Domestic Homicide Review (DHR)

West Cumbria Community Safety Partnership

Executive Summary

"Jessica"

May 2021

Julia Greig

Date: 28th January 2023

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THE REVIEW PROCESS

1.1 This summary outlines the process undertaken by West Cumbria Community Safety Partnership domestic homicide review panel in reviewing the homicide of Jessica who was a resident in their area. This DHR was undertaken jointly with the Cumbria Safeguarding Adults Board and a Safeguarding Adults Review (SAR) undertaken in conjunction with this DHR. A separate SAR report has been produced and will be published by the Cumbria Safeguarding Adults Board.

1.2 The pseudonyms have been in used in this review for the victim to protect their identity and those of their family.

1.3 Jessica was 36 when she died. She was a white British woman experienced vulnerabilities in relation to her physical health and learning disability. Her vulnerabilities made her reliant on others, particularly her parents to ensure her safety, wellbeing and access to services. At the time of her death she lived with her parents who were in their eighties.

1.4 There were no criminal proceedings in this case. A Learning Disability Mortality Review/Learning from Life and Death Review (LeDeR) was completed in April 2022 by the North Cumbria Integrated Care Board (formally the North Cumbria Clinical Commissioning Group).

1.5 The process began when the West Cumbria Community Safety Partnership (CSP) agreed that the criteria for a DHR had been met on the 24th February 2022. All agencies that potentially had contact with Jessica prior to her death were contacted and asked to confirm whether they had involvement with them. Six of the agencies contacted confirmed contact with Jessica and her family and were asked to secure their files.

CONTRIBUTORS TO THE REVIEW

2.1 The agencies that contributed to the review are as follows:

- Adult Social Care, Cumbria County Council
- North West Ambulance Service
- North Cumbria Integrated Care NHS Foundation Trust
- North Cumbria Integrated Care Board
- Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust
- Cumbria Constabulary

2.2 IMR authors were independent with no direct involvement in the case, or line management responsibility for any of those involved.

THE REVIEW PANEL MEMBERS

3.1 The DHR panel members were as follows:

Name	Role	Agency
Simone Eagling	CSAB Business Manager	Cumbria County Council
Clare Stratford Angela Rush	DHR Coordinator DHR Coordinator	Eden District Council
Julia Greig	Independent Reviewer	Octavia Consulting
Lorraine Rudd-Williams	Service Manager, Learning Disability/Transition & Autism Team	Adult Social Care, Cumbria County Council
Sharon McQueen	Safeguarding Practitioner	North West Ambulance Service
Michael Lloyd	Learning Disability & Autism Practitioner	North West Ambulance Service
Sarah Edgar	Detective Constable	Cumbria Constabulary
Sheona Duffy	Acting Team Manager Safeguarding and Public Protection / Named Nurse	Cumbria Northumberland Tyne & Wear Trust
Kelly Marsden	Named Nurse for Safeguarding Adults	North Cumbria Integrated Care NHS Foundation Trust
Molly Larkin	Designated Nurse Safeguarding	North Cumbria Integrated Care Board
Justine Parker	Team Leader	Victim Support

3.2 Independence and impartiality are fundamental principles of delivering DHR and the impartiality of the independent chair and report author and panel members is essential in delivering a process and report that is legitimate and credible. None of the panel members, had direct involvement in the case, or had line management responsibility for any of those involved. The panel met on three occasions.

AUTHOR OF THE OVERVIEW REPORT

4.1 West Cumbria Community Safety Partnership appointed Julia Greig to chair the review and to author the Overview Report. She works both independently and for a local authority as a registered social worker with extensive social work experience in the statutory sector working with adults. She has completed the Home Office approved course for Domestic Homicide Review Authors provided by AAFDA and is an accredited reviewer using the Serious Incident Learning Process. She maintains her CPD through Review Consulting and the AAFDA Network. Julia is independent of all agencies involved in this case and has never worked in Cumbria or for any of its agencies.

TERMS OF REFERENCE FOR THE REVIEW

Statutory Guidance (Section 2.7) states the purpose of the DHR Review is to:

- Establish what lessons are to be learned from the domestic homicide regarding the way in which local professionals and organisations work individually and together to safeguard victims;

- Identify clearly what those lessons are both within and between agencies, how and within what timescales they will be acted on, and what is expected to change as a result;

- Apply these lessons to service responses including changes to inform national and local policies and procedures as appropriate;

- Prevent domestic violence and homicide and improve service responses for all domestic violence and abuse victims and their children by developing a coordinated multi-agency approach to ensure that domestic abuse is identified and responded to effectively at the earliest opportunity;

- Contribute to a better understanding of the nature of domestic violence and abuse;

- Highlight good practice.

Specific terms of reference set for this review

Mental Capacity

- Was professionals' understanding and interpretation of the Mental Capacity Act 2005 accurate; including the legal powers and Lasting Powers of Attorney?

- Was there an overreliance and assumption of consent and capacity? Was there any evidence of assessing Jessica's capacity to make decisions in relation to her care and treatment (including weight loss and the impact on her health)?

Parental carers

- Why was there an overreliance on parental decision making by practitioners? Was there any influence by parents which made parents accept decision making and care, positive or negative factors?

- Were there any signs of domestic abuse or coercive and controlling behaviour, identified by, or disclosed to any agencies?

- Were procedures relating to domestic abuse followed and what action was taken?

- Was there consideration of possible safeguarding concerns?

- How did professionals respond when parents refused respite, treatment or interventions in respect of Jessica's physical health needs? Including appropriate escalation.

Risk assessment & Care Planning

- Was there any escalation of concerns in response to the decline in Jessica's physical health, including a rapid decline in weight.
- Was consideration given to convening a multi-agency meeting to address the increasing risks in this situation and to identify the decision maker?

Professional Curiosity & Challenge

- Did practitioners feel able to challenge parental decisions, views, and opinions? What if any strategies did practitioners use to challenge parents?
- Was the format and membership of MDT's effective in ensuring relevant professionals were involved?

