Domestic Homicide Review (DHR)

West Cumbria Community Safety Partnership

Overview Report into the death of ‘Jessica’

May 2021

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v.5

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Preface

This is a Domestic Homicide Review Report referring to the life and death of Jessica. This is the pseudonym chosen by the panel and will be used throughout this report.

I would like to begin by expressing my sincere sympathies, and that of the panel, to the those who knew Jessica and thank them for their engagement. This review has been undertaken in order that lessons can be identified to inform future responses to domestic abuse.

I would like to thank the panel and those that provided chronologies and individual management reviews for their time and co-operation.

1. Introduction

1.1 This report of a domestic homicide review (DHR) examines agency responses and support given to Jessica, a resident of Cumbria prior to her death in May 2021.

1.2 In addition to agency involvement the review will also examine the past to identify any relevant background or trail of abuse before the homicide, whether support was accessed within the community and whether there were any barriers to accessing support. By taking a holistic approach the review seeks to identify appropriate solutions to make the future safer.

1.3 The review considers agencies contact and involvement with Jessica from 10th 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 Jessica did not require their service, to the date of Jessica's death in May 2021.

1.4 The key purpose for undertaking DHRs is to enable lessons to be learned from homicides where a person is killed as a result of domestic violence and abuse. In order for these lessons to be learned as widely and thoroughly as possible, professionals need to be able to understand fully what happened in each homicide, and most importantly, what needs to change in order to reduce the risk of such tragedies happening in the future.

1.5 Every effort has been made to conduct this review process with an open mindset and to avoid hindsight bias. Those leading the review have sought the views of family members and made every attempt to manage the process with compassion and sensitivity.

1.6 This DHR was commissioned by the West Cumbria Community Safety Partnership. Following local government reorganisation, the West Cumbria Community Safety Partnership will become the Cumberland Community Partnership from April 2023.

2. Timescales

2.1 A referral was received by West Cumbria Community Safety Partnership (CSP) on the 2nd February 2022 and the CSP agreed that the criteria for a DHR had been met on the 24th February 2022. It is understood that delay in this referral was incurred as Jessica's death was subject to a Learning Disability Mortality Review/Learning from Life and Death Review (LeDeR), the undertaking of which led to a referral to the Cumbria Safeguarding Adults Board for a Safeguarding Adults Review. It was at that Board meeting in January 2022 that it was recommended a referral was made for a DHR.

2.2 The Home Office Statutory Guidance advises that where practically possible the Domestic Homicide Review should be completed within six months of the decision to proceed with the review. Delays in commencing the DHR were incurred as there were a number of DHRs being undertaken at the time and there were a limited number of Independent Chairs available.

2.3 The DHR Chair recruited via AAFDA and was appointed in May 2022. The first scoping meeting was held on the 9th June 2022 and the review was concluded in December 2022.

2.4 The panel met on three occasions. The chair contacted agencies to gain additional information and clarifications outside of the formal panel meetings.

3. Confidentiality

3.1 The findings of each review are confidential. Information is available only to participating officers/professionals and their line managers.

3.2 Whilst pseudonyms would ordinarily be agreed by or with the family, on this occasion that was not possible as both parents were deceased by the commencement of the review. Pseudonyms have been agreed with the panel and used in the report to protect the identity of the individuals involved.

4. Terms of Reference

4.1 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.

5. Methodology

5.1 The method for conducting DHR's are prescribed by the Home Office Guidelines. These guidelines state: "Reviews should illuminate the past to make the future safer and it follows therefore that reviews should be professionally curious, find the trail of abuse and identify which agencies had contact with the victim, perpetrator or family and which agencies were in contact with each other. From this position, appropriate solutions can be recommended to help recognise abuse and either signpost victims to suitable support or design safer interventions".

5.2 Following the decision to undertake the review, all agencies were asked to check their records about any interaction with Jessica.

5.3 Where it was established that there had been contact all agencies promptly secured all relevant documents, and those who could make an appropriate contribution were invited to become panel members. Agencies that were deemed to have relevant contact were then asked to provide an Agency Report and a chronology detailing the specific nature of that contact. Where contact was minimal or outside of the scoping period agencies were invited to complete a summary report.

