home to her house whilst a resident at the Care Home. During her stays at Mrs Rogan's house the deceased did not have a person sitting up observing her all night but rather was monitored by way of a baby type monitor.

[6] As regards the sleeping position, Mrs Rogan stated that as the deceased was a rather large lady she would not have slept on her stomach and that the head of her bed at home would be kept at a 25 degree angle to aid with her sleep. Mrs Rogan had asked the Care Home to keep the head of the bed there raised but she did not believe that was ever done.

[7] In her evidence, Ms Toni-Rose Rogan, sister of the deceased and her main carer, stated that on the 5th October 2017 she received a phone call from the manager of the Care Home advising her that the deceased was unwell and that she needed to attend the Care Home as soon as possible. The manager explained that she had been unable to contact the deceased's mother. Ms Rogan arrived at the Care Home around 9.30 a.m. There was an ambulance crew as well as police in attendance. Within the Care Home she noticed that there was not a chair outside the deceased's bedroom. The manager informed Ms Rogan that the deceased had been a "handful the previous night". Within her room Ms Rogan noticed that the buzzer was off the wall and in her drawer and that the remote from her bed was absent.

[8] In her evidence to the Inquest, Ms Caroline Grierson stated that she was a friend of the family of the deceased since 2013. She had driven Ms Rogan to the Care Home on the morning of 5th October 2017. Prior to this she stated that she had been at what she considered was a Care Plan meeting in April /May with the deceased's mother at which sitting someone outside the deceased's room at night time as opposed to within the room was discussed. She also described how the Care Home manager did not agree with this proposal. She subsequently clarified that this meeting occurred on the 18th May 2017. However, records of that meeting did not record Ms Grierson as one of the attendees.

[9] On the morning of 5th October Ms Grierson explained that she queried with the Care Home manager how the deceased was found and she recalled being informed that the deceased had been a "handful the day before" and that her one to one could be outside the room up to 20-40 feet away. Ms Grierson stated that there was no chair outside the room whenever she went to the room that morning. She had the opportunity to enter the deceased's room and see the deceased a considerable time after the deceased had passed away.

[10] In her evidence to the Inquest, Ms Claire Quail, stated that she was the Care Home manager and had been since 2009. She had been employed in the Care Home from 1994. She explained that she first encountered the deceased in March 2012 when she was asked by the deceased's social worker to assess the deceased with a view to providing respite care. Following an assessment Ms Quail felt that the Care Home could meet the deceased's needs and the SEHSCT agreed that her care would be supported by one to one care which was provided by the Care Home staff. The deceased availed of respite care for periods from May 2012 until 2017. During respite the deceased's one to one care meant that she had constant supervision on a 24 hour basis and her night time supervision meant that a staff member would sit in her bedroom with the deceased.

[11] The deceased's permanent placement commenced within the Care Home on 17th April 2017. Assessments were conducted and various Care Plans developed. Ms Quail explained that on 24th April 2017 during a Physiotherapy or Occupational Therapy assessment, there was a discussion with Mrs Rogan whereby Mrs Rogan requested that the night time supervision take place from outside the deceased's bedroom. Ms Quail stated that there were no minutes of this discussion as it was not a planned meeting. Part of Mrs Rogan's rationale was that there would not be someone supervising the deceased in her bedroom whenever she came home for overnight stays and therefore it would be better to have continuity in the supervision so that what occurred in the Care Home would be replicated in her own home.

[12] Ms Quail explained that this was immediately put in place and the care plan notes updated to reflect this request and change. She did not feel it necessary to report this back to Mrs Rogan as the request had emanated from her initially. No trial run was tried and Ms Quail stated that there were no complaints or issues raised by staff about the arrangement. Furthermore, staff did not report any difficulty in being able to observe the deceased in the type of bed that she was sleeping in from their position outside the room.

[13] During the night time, "Nightly Checks" sheets were used by the Care Home which recorded each hour whether the deceased was sleeping or awake denoted by an "A" or an "S" or an "A/S" if the deceased had periods of both being asleep and being awake. These were signed off by the supervising member of staff and a nurse. Ms Quail explained that following this tragedy this form has now been revised to

include a lot more detail, to include the resident's sleeping position, and to be signed off each hour.

[14] I commend this change as I find that the "Nightly Checks" sheets that were in use at the time were of very limited value and insufficient to reflect accurately what may have occurred with a resident during one to one night time supervision.