Communication & Information Sharing

- How effective was the multi-agency working and information sharing in relation to Jessica's care and what challenges did agencies face in achieving this?
- Were practitioners supported through professional supervision?
- How effective was communication with the family and Jessica; including strategies used when they were hard to engage.

Impact of COVID-19

- To what extent did the lockdown impact on the provision of single and multi-agency support, and safeguarding and domestic abuse responses for Jessica?
- Was the service provision during this time appropriate to meet Jessica's needs?

Other

- What organisational or partnership systems factors aided or acted as a barrier to effective practice?
- What good practice was identified?
- What have been the key points of learning for the agency and what relevant changes have been put in place subsequent to the review scope period
- What were the barriers to Jessica seeking support, giving consideration to equal opportunities and protected characteristics.

SUMMARY CHRONOLOGY

Background information and history

6.1 Jessica had a terminal ileostomy[1] after a total colectomy[2] in her mid-teens for complications with inflammatory bowel disease. She had an under active thyroid and on occasions required transfusions due to low iron.

6.2 As a young girl she would only eat specific foods and had specific eating habits. For breakfast she would only eat 2 slices of toast with the crusts cut off which had been cut into quarters (if it wasn't presented in this way she would refuse to eat it), she ate the insides of two meat pies with gravy for lunch (always believing that they were from Greggs), she would eat cheese sandwiches, crisps, yoghurt and chocolate for her tea.

6.3 Jessica lived at home with her elderly parents, her mother and father were the most important thing to her, especially her mother. Jessica would often mirror her mother's behaviour, if her mother wasn't well Jessica would "take to her bed". There were times during Jessica's life that she shared a bed with her mother. Jessica had a wicked sense of humour; she knew who and what she did and didn't like. Jessica and her mother would often tease Jessica's father and on occasions they could both be cruel to him. She would often pretend not to do be able things but whilst in respite care she would do things independently, such as, go into the kitchen to get things out of the fridge and running her own bath, but when Jessica was at home, she insisted that her mother and father did everything for her.

6.4 Jessica's parents were in their eighties and had cared for Jessica her whole life. Her father experienced poor health and her mother had care and support needs and was in receipt of a package of home care. Jessica's father cared for his wife and both parents cared for Jessica. Both had been offered a carer's assessment in the past but had declined.

6.5 The home environment was very important to Jessica's mother and father, and the home was always immaculate. This declined somewhat when Jessica's mother was admitted to hospital in February 2021.

6.6 Jessica's father had a heart condition; he was generally independent but when he was experiencing ill-health he really struggled. He also had a hearing impairment and struggled with technology such as the phone. He found it difficult to accept help and did not want others to think he could not cope. Concerns about the parents ability to cope and care for Jessica were raised on many occasions dating back to at least 2019. In response, Jessica had an allocation of residential respite provision and attempts had been made to move Jessica onto living independently from the family home, yet she had always withdrawn her wish to do so.

6.7 Jessica was underweight throughout most of her life and was significantly underweight during the period subject to review. Jessica was visited regularly by community nurses for the purposes of monitoring her thyroid and iron levels and monitoring her weight, however, she often refused to have her weight measured.

[1] An ileostomy is where the small bowel (small intestine) is diverted through an opening in the tummy (abdomen). The opening is known as a stoma.

[2] Colectomy is a surgical procedure to remove all or part of the colon. Colectomy may be necessary to treat or prevent diseases and conditions that affect the colon.

6.8 Jessica became unwell and was admitted to hospital. Jessica died of multi-organ failure with sepsis and acquired pneumonia following an operation for an obstructed bowel.

Summary Chronology

6.9 The review considered agency involvement with Jessica from June 2020, when a referral was made to dietetics and was discharged from the service following failed attempts to speak with Jessica and her parents advising that she did not require their service, to 25th May 2021 the date of Jessica's death.

6.10 On the 10th June 2020, a referral was made for Jessica to dietetics in response to Jessica's weight loss. Dieticians made telephone calls on 23/07/20, 06/08/20 & 20/08/20, they spoke with both parents but on each occasion were unable to speak to Jessica. Jessica's mother stated that Jessica had not received any appointment letters and did not want dietician involvement and so she was discharged from the service. Jessica's GP was informed.

6.11 Also on the 10th June 2020, adult social care undertook a review for Jessica involving the Community Nurse (Community Learning Disability Team), and the Transforming Care Project Lead, and consultation with Jessica's parents. The review referenced the exploration of Jessica moving from the family home to a long-term placement, which had been considered on and off over the last two years. The review noted that district nurses were visiting Jessica every 2 months to check iron levels and that no concerns had been raised by them. It was also noted that a domiciliary care agency was supporting Jessica's mother twice a day due to her own poor health.

6.12 On the 29th June 2020, the GP was notified by Jessica's father that Jessica had been experiencing abdominal pain for the last two days, she was refusing any pain relief. Within an hour Jessica was visited at home by the home visiting paramedic. Her blood pressure, pulse and temperature were all normal. The paramedic observed Jessica to be 'dirty and unkempt', and that the home situation seemed difficult. The paramedic recommended a care coordinator and referred back to the GP. On the 8th July 2020 GP recorded that it would be inappropriate for care coordinator involvement as Jessica has complex needs, and Adult Social Care and the Community Learning Disability Team were involved.

6.13 On the 1st July, the social worker updated Jessica's support plan to reflect the contingency plan which included a 21 night allocation of respite care at a supported accommodation placement and that in the event of her mother being admitted to hospital her support from Jem Care would be transferred to Jessica. The social worker contacted Jem Care to request notification should there be any changes in support in the home relating to Jessica.

6.14 On the 23rd July, the community nurse visited Jessica at home. Jessica's weight was recorded as being 34.2kg. A blood test was completed, and indicated under active thyroid and anaemia.