5.4 The aim of the Agency Report is to look openly and critically at individual and organisational practice to see whether the case indicates that changes could or should be made to agency policies and practice. Where changes were required then each Agency Report also identified how those changes would be implemented.

5.5 Each agency's Agency Report covered details of their interactions with Jessica, and whether they had followed internal procedures. Where appropriate the report writers made recommendations relevant to their own agencies and prepared action plans to address them. Participating agencies were advised to ensure their actions were taken to address lessons learnt as early as possible. As part of this process Agency Report authors, where appropriate, interviewed the relevant staff from their agencies.

5.6 The findings from the Agency Reports were endorsed and quality assured by senior officers within the respective organisations who commissioned the report and who are responsible for ensuring that the recommendations within the Agency Reports are implemented.

5.7 Following receipt of the agency reports and initial analysis by the panel, a Practitioner Learning Event was held in order to further explore hypotheses, draw out themes, good practice and key learning from the case including any recommendations for the development or improvement to systems or practice, with practitioners and managers who were directly involved with Jessica and her family. The Practitioner Learning Event took place on the 27th October 2022.

5.8 On request from the independent chair, some authors provided additional information to clarify issues raised individually and collectively within the Agency Reports. Contact was made directly with those agencies outside of the formal panel meetings.

5.9 Those agencies who provided Agency Reports are detailed within section 7 of this report.

6. Involvement of Family, Friends, Work Colleagues, Neighbours and Wider Community

6.1 Jessica's mother died shortly after Jessica and her father passed away in April 2022. The Panel identified a half-sister who was estranged from the family. Significant efforts were made by Panel members to identify contact details for the sister, unfortunately no contact details could be found.

6.2 A neighbour, who knew the family well, contributed to the review via a written statement. They said that they had spent time with Jessica's father in his garden shed where he would retreat to for a few hours a day to have space from his wife and daughter. The neighbour said that Jessica's father loved his wife and daughter and despite not having very much money he would buy whatever his wife and daughter wanted, they needed for nothing. Jessica's mother had a shed full of freezers where she would stockpile food, her kitchen was loaded with pots, pans and gadgets, ornaments and pictures, there wasn't any space on any surface.

6.3 The neighbour further stated that Jessica's mother 'was queen of her house; she would be demanding and insistent that [Jessica's father] needed to do certain things around the house. He simply couldn't do what she wanted because of his age and poor health. Everything that she wanted she got, it didn't matter if [Jessica's father] could afford it or that it wasn't needed, [Jessica's mother] was in charge.' However, they did not witness any domestic abuse between Jessica's parents, although Jessica's father said he would have left had he had been able to afford to do so or had been young enough.

6.4 Everyday Jessica's father would drive into town to buy Jessica's favourite pies from the butchers. Jessica was a fussy eater and very underweight. She would refuse to eat certain foods that were given to her, so her mother let her eat crisps and biscuits.

6.5 Jessica very rarely went out of the house, despite the best efforts of her father, and she was embarrassed about how she looked. Jessica told her father that she didn't like his car so he bought another one in the hope that she would go out more.

6.6 When Jessica's mother went into hospital her father was lost. He couldn't cope looking after Jessica. At the time Jessica was not eating or sleeping, this really worried her father as he did not know where to turn for help. When Jessica's mother came back from Hospital, she was annoyed at the neighbour for interfering and blamed Jessica's father for ganging up on her.

6.7 Another of the family's neighbours attended the Learning Event and said Jessica's father wanted the best for Jessica. Jessica's father had a heart condition and was very independent, however, when he experienced periods of ill health he really struggled. He found it difficult to accept help as he did not want people to think he could not cope.

6.8 An advocate who had worked with Jessica between 2014 and 2018 said that Jessica was very strong willed. Her parents loved her very much and there

was no evidence of any coercive and controlling behaviour or fear of her parents.

7. Contributors to the Review

7.1 The agencies that have contributed to this 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

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

8. The Review Panel Members

8.1 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

8.2 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.

9. Author Of The Overview Report

9.1 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 both the private and statutory sector working with adults. Julia worked exclusively with people with learning disabilities from 1996 until 2011; she continues to work with people with learning disabilities as an independent social worker and Best Interest Assessor. Julia 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.