[15] Ms Quail did recall a conversation taking place in the corridor of the Care Home on the morning of the tragedy with an individual other than Ms Toni Rogan. She could not however recall if it was Ms Grierson with whom she spoke. She did recall that she was questioned as to how the tragedy had occurred but she believed that she did not state that the deceased had been a "handful" but she may have said "unsettled" the day before, meaning the 3rd October, and hence the reason why the deceased slept so soundly the night before the tragedy . An entry in the progress sheets dated 3rd October 2017 stated: "In bad form today" and the "Nightly Checks" sheet for 3rd October showed the deceased awake quite a bit. The progress sheet on 4th October stated: "In settled form today". She further was of the opinion that she did not state that the supervising member of staff could be 20-40 feet away from the deceased but more likely she did say 2-3 feet away.

[16] No-one in the Care Home had witnessed any seizure activity occur since the deceased became a permanent resident in April 2017. As regards the chair which would sit outside the deceased's room, Ms Quail stated that she assumed that it had been moved to another room that morning as that was what would usually happen in order to be out of the way during the day.

[17] In relation to the night time supervision Ms Quail accepted that staff would take quick toilet breaks without seeking cover for their absence. She further accepted that staff were not familiar with the deceased's epilepsy plan but she was of the view that staff would know what to do in the event they witnessed the deceased having a seizure.

[18] Mr Michael Crothers gave evidence to the Inquest. He stated that he is a registered nurse and at the time he was employed by Four Seasons Healthcare working in Strangford Court Care Home since 2008. At that time he had been nursing for around 40 years. On Wednesday 4th October 2017 he was working nightshift in Oakland Suite starting at 8 p.m. and finishing at 8 a.m. As the off-duty nurse had not designated one supervisor to the deceased, he organised a rota between himself, Ms Martina Savage and Mr Conrad Walker. He knew the deceased and was familiar with her epilepsy plan. At 10 p.m. he administered regular medication to the deceased which she received each night. He observed no adverse effects following administration of the medication. He stated that the deceased could lie on her side or in a prone position in the bed. He was again with the deceased from 3.30-5 a.m. and at no time did he observe anything out of the ordinary. At this time the deceased was prone on her stomach and the bed was not raised. He explained that he had a good view of the deceased from the chair outside the room

and from his position he could observe movement and hear sounds if there were any. He did not hear any audible noises that morning. He peered into the deceased's room, which he accepted would have been a "fleeting glimpse" at approximately 7.30 a.m. and all appeared as before. He told the Inquest that the fact the deceased was still sleeping on her stomach at 7.30 a.m. as was the case when he last observed her at 3.30 a.m. did not cause him any concern as he thought that the deceased had simply moved at some stage and moved back onto her stomach. Mr Crothers stated that he was satisfied that there had been constant supervision that night for the deceased. Mr Crothers accepted that his epilepsy training at the time had lapsed by some 18 months but notwithstanding this he was of the view that he would still have known what to do and how to administer the emergency medication if the deceased had had a seizure.

[19] Mr Crothers was of the opinion that being within the resident's bedroom for night time supervision was preferable to sitting on a chair outside the room.

[20] In her evidence to the Inquest, Ms Naomi O'Brien stated that at the time she was employed by Four Seasons Healthcare as a Care Assistant working in Oakland Suite in Strangford Court Care Home. Prior to the deceased becoming a permanent resident in April 2017, Ms O'Brien had performed night time supervision by sitting within her room as per the care plan then in place. She could not recall if she had performed this duty after the deceased had become a permanent resident. She did recall a brief conversation with Mrs Rogan whenever Mrs Rogan told her that she wanted a staff member outside the room rather than within it at night time. On Thursday 5th October 2017 she commenced her shift at 8 a.m. No issues were raised on the handover by night staff. At around 8.10 a.m. she went to waken the deceased. On entering the room she turned on the light and pulled back the duvet. The deceased was lying on her front which Ms O'Brien stated was a normal sleeping position for the deceased. The deceased did not move and on checking the deceased Ms O'Brien could not detect any movement. There was no response to her name. Ms O'Brien called the nurse and whenever she came into the room, Ms O'Brien turned the deceased and could see that her face was blue. Other staff arrived and CPR was commenced and an ambulance tasked. Ms O'Brien could not recall if there had been a chair outside the deceased's room that morning.