6.15 On the 27th July, the GP informed Jessica's mother that Jessica was anaemic and that her thyroid stimulating hormone (TSH) level was very high. The GP checked Jessica's compliance with medication and advised that she should take regular doses and that her TSH would be checked again in four weeks.

6.16 On the 30th July 2020 the Community Learning Disability Team conducted a telephone review. It was noted that Jessica remained well, with no evidence of mood disorder, and was maintaining weight. A plan was agreed to consider discharge from mental health services in the forthcoming months. The GP was informed.

6.17 On the 20th August, the community nurse visited Jessica. A blood test was completed but no weight or other observations were recorded. The GP made a home visit due to worsening anaemia but found no source of bleeding upon examination, therefore a transfusion was organised with the day hospital.

6.18 On the 24th August, the community nurse visited, and a blood test was completed for cross match in preparation for the blood transfusion.

6.19 On the 28th August 2020 Jessica's father rang the day hospital to inform them that Jessica would not be attending as she was unable to get out of bed and was not drinking. He was advised to contact GP. The GP practice was also notified by email.

6.20 On the 1st September 2020, the community nurse visited Jessica. Visits recorded for blood tests but only one weight recorded in this time 33.2kg. Noted that a review of the notes back to 2017 showed that weight had stayed in a similar range.

6.21 On the 2nd September, the GP spoke with Jessica's father who stated that Jessica was difficult at times and had refused to attend the transfusion unit. It was confirmed that Jessica was self-administering her iron replacement tablet and so the GP asked Jessica's father to take over administration of medication.

6.22 On the 22nd September, the GP noted that Jessica's thyroid was still underactive but improving and, on the 6th October, noted that haemoglobin levels were slightly improved.

6.23 On the 8th October the Community Learning Disability Team held a multidisciplinary discussion regarding role of their service. Jessica's physical health needs were being addressed via district nursing services and the GP. Jessica had continued Adult Social Care involvement. In light of the sustained absence of mental health problems it was proposed that the Community Learning Disability Team discharge Jessica. Information was shared regarding the planned discharge with partner agencies.

6.24 Also, on the 8th October 2020 the GP spoke with the Community Learning Disability Team Nurse who requested that Jessica have regular bloods and weight checked by the district nursing team. The CLDT reported that Jessica's mother was unwell, her father was struggling to cope, and medication had not been ordered. The GP identified safeguarding concerns and escalated to the safeguarding lead.

6.25 On the 21st October 2020, the GP called the Community Learning Disability Team nurse to organise an MDT for Jessica.

6.26 On the 23rd October 2020, the district nurse recorded Jessica's blood pressure as normal.

6.27 On the 26th October 2020, the GP questioned the proposed discharge from the Community Learning Disability Team and ongoing care for the family. The Community Learning Disability Team practitioner agreed to share information regarding crisis and contingency planning with all partners, prior to discharge.

6.28 On the 28th October 2020 the Community Learning Disability Team telephoned Jessica's father to discuss her discharge from their service. Jessica's father confirmed his agreement with the contingency plan.

6.29 On the 3rd November 2020 the Community Learning Disability Team held a multi-agency meeting which included the social worker, GP, Community District Nursing, the Learning Disability Nurse and the Dietician. It was confirmed that the GP and district nursing would continue to monitor Jessica's physical health, including weight, stoma care, skin integrity and bloods for iron deficiency and thyroid. The three-monthly bloods and monthly weight monitoring would be reported to the GP. Jem Care would visit daily and alert Adult Social Care if health deteriorated within the family network. On the 4th November Jessica was discharged from the Community Learning Disability Team.

6.30 On the 12th November 2020, the community nurse visited to obtain bloods. There were a number of failed attempts, and no weight was recorded. Whilst there was no mention made of Jessica refusing to be weighed it was noted that the environment was not easy to work in and that Jessica was often in bed and refused to participate in the required procedures.

6.31 On the 23rd November 2020, the duty social worker received telephone contact from the Community Learning Disability Team. Jessica's father had contacted the Community Learning Disability Team requesting respite for Jessica. The duty social worker contacted Jessica's father, he appeared stressed on the phone, he said he wanted residential care for Jessica and Jessica was in agreement. It was agreed that residential care options would be explored.

6.32 On the 24th November 2020, the social worker contacted Jessica' father who confirmed that both himself and Jessica wanted to pursue supported accommodation. The social worker spoke to the Community Learning Disability Team nurse who advised that although Jessica had been discharged from the service she would assist with any transition from home to new accommodation.

6.33 On the 25th November 2020, the social worker contacted Jessica's father to further discuss a potential move to supported accommodation and the suitability of the placement identified. Jessica's father reported that he was managing caring for his wife with assistance from Jem Care.

6.34 On the 30th December 2020, the GP discussed Jessica's compliance with thyroid medication with her father who agreed to reorder the medication.

6.35 On the 1st January 2021 police were called to attend the family home. The caller, an off-duty officer, was concerned for the occupants. Someone had been heard to be shouting ""HELP"" during the day and the off-duty officer checked on Jessica's father who appeared frail and tired. Police attended; Jessica's father explained that he was the carer for his wife who had had a stroke. In addition to this he cared for his daughter who had Downs Syndrome. Police observed that the house was clean and tidy, and everyone appeared to be ok, although Jessica was not seen by police. Police referred to Adult Social Care stating that Jessica's father was struggling with the caring role and seemed depressed.

6.36 On the 14th January 2021, the community nurse visited Jessica who refused to be weighed.

6.37 On the 19th January 2021 Adult Social Care contacted Jessica's father. He reported a sore foot following a fall but that he was managing with the caring role.

6.38 On the 28th January 2021, the community nurse visited to do a blood test. Following an unsuccessful attempt to take bloods Jessica refused any further attempts. On the 2nd February 2021, the community nurse visited again. Jessica again refused despite numerous attempts. The community nurse agreed to visit the next day.