10. Parallel Reviews

10.1 There were no criminal proceedings in this case. As Jessica died in hospital, and it was considered to be a known/expected death, the doctor gave a cause of death. Therefore, there no referral to the coroner and therefore no inquest into Jessica’s death.

10.2 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). The LeDeR identified the following issues, concerns and potential problems with the care Jessica received: the crisis plan was not followed; Jessica’s weight was not monitored by district nursing staff; there was a delay in seeking specialist learning disability advice upon Jessica’s admission to hospital; there was a misunderstanding and delay in the planning of the Best Interest Meeting which led to a delay in operating; Jessica’s parents made health related decisions on her behalf; Jessica did not take medication whilst in hospital; district nursing did not recognise the need to make a safeguarding referral; Jessica received her Annual Health Check via telephone despite the practice knowing she was vulnerable, the caller did not converse with Jessica; there was little contact by the GP practice following concerns raised in October 2020; there were significant delays in the care and treatment Jessica received during the last episode of care whilst in hospital; Jessica’s health significantly deteriorated during the final year of her life; and it was repeatedly written throughout notes that Jessica had mental capacity yet no assessment was carried out.

10.3 The LeDeR led to a referral for a SAR and DHR. The findings of the LeDeR assisted in scoping the terms of reference for this review.

10.4 This DHR was undertaken jointly with the Cumbria Safeguarding Adults Board and a Safeguarding Adults Review (SAR) undertaken in conjunction with this DHR. Whilst the review process was undertaken jointly to avoid duplication, a separate SAR report has been produced and will be published by the Cumbria Safeguarding Adults Board.

11. Equality And Diversity

11.1 The nine protected characteristics in the Equality Act 2010 were assessed for relevance to the Review.

11.2 Jessica was a 36-year-old white British woman. She 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.

11.3 In a review of DHRs undertaken by the Home Office[1] it was found that seventy-seven percent of domestic homicide victims were female, with an average age of 43. Seventy-four percent of victims were white, and ninety percent were British. In contrast with this case, where reported, the relationship between victim and perpetrator was predominately partner/ex-partner; for only thirty-three percent was the relationship described as familial and only three out of thirty-five victims were the child of the perpetrator.

11.4 Fifty-eight percent of the victims had at least one vulnerability. Vulnerabilities predominantly related to mental ill-health, problem alcohol use and illicit drug use; physical disability featured for less than ten percent of victims and learning disability was not specifically identified.

11.5 There are 1.5 million people with a learning disability in the UK: 870,00 of working age. People with a learning disability experience a range of inequalities; only 5.1% are in paid employment, compared to around 76% of the general population, and are twice as likely to be bullied. People with a learning disability experience worse health and are more likely to have a number of health conditions. Life expectancy for women is eighteen years shorter than women in the general population and they experience a range of barriers to good quality healthcare. These barriers include: a lack of accessible transport links, patients not being identified as having a learning disability, staff having little understanding about learning disability, failure to recognise that a person with a learning disability is unwell, failure to make a correct diagnosis, anxiety or a lack of confidence for people with a learning

[1] Annex_A_DHRs_Review_Report_2020-2021.pdf (publishing.service.gov.uk)

disability, lack of joint working from different care providers, not enough involvement allowed from carers and inadequate aftercare or follow-up care.[2]

11.6 In 2022, LeDeR received 3,362 notifications of deaths of adults aged 18 years or older, forty-two percent of which were deemed avoidable deaths. Fifty-five percent of these deaths were of a female with a learning disability and/or autism, seventeen percent were aged 25 to 49 years, and 90% were white. Deaths were more likely to be classified as avoidable with increasing age, peaking in the 25-49 age group before decreasing again for those who died over the age of 65 years. Fifty-seven percent of deaths occurred in hospital, compared to forty-five percent for the general population. The median age of death for people with a learning disability in 2022 was 62.9.[3]

11.7 The annual LeDeR review suggested that appropriate care was associated with reductions in premature death. For example, care packages that meet a person's needs and have an appropriate use of Deprivation of Liberty safeguards to deliver care are associated with a reduced risk of a premature death. In addition, appropriate treatment and prevention was associated with a reduction in premature deaths.

11.8 Jessica was also reliant on agencies making reasonable adjustments to maximise her access to their services and to ensure Jessica's inclusion and participation.