[21] In her evidence to the Inquest, Ms Martina Savage, stated that at the time she was a night care worker with Four Seasons Healthcare at Oakland Suite, Strangford Court Care Home. She commenced nightshift on 4th October 2017 at 8 p.m. She was working with Conrad Walker. At around 10 p.m. she and Mr Walker were putting the deceased to bed having previously fed the deceased her supper of cereal, yoghurt and tea. Ms Savage stated that the deceased seemed ok and ate all her food and no issues were noted on putting her to bed. She was on supervision duty from 1-3.30 a.m. During the night at around 1.30-2.30 a.m. whilst observing the deceased, she moved in her bed in order to sleep on her stomach which according to Ms Savage was normal for the deceased. At no time did she enter the deceased's room but she would stand up on occasions from her position in order to look into the

room although she stated that she did not need to do this in order to get a better view. She recalled hearing the deceased breathing during this period of supervision but could not recall if she heard the deceased breathing during her supervision period from 6.30 a.m.

[22] Ms Savage explained to the Inquest that she placed the chair which was used to observe the deceased in an adjoining room around 7.55 a.m. on the morning of 5th October. At around this time Mr Walker came down the corridor and said that they could leave and they did. Ms Savage accepted that this meant that there was a period of approximately ten minutes that the deceased was unsupervised as Ms O'Brien did not enter the deceased's room until 8.10 a.m.

[23] Ms Savage had no concerns about the deceased being on her stomach for a long period of time and she accepted that the fact that she was unaware that this could be significant in a person with severe epilepsy was a deficit in her training. She also was of the view that being within the bedroom whilst supervising was better than being situated outside the door.

[24] Mr Conrad Walker gave evidence to the Inquest. He stated that he was employed at the time by Four Seasons Healthcare as a Care Assistant in Strangford Court Care Home. He commenced nightshift at 8 p.m. on 4th October and was with the deceased between 10 p.m. and midnight. The deceased was awake between those hours which he stated was not out of the ordinary for the deceased. He supervised the deceased between 5-6.30 a.m. and during that period he would stand up in order to get a better view of the deceased in her room. According to Mr Walker there was nothing to cause any concerns regarding the deceased that night. Whilst he had received no training regarding the deceased's epilepsy management he did explain that he knew what to do in the event she had a seizure.

[25] In her evidence to the Inquest, Ms Diana Pinheiro stated that she qualified as a general nurse in 2013 and has worked in Strangford Care Home from 2014. She stated that on 5th October 2017 her shift began at 7.45 a.m., ending at 8 p.m. She did not recall there being any issues at the morning handover from night staff. She was aware that the night time supervision was to be outside the room following a settling in period. Whilst she could recall supervising the deceased at night within her room during the respite periods she could not recall if she performed supervision outside the room after April 2017. She too also observed the deceased sleep on her front on occasions. On the 5th October she was in the treatment room which was to the left and across the corridor from the deceased's room. The door was open and she heard Ms O'Brien call her. Ms O'Brien stated that something was not right with the deceased. Ms Pinheiro made her way to the room and Ms O'Brien explained that the deceased was not reacting to her. Ms O'Brien had turned the deceased onto her back and stated "she is dead". Ms Pinheiro observed that the deceased was not breathing or moving. She in turn called two care assistants who were coming along the corridor. The deceased was placed onto the floor ad CPR commenced and continued until the arrival of paramedics.

[26] In her evidence to the Inquest, Dr Orla Gray, Consultant Neurologist, stated that the deceased was transferred to her care in February 2012 having first attended the neurology clinic in November 2010. The deceased had medical refractory epilepsy with 5 different seizure types, namely:

i) Generalised tonic clonic seizures preceding hysterical laughing or screaming which could be suggestive of a focal onset;

ii) Atonic seizures preceded by hysterical laughing or screaming suggesting a focal onset;

iii) Complex partial seizure;

iv) Myoclonic jerks;

v) Absences seizures.

[27] The deceased was last assessed by her in November 2012. She had a comprehensive epilepsy management plan which was reviewed on an annual basis. This plan described in detail each of the 5 seizure types, how to discriminate between each and how to manage each. As regards the administration of Midazolam, same was for tonic clonic seizures lasting more than two minutes or if a second tonic clonic seizure was to occur without the deceased having regained consciousness in between. Dr Gray explained that Sudden Unexplained Death in Epilepsy (SUDEP) is recognised as a leading cause of premature death in young adults with epilepsy. According to Dr Gray, persons suffering from epilepsy and learning disability have a significantly higher risk of SUDEP. Dr Gray explained that the deceased had a number of specific risks for SUDEP in addition to learning disability. These were: early onset of seizures, duration greater than 15 years of active seizures, seizure rate greater than 3 tonic clonic seizures per year, seizure type (tonic clonic seizures), and the number of antiepileptic drugs being prescribed.