6.39 On the 3rd February 2021, the blood test was successful and showed an underactive thyroid and anaemia. Jessica's mother had been admitted to hospital with dehydration and her father reported that he no longer felt able to care for Jessica. The Adult Social Care duty social worker was informed.

6.40 The social worker contacted Jem Care who confirmed they could transfer the hours from Jessica's mother to Jessica, but stated they were unaware of the contingency plan.

6.41 The social worker contacted Jessica's father who said he was "struggling" to cope with meeting Jessica's personal care needs and changing of her stoma bag. He asked about the supported accommodation placement that was being considered. The social worker agreed to explore this. It was noted that placement was still uncertain due to compatibility of residents, building adaptations and Covid-19 restrictions.

6.42 On the 5th February Adult Social Care approved for the transfer of support, provided by Jem Care, to Jessica as an emergency due to her mother being in hospital and concern that her father was unable to cope.

6.43 On the 12th February 2021 Jem Care notified Adult Social Care that Jessica's father had asked carers not to visit from 12 February, there were further reports that he had 'chased them away'. Jem Care reported that Jessica looked unkempt, but there were no concerns that she was being neglected.

6.44 On the 19th February 2021 Jem Care confirmed with Adult Social Care that Jessica's mother had been discharged on 17th February and care had been reinstated from that day. Adult Social Care made a welfare telephone call to Jessica's father. He confirmed that they were coping, and that Jessica had received her Covid injection and was feeling unwell. Accommodation for Jessica was discussed and the social worker overheard Jessica in the background confirming that she wished to move.

6.45 On the 26th February, the community nurse visited the home, but the visit was recorded as a failed encounter and the visit would be rescheduled.

6.46 On the 3rd March, the GP discussed medication compliance again with Jessica's father and reiterated her need for the medication.

6.47 On the 4th March community nurses completed a blood test successfully but noted that they were unable to weigh Jessica as the scales were not available.

6.48 On the 11th March community nurses completed a blood test successfully. Jessica's bloods showed stable haemoglobin and TSH.

6.49 On the 25th March, a blood test was completed successfully.

6.50 On the 29th April 2021 community nurses visited. Jessica’s weight was 29.1kg and a Malnutrition Universal Screening Tool (MUST) level of 4 was recorded . Jessica’s weight loss was noted and that no weight had been recorded since December 2020.

6.51 On the 13th May community nurses visited. On their arrival Jessica’s father reported that paramedics had been out during the night, as Jessica had been complaining of abdominal pain, and they monitored her for three hours. The community nurse attended to Jessica who was in bed curled up and were unable to complete observations. Her father had already contacted the GP surgery for an urgent review. The nurse also contacted the GP surgery to raise concerns and the need for a GP review. Jessica’s father asked the nurse for the phone number for Social Services but did not say why, the number was provided.

6.52 Adult Social Care received a telephone call from the Community Learning Disability Team nurse to say that Jessica’s father had contacted them to say he had called the paramedics the night before as Jessica was demonstrating signs of cystitis. She was not admitted as her blood pressure was fine. The Community Learning Disability Team advised Jessica’s father to contact the GP. The Community Learning Disability Team nurse relayed to Adult Social Care that Jessica’s father had described that he was "dead on his feet".

6.53 The GP visited Jessica and noted that she had lost all mobility, was experiencing pain in passing urine and was vomiting. Initial thoughts were a Urinary Tract Infection but her condition was worsening and she required assessment in hospital. The GP admitted Jessica to hospital with vomiting and possible intestinal obstruction and dehydration. An ambulance conveyed her to hospital.

6.54 Adult Social Care telephoned Jessica’s father who informed them that Jessica had been admitted to West Cumberland Infirmary, following the GP visit, with suspected cystitis. The social worker called the hospital to seek an update but were unable to make contact, the social worker then updated Jessica’s father that she had been unable to get through.

6.55 On the 14th May West Cumberland Infirmary requested a transfer to Cumberland Infirmary in Carlisle (CIC). Jessica had been reviewed and it was found that she had a bowel obstruction. She was reported to have been non-compliant with medical interventions and this resulted in a transfer of care to provide treatment. Hospital staff reported they had been unable to contact Jessica’s father to inform him of the transfer of care.

6.56 On the 14th May the social worker spoke to West Cumberland Infirmary who confirmed that Jessica had been transferred to CIC. The social worker phoned Jessica’s father to update him. He was not aware that Jessica had been transferred or that she was awaiting a bed on the surgical ward at CIC. Later that morning he contacted Adult Social Care and was described as "in a panic" as he was unable to get through to CIC.

6.57 A social worker contacted Jessica’s father who was concerned he had not been informed that Jessica had been transferred and that she was to have an operation. The social worker agreed to email the Discharge Nurses to request that he was contacted by the ward to provide an update.

6.58 The social worker phoned CIC. The hospital stated that Jessica’s father had seemed distressed, as he had called the ward but was unable to understand the conversation

due to being "hard of hearing". Arrangements were then made for a neighbour to speak with the ward and who could then relay the information to him. There was a query that Jessica had a bowel obstruction, and she was awaiting a bed on the surgical ward in case an operation was required. The hospital highlighted the need for a Best Interest decision meeting to be held as Jessica did not have the capacity to consent to medical treatment and should this be the case, her father would be notified.

6.59 On the 19th May the Community Learning Disability Team nurse phoned the social worker. The hospital had raised concerns with the Community Learning Disability Team nurse about Jessica's weight as she was only 26 kilograms. The doctor had decided to carry out a surgical procedure on Jessica and as she lacked capacity, would need a Best Interest decision. The doctor had contacted her father by telephone to discuss, who was described as "aggressive". The social worker agreed to contact Jessica's father.