11.9 Specialism in learning disability was represented on the panel by the Learning Disability/Transition & Autism Team, the Learning Disability & Autism Practitioner from North West Ambulance Service, and CNTW. The chair also bought knowledge and experience of working with people with a learning disability and their carers. Jessica was also represented by an advocate from Victim Support.

11.10 Jessica's parents were in their eighties. Both had health issues and her mother had social care needs which were being met through provision of home care. Both parents were informal carers. Jessica's father had a hearing impairment.

11.11 In relation to perpetrators, Home Office analysis shows that the average age was 39, the youngest being 14 and the oldest 88 years of age. Eighty-nine percent of perpetrators were male, and ten percent were female. Sixty-eight percent of perpetrators had at least one vulnerability and eleven percent were carers, although none were recorded as having received a Carer's Assessment under the Care Act 2014.[4]

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[2] Learning Disability Research and Statistics | Mencap

[3] LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People. kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf

[4] Annex_A_DHRs_Review_Report_2020-2021.pdf (publishing.service.gov.uk)

11.12 Equality and diversity is addressed further in the analysis in terms of decision making, communication and information sharing.

12. Dissemination

12.1 In accordance with Home Office guidance all agencies are aware that the final Overview Report will be published. IMR reports will not be made publicly available. Although key issues if identified will be shared with specific organisations the Overview Report will not be disseminated until clearance has been received from the Home Office Quality Assurance Group.

12.2 The content of the Overview Report has been suitably anonymised to protect the identity of the female who died and relevant family members. The Overview Report will be produced in a format that is suitable for publication with any suggested redactions before publication.

13. Background Information (The Facts)

13.1 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, Jessica often refused to have her weight measured.

13.2 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.

14. Chronology

Background History

14.1 Jessica had a terminal ileostomy[5] after a total colectomy[6] 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.

14.2 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.

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[5] 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.

[6] 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.

14.3 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.

14.4 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.

14.5 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.

14.6 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.

Combined Narrative Chronology

14.7 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.

14.8 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.

14.9 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.

14.10 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[7] 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.

14.11 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.

14.12 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.

14.13 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.

14.14 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.

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

14.16 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.

[7] 30 minute call, twice a day, seven days a week

14.17 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.

14.18 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.

14.19 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.

14.20 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.

14.21 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.

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

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

14.24 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.

14.25 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.

14.26 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.

14.27 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.

14.28 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.

14.29 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.

14.30 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.

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

14.32 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.

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

14.34 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.

14.35 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.

14.36 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.

14.37 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.

14.38 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.

14.39 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.

14.40 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.

14.41 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.

14.42 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.

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

14.44 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.

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

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

14.47 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[8]. Jessica's weight loss was noted and that no weight had been recorded since December 2020.

14.48 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.

14.49 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".

14.50 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.

14.51 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.

14.52 On the 14th May West Cumberland Infirmary requested a transfer to Cumberland Infirmary in Carlisle (CIC). Jessica had been reviewed and it was

[8] '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)

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.

14.53 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.

14.54 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.

14.55 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.

14.56 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.

14.57 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.

14.58 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[9] 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.

14.59 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[10], and her bowel was found to be obstructed. Her father had been updated and planned to visit.

14.60 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.

14.61 A few days later, 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.

15. Overview

15.1. The overview summarises what information was known to the agencies and professionals involved about the victim and the perpetrator.

[9] An examination of the abdominal organs using surgical methods to determine the reason of pain or other complications of the pelvic region or abdomen.

[10] Laparotomy is a surgical procedure that involves a surgeon making one large incision in the abdomen. Doctors use laparotomy to look inside the abdominal cavity to diagnose or treat abdominal health conditions.

Overview of Involvement with Adult Social Care

15.2. Jessica was first referred to the Learning Disability/Transition and Autism Team, Adult Social Care (Cumbria County Council) at the age of sixteen as a young person in transition from children's services.

15.3. The overview of Jessica was that she was a woman who could express her own opinions and could be non-compliant at times, with some understanding of basic decision making, but was deemed to lack capacity around more complex decisions relating to weighing up her care and support needs, where to reside and the underlying complexities of the dynamic in living with her parents.