[28] The fact that the deceased had bitten her tongue prior to death was in Dr Gray's opinion suggestive of, but not definitive of, a seizure. She had no issue with the deceased lying in the prone position as there was no body of evidence to indicate that this would cause a seizure. Dr Gray further opined that she would expect someone observing the deceased to witness a tonic clonic seizure if the deceased was having one. She further explained that all of the seizures as outlined by her which the deceased suffered from could occur during sleep. She believed that there were markers of seizure activity here although she could not be absolutely sure that a seizure had occurred.

[29] In her evidence admitted under Rule 17, Dr Mulhall stated that the deceased joined her practice on 10th May 2017 and that she pronounced life extinct on 5th October 2017 at Strangford Court Care Home at 9.20 a.m.

[30] In his evidence to the Inquest, Dr Christopher Johnston, Assistant State Pathologist for NI, stated that he performed an autopsy on the deceased on 6th October 2017. There was no evidence of any serious trauma that could have played a role in her death nor any natural disease process. He did record that the tongue was bitten between the upper incisors and the remaining teeth of the lower jaw. As regards the time of death he explained how that estimating that is particularly unreliable. He did believe on the evidence presented that the deceased had died at least one hour before she was discovered with a few hours being the "ballpark". He explained that Dr Brian Herron, Consultant Neuropathologist, examined samples of the deceased's brain and the findings indicated a period of acute neuronal necrosis (death of brain cells).

[31] Dr Herron explained that this finding could be due to cerebral perfusion failure, (insufficient blood being supplied to the brain) or seizure activity particularly status epilepticus (epileptic seizure). He also explained that the fact that the deceased had bitten her tongue may have suggested seizure activity prior to death.

[32] Dr Herron stated that SUDEP was still a grey area as to what exactly causes same and that a lot remains unknown about same. He referenced an article from "Frontiers in Neurology", published 20th July 2017, entitled, "Genetic Basis of Sudden Unexpected Death in Epilepsy". It stated:

"People with epilepsy have a twofold to threefold increased risk of premature mortality compared to the general population, which is attributed to factors both related and unrelated to epilepsy. The most common cause of death that is related to epilepsy is sudden unexpected death in epilepsy (SUDEP), defined as "a sudden, unexpected, witnessed or unwitnessed, non-traumatic, and non-drowning death in patients with epilepsy with or without evidence for a seizure, and excluding documented status epilepticus, in which postmortem examination does not reveal a structural or toxicologic cause of death".
Case–control studies analyzing clinical variables associated with SUDEP have highlighted generalized tonic–clonic seizures as the major risk factor. In addition, a long history of epilepsy, young age at diagnosis, early adulthood (aged 20–40 years), intellectual disability, and male gender, are also associated with elevated risk. While awareness of the health burden and risk factors of SUDEP is increasing among patients, doctors, and the community, the underlying causes of SUDEP are unknown.
Because many SUDEP cases are unwitnessed, the exact sequence of events is not known for the majority of cases. However, when witnessed, SUDEP almost always occurs in the aftermath of a generalized tonic–clonic seizure, and people with genetic epilepsies associated with this seizures type may be at heightened SUDEP risk. During the seizure, depressed autonomic control of respiratory drive may result in severe oxygen desaturation and a rise in blood carbon dioxide levels. The adverse effects of cessation of breathing may be exacerbated by airway obstruction in people sleeping face down, as is a common circumstance in SUDEP.

Dr Johnston agreed that the exact cause of SUDEP is poorly understood.

[33] I find that two of the members of staff who were detailed to perform the night time supervision on the night in question were not familiar with the deceased's specific epilepsy care plan. Whilst I find that this represented a deficit in their training I find that it had no bearing on the outcome.

[34] Similarly, although Nurse Crother's epilepsy training had lapsed by some 18 months again I find that this had no bearing on the outcome. However, I find that it is incumbent upon employers to ensure that all staff are appropriately trained and up to date with their training.

[35] I find that nighttime supervision was undertaken from outside the room at the request of the deceased's mother but that the Care Home did not assess all of the implications of this change and that supervision within the room would have been preferable. I find on the balance of probabilities that the deceased died as the result of a seizure but that supervision within the room would not have altered the outcome. Whilst it was possible for the staff undertaking the night time supervision to take toilet breaks without seeking cover I do not find that this occurred on this occasion but for the ten minutes between Ms Savage going off duty at 8am and Ms O'Brien coming to the deceased's room at 8.10am. However, I find that the deceased had passed away some time before this change over.

[36] The autopsy records and I find that death was due to:

I(a) Epilepsy.