6.60 The social worker phoned Jessica's father, who confirmed he was planning on visiting Jessica. He reported that he had just learned that his wife had been diagnosed with cancer and that this had "knocked the sails out of him". He said he was unable to get any assistance from anyone relating to Jessica and that he had been contacted by the doctor from CIC who had seemed more interested in "bits of paper" about "Guardianship" and no one was visiting him to discuss. The social worker agreed to contact the Community Learning Disability Team to request they visit to explain the situation to him. The Community Learning Disability Team confirmed that Adult Social Care would need to do this as Jessica was no longer open to their service and that the issues were "social" not "health". The Community Learning Disability Team also referred to the hospital wanting to see legal documents regarding whether Jessica's father had any rights to make decisions for her regarding the health procedure.

6.61 The hospital reported to Adult Social Care that Jessica was not well, was significantly underweight, and severely malnourished. Jessica had a blocked stoma requiring surgery and possible need for a full laparoscopy depending on position of the blockage. It was reported that the doctor was trying to complete a Best Interest decision with Jessica's father but had found it very difficult to speak with him due to hearing problems. A safeguarding concern of neglect was raised by the hospital. Jessica needed an operation urgently, and they felt this had been restricted by her father over a period of seven days, he would not "allow" them to operate. Jessica's father stated that he had Lasting Power of Attorney (LPA) for welfare for Jessica. Jessica lacked capacity to make this decision and further delay would increase the urgency for the procedure.

6.62 On the 20th May Adult Social Care telephoned the hospital who reported that Jessica had undergone surgery and was on a ventilator. Jessica had a laparotomy , and her bowel was found to be obstructed. Her father had been updated and planned to visit.

6.63 On the 21st May 2021 Adult Social Care telephoned the hospital. The social worker advised that the safeguarding concern would not proceed to an enquiry and would be addressed via case management. The social worker said that there would need to be a multi-agency meeting prior to Jessica's discharge to consider the formulation of care plans and risk assessments. The hospital expressed concerns about whether her father would cope if she returned home as her mother would be receiving palliative care at home and that respite may be required for Jessica.

6.64 On the 24th May 2021, the off-duty officer and neighbour raised concerns for Jessica's father as his wife had been diagnosed with cancer and he had been told that he should travel to Carlisle as Jessica was not expected to live much longer. Jessica's father had been knocking on next door's wall to gain attention so that he can inform them of his situation, he had said 'If she doesn't make it, I will take every pill in that kitchen because I have nothing to live for without her' and had made similar comments to hospital staff. The police spoke to the hospital who confirmed that Jessica had died and would keep her father in overnight. Following further correspondence with his GP the police were satisfied that no further action was required on their part.

KEY ISSUES ARISING FROM THE REVIEW

Mental Capacity

7.1 The Mental Capacity Act 2005 provides the legal framework for assessing mental capacity and acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves[3].

7.2 Prior to the period under review, Jessica's mental capacity was assessed on at least two occasions, on both occasions Jessica was assessed as lacking capacity. Jessica had reportedly been self-administering her medication, but concern arose that she was refusing to take levothyroxine[4], it was agreed that it was in her best interests for her parents to covertly administer the medication in milk. With regards to care and accommodation, Jessica was assessed as lacking capacity to make a decision about respite care. It was determined to be in her best interests to receive respite at Placement 1 and a deprivation of liberty safeguards authorisation was granted for her period of respite at the home.

7.3 During the period subject to review, Jessica was assumed to have capacity in relation to health issues including nutrition, management of hypothyroidism and anaemia, treatment on admission to hospital and decisions about her care and accommodation. Jessica's mental capacity was not assessed again until the 18th May 2021, four days after her admission to hospital, with regard to the use of a nasogastric (NG) tube.[5]

7.4 Practitioners who worked with Jessica described her as being very strong willed, she was able to express an opinion, knew what she liked and did not like. However, Jessica had received support from advocacy between 2014 and 2018 and were able to provide a view on her mental capacity to make decisions about her health. Whilst acknowledging that mental capacity is time and decision specific, the professional opinion of advocacy was that whilst Jessica was able to express an opinion, in all probability she lacked the ability to weigh-up more complex decisions.

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[3] Mental-capacity-act-code-of-practice.pdf (publishing.service.gov.uk) para. 1.1

[4] Levothyroxine is a medicine used to treat an underactive thyroid gland (hypothyroidism). The thyroid gland makes thyroid hormones which help to control energy levels and growth. Levothyroxine is taken to replace the missing thyroid hormone thyroxine. NHS (www.nhs.uk).

[5] A nasogastric (NG) tube is a thin, soft tube made of plastic or rubber that is passed through the nose, down through throat, and into the stomach. It is used to deliver food or medicine to the stomach for people who have difficulty eating or swallowing.

7.5 When someone repeatedly makes unwise decisions that put them at significant risk of harm or exploitation, it does not necessarily mean that somebody lacks capacity but there might be a need for further investigation[6]. It cannot be known for certain whether Jessica had capacity, or not, in respect of the above issues. Nevertheless, assumptions were made that Jessica had capacity during the period and this was not explored further. There were however a number of times during the scoping period that the need for a mental capacity assessment was triggered, including, refusal of blood tests, low weight and refusal to have her weight monitored, non-compliance with medication, refusal of non-surgical interventions in hospital. Had mental capacity assessments been undertaken and determined that Jessica had capacity, consideration could have been given to whether despite having capacity Jessica was otherwise unable to make a decision free from undue influence or coercion.

7.6 Whilst Jessica had previously been assessed to lack mental capacity around administration of levothyroxine this was not kept under review and given the issues relating to her anaemia and hypothyroidism, this was a trigger to revisit the matter and explore compliance further. However, what transpired was an overreliance on her parents to ensure Jessica took her medication.

7.7 Upon admission to hospital Jessica refused all non-surgical interventions, including IV nutrition. No capacity assessments were undertaken with regards to her initial treatment. Although it was likely that she would have lacked capacity to consent to her hospital admission and associate care and treatment in hospital, there was no evidence that an urgent deprivation of liberty safeguards authorisation, or request for a standard authorisation, were considered.