15.4. From the point of referral until Jessica's death, the Adult Social Care had focused on maintaining Jessica's safety at home with her parents and the risks appertaining to this. Alternative accommodation was explored for Jessica but was ultimately not pursued by her and her family, although there was provision for 21 nights respite care in her care plan.

15.5. Jessica's parents periodically presented as being unable to cope with their caring role and some there were some concerns relating to parents' non-compliance with services. Safeguarding concerns had been raised in 2014 and 2016 alleging that Jessica's father had hit her and that her mother had been abusing her, however no such concerns were raised during the scoping period.

15.6. As a statutory agency, Adult Social Care undertook four Care Act 2014 assessments (May 2017; August 2018; June 2019 and November 2019). In addition, Adult Social Care had responded to their statutory responsibilities relating to safeguarding adults'. A safeguarding concern was raised on the 19th May 2021 relating to self-neglect and concerns that family had restricted the decision to carry out urgent surgery for Jessica. The decision was taken to address via case management.

Overview of Involvement with Primary Care, North Cumbria Integrated Care Board

15.7. Jessica was registered with Practice 1 for general medical services, was identified on the Learning Disability register and thus eligible for annual health checks.

15.8. The GP analysed test results and took the necessary action in response, including a referral for a blood transfusion.

15.9. The GP made home visits where appropriate and maintained contact with Jessica's family.

15.10. There was an assumption by primary care that the specialist services were the lead agency in Jessica's care and treatment and were unclear about the

professionals involved once Jessica was discharged from Cumbria, Northumberland Tyne and Wear NHS Foundation Trust (CNTW).

Overview of Involvement with Cumbria, Northumberland Tyne and Wear NHS Foundation Trust

15.11. Jessica was referred by her GP to CNTW Community Mental Health and Recovery Team in December 2017 for assessment and continued support for her mental health. The referral detailed that Jessica had experienced a significant amount of weight loss and low mood and anorexia nervosa was suggested.

15.12. At assessment by a Consultant Psychiatrist and psychiatric nurse, anorexia nervosa was excluded but it was identified that Jessica was suffering from low mood and referral to Adult Learning Disability Services was indicated. Due to the apparent complexity of needs of the family network, referral was then made to Adult Social Care and Dietetics services.

15.13. The Learning Disability team's focus was to continue to monitor and treat Jessica's low mood and support her to access physical health services to address her malnourishment and to support the family network. The agency identified in 2018 that the parents were struggling to cope. In September 2018, Jessica was reported to be neglecting her physical health, remaining in bed for prolonged periods and refusing to shower, her parents were unable to support her to carry out her activities of daily living.

15.14. Practitioners found engagement with the family challenging at times. Jessica's parents declined and postponed support on occasion and on initial referral in January and February 2017, they reported feeling overwhelmed with the number of professionals offering appointments and assistance. With persistent follow up, Jessica's parents acknowledged that additional support would be helpful.

15.15. Jessica was discharged from the service in November 2021 in the absence of any ongoing mental health issue.

Overview of Involvement with North Cumbria Integrated Care (NCIC) NHS Foundation Trust

15.16. Jessica was open to the NCIC Community Teams, including Copeland Community Services, Dietetics Department and also spent time as an inpatient at both the West Cumberland Hospital and the Cumberland Infirmary.

15.17. A new referral was made to dietetics in June 2020 with regards to weight-loss, but the family declined the service and so Jessica was discharged.

15.18. Jessica received monthly home visits from community nurses to undertake blood tests. The blood samples were for Urea and Electrolytes and a Full Blood Count and Ferretin. The community nurses were also tasked with monthly weight monitoring however, Jessica almost always declined to be weighed.

15.19. The community nurses found the parents obstructive and on occasions Jessica's father was rude and would be critical when community nurses were unable to take blood.

15.20. In May 2021 Jessica was admitted to the West Cumberland Hospital and then transferred to Cumberland Infirmary Carlisle.

Overview of Involvement with North West Ambulance Service

15.21. North West Ambulance Service (NWAS) provides emergency pre-hospital care and transport to communities within the North West region. The organisation further provides medical assessment and triage via the 111 service.

15.22. NWAS provided pre-hospital emergency care to Jessica during times of need and were aware of Jessica's complex medical history and learning disability.