7.8 It is unclear whether a mental capacity assessment was undertaken with regards to the proposed operation or whether she was assumed to lack capacity based on the assessment relating to the use of the NG tube. However, there was evidence of a best interest decision being taken with regards to the operation, where comments from Jessica's father and other clinicians were recorded.

7.9 There were reported delays in deciding whether to operate on Jessica that were attributed to her father's lack of cooperation. It was reported that he claimed to hold Lasting Power of Attorney (LPA) for Health and Welfare. However, the presence of an LPA was not checked with the Office of the Public Guardian, and it is unclear how this was resolved. Despite the potential conflicts around decision making authority for Jessica's treatment, no consideration was given to the appropriateness of a fast-track application to the Court of Protection.

Parental carers

7.10 Given that Jessica's mental capacity was not assessed during the period under review, save for the occasion in May 2021, there was an overreliance on her parents to make decisions about her care and health.

7.11 However, it is unclear what influence Jessica had over her parents. Some of the practitioners who had worked with Jessica and the family stated that her father would have done anything for her and wanted the best for her. Professionals commented that the family did not like outside interference and that it was difficult to build relationships. The family were observed as obstructive regarding times of

[6] Mental-capacity-act-code-of-practice.pdf (publishing.service.gov.uk). Para. 2.11

visits, and Jessica's father was described as rude and obstructive. He was particularly critical of the community nurses when they were unable to obtain bloods. Others commented that Jessica had a very strong will and that her father did what she wanted him to. However, during the scoping period Jessica's voice is not prominent. Most contact was with her parents who spoke on Jessica's behalf, only those who visited the home in person were able to speak to Jessica, therefore when care, treatment or interventions were declined it is not possible to establish whether it was the parents or Jessica, via her parents, which were declining. Nevertheless, practitioners acknowledged that they were over reliant on the parents to make decisions.

7.12 On occasions when Jessica declined interventions, or her parents did so on her behalf, this was shared, when required, with the relevant professionals. However, this did not result in an escalation in concern or response by agencies, or any challenge of the parents by practitioners.

7.13 Safeguarding concerns had been raised in 2014 and 2016 alleging that her father had hit Jessica and that her mother had been abusing her, however these allegations were unconfirmed. No such concerns were raised during the scoping period.

7.14 The cross-Government definition of domestic violence and abuse outlines controlling or coercive behaviour as follows:

> *Controlling behaviour* is: a range of acts designed to make a person subordinate and/or dependent by isolating them from sources of support, exploiting their resources and capacities for personal gain, depriving them of the means needed for independence, resistance and escape and regulating their everyday behaviour.
>
> *Coercive behaviour* is: a continuing act or a pattern of acts of assault, threats, humiliation and intimidation or other abuse that is used to harm, punish, or frighten their victim."7

7.15 The Statutory Guidance states that the types of behaviour associated with coercion or control may or may not constitute a criminal offence in their own right. However, the perpetrator may limit space for action and exhibit a story of ownership and entitlement over the victim. Such behaviours might include:

- isolating a person from their friends and family;
- depriving them of their basic needs;
- monitoring their time;
- monitoring a person via online communication tools or using spyware;
- taking control over aspects of their everyday life, such as where they can go, who they can see, what to wear and when they can sleep;
- depriving them of access to support services, such as specialist support or medical services;
- repeatedly putting them down such as telling them they are worthless;
- enforcing rules and activity which humiliate, degrade or dehumanise the victim;
- forcing the victim to take part in criminal activity such as shoplifting, neglect or abuse of children to encourage self-blame and prevent disclosure to authorities;

[7] Controlling or coercive behaviour - statutory guidance.pdf (publishing.service.gov.uk)

- financial abuse including control of finances, such as only allowing a person a punitive allowance;
- threats to hurt or kill;
- threats to a child;
- threats to reveal or publish private information (e.g. threatening to 'out' someone).
- assault;
- criminal damage (such as destruction of household goods);
- rape;
- preventing a person from having access to transport or from working.
- This is not an exhaustive list[8]

7.16 For an offence to apply, the controlling or coercive behaviour must take place 'repeatedly or continuously' and the pattern of behaviour has to have a 'serious effect' on the victim[9] The behaviour must be such that the perpetrator knows or "ought to know" that it will have a serious effect on the victim, The perpetrator and victim have to be personally connected when the incidents took place[10]

7.17 There is no evidence that Jessica's parents controlled or coerced her and on reflection practitioners did not think the parents were controlling or coercive; they did not identify any coercive and controlling behaviour and it was not disclosed to any agency. As such, agencies did not consider domestic abuse policy and procedure. The narrative suggests that Jessica was assertive in expressing her wish to engage or not in health and social care interventions and that she dictated what did and did not happen. There is also evidence that her father sought assistance with regards to Jessica's health and social care when she was exhibiting signs of illness and when he was finding it difficult to cope.

7.18 The action or inaction of Jessica and her parents should be seen in the context of a family that had become used to a long and firmly established way of life. The imposition of care packages on familiar daily routines may not always be welcomed by older parent carers and may be perceived as an unwelcome intrusion and undermining their ability to care for their child. Older parents may be concerned that their own intimate knowledge and understanding of their son's or daughter's needs will not be respected and taken on board. Continuity of care and sensitive communication with families is essential in order to ensure that the support needs of individuals are met.

Risk assessment & Care Planning

7.19 With regards to monitoring Jessica's weight community nursing were tasked with monitoring weight on a monthly basis. There was no record of this plan being discussed or agreed with Jessica or her parents. Jessica often refused to be weighed and as such she was only weighed in September 2020 and April 2021, shortly prior to her admission to hospital. Whilst the refusal of blood tests was reported to the GP there was no evidence that the inability to monitor weight was. The learning event

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[8] n8

[9] 'serious effect' means - a fear that violence will be used against them on "at least two occasions", OR they have been caused serious alarm or distress which has a substantial adverse effect on the victim's usual day-to-day activities,

[10] Serious Crime Act 2015, s. 76.

reflected that sometimes practitioners are less likely to raise fresh safeguarding concerns as they are familiar with working with the known risks.

7.20 When Jessica was weighed on the 29th April 2021 a MUST score of 4 was calculated[11]. According to the MUST tool, a score of two or more should result in the following action being taken: a referral to a dietitian, Nutritional Support Team or implement local policy; set goals, improve and increase overall nutritional intake; monitor and review care plan monthly. The plan initiated was to increase weight monitoring to fortnightly, although there was no consideration of how this would be implemented effectively given Jessica's regular refusal. A referral to dietetics was not made but would have been considered if future concerns arose.

7.21 When Jessica's blood results indicated anaemia and high TSH levels the GP took appropriate action following up with the parents about compliance with medication. On one occasion the GP arranged for a blood transfusion, however there was no escalation or response to risk when Jessica refused to attend for the procedure.

7.22 There was one multi-agency meeting held during the scoping period in November 2020, convened by the CLDT, in anticipation of discharging Jessica, and was attended by the social worker, GP, Community District Nursing, the Learning Disability Nurse and Dietician. The meeting confirmed the ongoing role of community nursing to monitor Jessica's physical health and the contingency plan in place. The multi-agency meeting did not address the emerging concerns as a result of Jessica's refusal to attend for a blood transfusion and her non-compliance with weight monitoring.

Communication & Information Sharing

7.23 The review found examples of good practice in relation to sharing information. There was evidence of agencies speaking to each other and escalating concerns in relation to Jessica's father's ability to cope and Jessica's refusal of blood tests which resulted in action being taken. However, the inability to weigh Jessica on a monthly basis, as per her care plan, was not escalated or shared with other agencies and as a result her weight was not effectively monitored, although it is acknowledged that when she was last weighed in late April 2021 (29.1kg) the plan was to increase weight monitoring to fortnightly and to refer to the dietician if concerned.

7.24 In terms of communication with Jessica, the agencies commented that they did not often see or get to speak with her on her own and as such her voice was not heard particularly well. This was identified by practitioners as an area of learning, to understand what Jessica wanted and what she understood, whether her views were being influenced and if so, what did that look like. Jessica had previously engaged well with advocacy, and this is something that could have been beneficial to her during the period with regards to her health, social care and wellbeing.

7.25 Communication with Jessica's father was compromised by his hearing impairment, he required face to face interaction to maximise his ability to communicate and

[11] 'MUST' is a five- step nationally recognised and validated screening tool to identify adults who are malnourished or at risk of malnutrition. It is the most commonly used screening tool in the UK and is suitable for use in hospitals, community and other care settings. [Malnutrition Universal Screening Tool (bapen.org.uk)]

understand information. This subsequently affected his ability to navigate the health service and understand what was happening to Jessica following her admission to hospital.

7.26 Whilst Jessica was in hospital Adult Social Care worked as a conduit between the hospital and her father but found it difficult themselves to navigate the health system. They reflected how difficult it must be for carers, and particularly for Jessica's father given his hearing impairment and the additional stress he was experiencing with regards his wife's diagnosis.

7.27 Jessica's father clearly felt comfortable communicating with the CLDT, as previously mentioned there was a good rapport between the CLDT and the family, and he continued to contact them after Jessica's case had been closed. Agencies felt that it would have been beneficial to utilise the CLDT to support Jessica's father navigate the health system whilst Jessica was in hospital, however Jessica had been discharged from the service and there was no longer a remit for their involvement.

7.28 This has highlighted again a potential role for advocacy services who could have developed a relationship with Jessica's father and supported to keep communication pathways open. Furthermore, the review identified a neighbour who was involved with the family and who Jessica's father would call upon when he needed assistance. The presence of the neighbour was not known to the agencies, highlighting the importance of exploring people's wider support networks beyond the immediate family.

7.29 Jessica's father's inability to understand what was happening whilst Jessica was admitted to hospital, alongside his anxieties for his wife's health, would have likely resulted in a perception of him being obstructive. Effective communication and support would have minimised his anxieties and possibly the subsequent delays in treatment.

Barriers to effective practice

7.30 As already stated, agencies found the parents hostile and obstructive and on reflection felt they were not as well equipped to deal with conflicting relationships as their counterparts in children's services. The agencies reflected that practitioners need to be empowered and supported to work with and involve family carers, and to challenge where appropriate.

7.31 Adult Social Care stated they found the health care system confusing and complex to navigate much did their own thing and focused on their remit, commenting that a coordinator in this case would have been beneficial in bringing oversight to what all the agencies were doing and the outcomes to be achieved.

7.32 NCIS highlighted how health systems could be a barrier to practice stating that they have both paper and electronic records held on different systems, which meant information was not easily accessible.

Impact of COVID-19

7.33 In March 2020, the UK Prime Minister introduced a nationwide lockdown. All non-essential contact and travel was prohibited, and many services moved to remote working. Restrictions began to ease in July 2020 and people were able to meet up in limited numbers outside. There was further easing of restrictions in August 2020.

7.34 There was a further national lockdown introduced for four weeks on the 2nd November 2020 and from the 21st December 2020 London and the Southeast entered its third lockdown, this was extended nationwide on the 6th January 2021. The 'stay at home' order was finally lifted on the 29th March 2021 with most legal limits on social contact being removed on 19th July 2021[12].

7.35 As such, the period under review coincided with a period of lockdown with agencies working remotely where possible. Despite the lifting of the stay at home order in March and the further lifting of restrictions in the following months, many agencies continued with their new working practices, not fully returning to how they worked and delivered services pre-pandemic. In addition, the family would have been considered vulnerable to covid infection which would have been considered in any risk assessment around visiting the home. This resulted in a reduced number of agencies having in-person contact with Jessica and her family with CNTW and Adult Social Care only having contact by telephone. Nevertheless, the services provided to Jessica by police, ambulance, and community nursing were not affected by the pandemic. Jem care continued to deliver home care and therefore had daily 'eyes on' the family and home environment. The GP also made home visits when appropriate, which also demonstrated a reasonable adjustment based on an understanding of Jessica's needs and the dynamics of the family.