15.23. It was concluded on a number of occasions that Jessica lacked capacity around the decision for the healthcare plan advised and best interest decisions were taken, keeping Jessica informed and consulting with her father who identified himself as her main carer. Jessica's capacity to consent to treatment was assessed during each individual contact and her own wishes and needs taken into consideration whilst balancing the most appropriate outcome for her at that time.

15.24. NWAS identified carer stress in Jessica's father. During interactions with her father, he was open and honest and did not make any decisions on Jessica's behalf. He became frustrated on one occasion during a phone call.

Overview of Involvement with Cumbria Constabulary

15.25. Police had been called to the property several times over the years by neighbours for welfare check reasons, and on one occasion for an allegation of domestic assault which was unconfirmed and therefore no further action was taken.

15.26. Police were not aware of Jessica's weight loss; however, police only attended the family's home address on one occasion during the scoping period. On this occasion Jessica was in bed and not physically seen. Police had not seen Jessica since 2019.

Overview of Involvement with Jem care

15.27. Jem care are a home care agency who provided home care services to Jessica's mother.

15.28. Jem care had no role with regards to Jessica and reported that they rarely saw Jessica; she was often in bed or under the covers in her mother's bed.

15.29. Jem cares were not aware of the contingency plan in place, which involved a transfer of the home care from Jessica's mother to Jessica when her mother was admitted to hospital. However, when the need arose, they were willing and able to fulfil the plan. However, Jessica's father chased the carers from the property and told them not to come back and therefore Jem care did not provide the intended support during the two week period Jessica's mother was in hospital. They resumed care once she was discharged.

16. Analysis

16.1 The analysis will address the terms of reference and the key lines of enquiry within them. In doing so it will examine how and why events occurred, information that was shared, the decisions that were made, and the actions that were taken or not taken. It will consider whether different decisions or actions may have led to a different course of events. It will also highlight examples of good practice.

Mental Capacity

16.2 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[11].

16.3 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[12], 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.

16.4 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

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

[12] 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).

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.[13]

16.5 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.

16.6 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[14]. 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.

16.7 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.

16.8 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.

16.9 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.

[13] 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.

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

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.

16.10 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

16.11 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.

16.12 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 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.

16.13 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.

16.14 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.

16.15 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."[15]

16.16 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.
- 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[16]

16.17 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

[15] Controlling_or_coercive_behaviour_-_statutory_guidance.pdf (publishing.service.gov.uk)
[16] n8

'serious effect' on the victim[17] 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[18]

16.18 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.

16.19 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. In addition, the use of non-statutory agencies and community based approaches should be considered as they may be more effective in engaging with isolated families.

Risk assessment & Care Planning

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

[17] '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,

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

16.21 When Jessica was weighed on the 29th April 2021 a MUST score of 4 was calculated[19]. 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.

16.22 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.

16.23 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

16.24 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.

16.25 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

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[19] '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)

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.

16.26 Communication with Jessica's father was compromised by his hearing impairment, he required face to face interaction to maximise his ability to communicate and understand information. This subsequently affected his ability to navigate the health service and understand what was happening to Jessica following her admission to hospital.

16.27 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.

16.28 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.

16.29 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.

16.30 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

16.31 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.

16.32 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.

16.33 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

16.34 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.

16.35 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[20].

16.36 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

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

when appropriate, which also demonstrated a reasonable adjustment based on an understanding of Jessica's needs and the dynamics of the family.

16.37 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.

16.38 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.[21]

17. Conclusions

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

17.2 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.

17.3 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.

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

17.4 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.

17.5 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.

17.6 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.

17.7 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.

18. Lessons Identified

The lessons drawn from this case are summarised below along with how those lessons should be translated into recommendations for action.
Early learning identified during the review process, and whether this has already been acted upon, is also highlighted.

- 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.

- 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.

- 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.

- 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.

- 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.

  In response to previous DHRs, the ambulance service have already developed and delivered Level 3 safeguarding training to their clinicians. The service also undertakes 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.

- 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.

- 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.

19. Recommendations

19.1 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, as such they are provided in Appendix 1. 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.

The following organisations made specific recommendations for their agency:

North Cumbria Integrated Care Board

- Strengthen the knowledge and application around the Mental Capacity Act 2005
- Highlight the offer of external safeguarding supervision.
- Ensure that all complex cases of patients with a learning disability are brought to the attention of the practice learning disability nurse.

Appendix 1

Safeguarding Adult Review Recommendations

- Cumbria Safeguarding Adults Board to survey practitioners on the application of the Mental Capacity Act 2005, exploring challenges in practice.

- Cumbria Safeguarding Adults Board to use the findings of the above survey to inform the Mental Capacity 'week of action'.

- Cumbria Safeguarding Adults Board to seek assurances that agencies are aware of the role and types of advocacy, and the circumstances in which a person is entitled to advocacy support.

- Cumbria Safeguarding Adults Board to seek assurances that health professionals understand the importance of Hospital Passports and know to ask for them.

- Cumbria Safeguarding Adults Board to raise awareness with agencies of the need to offer a further carer's assessment to a family carer on an annual basis, or when needs and/or circumstances of the carer, or cared for person, change.

- Cumbria Safeguarding Adults Board to seek assurances from all relevant providers within the agencies in Cumbria that weighing, and management of underweight adults is supported by guidance, which aims to cover recognition of malnutrition; management of nutrition and diet; referral to specialist services and multi-agency coordination.

- Cumbria Safeguarding Adults Board to seek assurance from partners of effective care co-ordination for adults with a learning disability and complex health needs.

- Cumbria Safeguarding Adults Board to seek assurances that health agencies are aware of their role in Deprivation of Liberty Safeguards and that they are preparing for the implementation of the Liberty Protection Safeguards.

- Cumbria Safeguarding Adults Board to seek assurances that agencies creating contingency plans do so in a multi-agency forum and that the plans detail: the agencies involved and contact details, a detailed plan and arrangements for review, identified risks and risk management, and the process for escalation.

Appendix 2

Glossary

Advocacy – Advocacy helps people to be listened to and to have their rights and choices respected. Advocates work alongside individuals and are on that person's side. There are many different types of advocacy, both statutory and non-statutory, which all follow the same key principles including independence, empowerment, equality and accessibility. Advocacy helps individuals understand what is happening, access services and challenge when things don't go the way they want them to. In Cumbria advocacy is provided by People First. Advocacy (cumbriasab.org.uk)

Anaemia – Anaemia is a condition where there are not enough red blood cells or haemoglobin to meet the body's needs. Red blood cells use haemoglobin to carry oxygen around the body. A common type of anaemia is iron-deficiency anaemia where there is not enough vitamin B12 or folate in a person's diet. This can happen if the person has a poor diet.

Carer's Assessment – Under the Care Act 2014 if a person cares for someone else and appears to have needs of their own, they are entitled to have an assessment to see what might help make their life easier. The assessment might recommend things like someone to take over caring so the carer can take a break; help with gardening and housework; training; connecting the carer with local support groups; advice about benefits for carers.

Court of Protection – The Court of Protection make decisions on financial, or welfare matters for people who can't make decisions at the time they need to be made (they 'lack mental capacity'). They are responsible for:

- deciding whether someone has the mental capacity to make a particular decision for themselves.
- appointing deputies to make ongoing decisions for people who lack mental capacity.
- giving people permission to make one-off decisions on behalf of someone else who lacks mental capacity.
- handling urgent or emergency applications where a decision must be made on behalf of someone else without delay.
- making decisions about a lasting power of attorney or enduring power of attorney and considering any objections to their registration
- considering applications to make statutory wills or gifts.
- making decisions about when someone can be deprived of their liberty under the Mental Capacity Act

Also see Court of Protection - GOV.UK (www.gov.uk)

Deprivation of Liberty Safeguards - The Deprivation of Liberty Safeguards is the procedure prescribed in law (Mental Capacity Act 2005) when it is necessary to deprive of the liberty of a resident or patient who lacks capacity to consent to their care and treatment in order

to keep them safe from harm. It only currently applies to those deprived of their liberty in a care home or hospital.