7.36 The covid-19 pandemic also compromised the ability to arrange and provide respite service due to limited availability of placements, the suspension of admissions due to covid outbreaks, and the inability to make visits to services as part of a transition due to restrictions on visiting and entering care homes.

7.37 Whilst Jessica and her family's experience of accessing services during the pandemic is not known anecdotal reports were that people avoided contacting services and a third of adults reporting that they struggled to access NHS services.[13]

CONCLUSIONS

8.1 There were no safeguarding concerns raised during the period subject to review and previous safeguarding concerns relating to alleged abuse by the parents were unconfirmed. There was no evidence of coercive and controlling behaviour, although

[12] timeline-coronavirus-lockdown-december-2021 (instituteforgovernment.org.uk)

[13] Revealed: A third of adults struggled to access NHS during pandemic, driving many to private healthcare | IPPR

there was a lack of professional curiosity into whether the parents were exerting any influence over Jessica.

8.2 Jessica experienced a number of health issues and had struggled to maintain a healthy weight for much of her life. She was supported by a range of services in regard to both her health and social care needs. Health agencies monitored Jessica's hypothyroidism and anaemia as well as monitoring her weight. However, she would often refuse interventions with regards to her health, to the extent that her weight was only successful recorded on two occasions in one year.

8.3 Jessica was assumed to have mental capacity in respect of decisions around her health and there were no mental capacity assessments undertaken to establish whether this was or was not the case. Had mental capacity assessments been undertaken this would have confirmed, or otherwise, Jessica's ability to understand, weigh-up, retain and communicate the information relevant to decision to be taken. The undertaking of mental capacity assessments would have supported practitioners to pursue the appropriate and legal pathway to support Jessica whether that be a best interest decision, referral to the Court of Protection, consideration of Inherent Jurisdiction or ensuring her right to make unwise decisions.

8.4 Jessica lived with and was cared for by her older parents, who both had their own health needs and impairments. Some of the agencies involved experienced hostility and obstruction from the parents. This review has highlighted the importance of an awareness of the lived experience of parent carers which might aid effective communication and engagement.

8.5 The review also demonstrated that Jessica's voice was not prominent, she was rarely seen or spoken to on her own and therefore practitioners could not be confident of her views and wishes. Jessica had previously engaged well with advocacy services, and this would have been beneficial to her during the period. It may have also aided communication between agencies and individual family members.

8.6 The interventions with Jessica during the period which has been subject to review must be viewed in the context of the covid-19 pandemic which affected both how services were delivered by practitioners and accessed by users of services. This did reduce the ability of some agencies to have face to face contact with Jessica, despite this those services which could only be delivered in-person continued to be delivered and she was seen regularly given the context of the pandemic and associated lockdown.

8.7 It is with regret that the review had not been able to include the views and experiences of Jessica's family as both her parents passed away within a year of her.

LESSONS IDENTIFIED

9.1 The lessons drawn from this case are summarised below along with how those lessons should be translated into recommendations for action.

9.2 Early learning identified during the review process, and whether this has already been acted upon, is also highlighted.

9.3 Mental capacity – no Mental Capacity assessments were undertaken during the review period, until Jessica required an operation. This and previous reviews have highlighted difficulties experienced by practitioners in applying the Mental Capacity Act and previous recommendations have focused on training. This review also suggested a lack of understanding around other processes such as how to check an individual's legal status and when to consider referral to the Court of Protection.

9.4 Deprivation of Liberty – practitioners need to be competent in recognising when someone might be deprived of the liberty, how to make an urgent authorisation and refer for a standard authorisation. This is particularly important for both health and social care given the forthcoming Liberty Protection Safeguards.

9.5 Advocacy – Jessica had previously engaged well with advocacy but there was no consideration of advocacy services for Jessica, or her parents, during the review period. Practitioners should be familiar with the types of advocacy available and when there is a legal duty to provide advocacy.

9.6 Working with older parent/carers – when working with older parent carers it is important to develop an awareness and understanding of their lived experience and consider ways to positively engage.

9.7 Coercive controlling behaviour – whilst there was no evidence of coercive controlling behaviour by Jessica's parents it was acknowledged that there was a lack of professional curiosity from practitioners, to consider whether this was a factor, when working with Jessica and her family. Practitioners should feel confident to question and consider a range of factors to explain behaviour and engagement including the possibility of coercion and control.

9.8 In response to previous DHRs, the ambulance service have already developed and delivered Level 3 safeguarding training to their clinicians. The service also undertake audits of clinician's responses to social care and safeguarding issues they are presented with to assure themselves that clinicians are being professionally curious and responding appropriately.

9.9 Communication – only some of the agencies had direct contact with Jessica. There was little evidence of any direct communication or adjustment of communication to maximise Jessica's participation in her health and care plans.

9.10 Reasonable adjustments – this review and others have highlighted the need to make reasonable adjustments for people with learning disabilities, particularly when accessing health services. Reasonable adjustments for carers should also be considered.

RECOMMENDATIONS

10.1 The Safeguarding Adults Review, undertaken in parallel to this review, was concluded shortly before this DHR. As a result of the Safeguarding Adults Review a number of recommendations were made which the Safeguarding Adults Board will take forward in early 2023. It was agreed by the panel that these recommendations

will not be repeated here as this would result in duplication. In addition, the following recommendations have been made as a result of this review.

West Cumbria Community Safety Partnership *(Cumberland Community Safety Partnership)*

- Increase practitioner understanding and awareness of coercive controlling behaviour, including the definition of 'personally connected' and how people with learning disabilities might be affected.

National recommendation

- Research to be undertaken into the prevalence of coercive control for people with a learning disability and prevalence in carer/cared for relationships.