Guardianship – The provision for Guardianship is provided by sections 7-10 of the Mental Health Act 1983. An Approved Mental Health Practitioner (AMHP) or the person's nearest relative can apply for guardianship if the person is putting their own health at risk or if they are a danger to themselves or others. An AMHP cannot apply for a guardianship order if the person's nearest relative does not agree to it. The person's local authority is usually named as their guardian, or occasionally a friend or relative of the person may be appointed as the guardian. A guardianship order will last for six months to begin with. After this it may be renewed for another six months and then for a year at a time. A guardian has three powers: to decide where the person lives, to require the person to go to specific places for medical treatment, work, education or training (but they can't use force to take the person there), to demand that a doctor, an AMHP or another specified person is able to visit the person where they live.

Hospital passport – The aim of the hospital passport is to assist people with learning disabilities to provide hospital staff with important information about them and their health when they are admitted to hospital. The hospital passport can be completed and kept at home in case of an emergency admission, deterioration in the individual's health or can be completed prior to a planned admission when it may also be used to aid assessment and planning.

Hyperthyroidism – The over production of hormones by the thyroid gland located at the front of neck. It causes rapid heartbeat, sudden weight loss, tremor, difficulty sleeping and changes in menstrual cycle.

Ileostomy – An ileostomy is an opening in the abdominal wall that's made during surgery. It's usually needed because a problem is causing the ileum to not work properly, or a disease is affecting that part of the colon and it needs to be removed.

Laparoscopy – Laparoscopy is an operation performed in the abdomen or pelvis using small incisions (usually 0.5–1.5 cm) with the aid of a camera. The laparoscope aids diagnosis or therapeutic interventions with a few small cuts in the abdomen.

Laparotomy – A laparotomy is a surgical procedure involving a surgical incision through the abdominal wall to gain access into the abdominal cavity.

Lasting Power of Attorney – Is a legal document where one person (the donor) gives another person the right to make decisions on their behalf. A Power of Attorney can only be set up while the donor has mental capacity to make that decision. An LPA has to be registered with the Office of the Public Guardian. Once registered, it can be used immediately, with the donor's permission if they still have capacity, or it can take effect from when the donor loses mental capacity. There are two types: Property and Finance - gives the attorney the power to make decisions about money and property; Health and Welfare - gives the attorney

the power to make decisions about medical care, moving into a care home, life-sustaining medical treatment and so on.

Levothyroxine – Levothyroxine is a thyroid medicine that replaces a hormone normally produced by the thyroid gland to regulate the body's energy and metabolism. Levothyroxine is used to treat hypothyroidism (low thyroid hormone). This medicine is given when the thyroid does not produce enough of this hormone on its own. One common side effect is weight loss.

Liberty Protection Safeguards – The Liberty Protection Safeguards will replace the Deprivation of Liberty Safeguards (DoLS) system. The Liberty Protection Safeguards will provide protection for people aged 16 and above who are or who need to be deprived of their liberty in order to enable their care or treatment and lack the mental capacity to consent to their arrangements. People who might have a Liberty Protection Safeguards authorisation include those with dementia, autism and learning disabilities who lack the relevant capacity.

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).

Nasogastric tube – 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. It can also be used to remove liquids or air from the stomach.

Office of the Public Guardian – Office of the Public Guardian (OPG) helps people in England and Wales to stay in control of decisions about their health and finance and make important decisions for others who cannot decide for themselves. The OPG is responsible for:

- taking action where there are concerns about an attorney, deputy or guardian.
- registering lasting and enduring powers of attorney, so that people can choose who they want to make decisions for them.
- maintaining the registers of attorneys, deputies and guardians
- supervising deputies and guardians appointed by the courts, and making sure they carry out their legal duties.
- looking into reports of abuse against registered attorneys, deputies or guardians

Thyroid stimulating hormone (TSH) – Thyroid stimulating hormone (TSH) is a hormone that's produced by the pituitary gland in the brain for the single purpose of sending a message to the thyroid gland. The pituitary gland constantly monitors blood for levels of thyroid hormones, and if it detects too little, it releases TSH.

Ulcerative colitis - Ulcerative colitis is a long-term condition where the colon and rectum become inflamed. If medicines are not effective at controlling symptoms or quality of life is significantly affected, surgery to remove some or all of the bowel (colon) may be an option. During surgery, the small intestine can be diverted out of an opening in the abdomen known as a stoma. This type of surgery is known as an ileostomy.