Salford Safeguarding Adults Board

Safeguarding Adult Review
Jayne
2022

Salford Safeguarding Adults Board (SSAB)
Approved the report
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Independent Reviewer
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1. Brief Summary of Circumstances resulting in the Review

1.1. This Safeguarding Adult Review (SAR) was commissioned following the agreement of the Salford Safeguarding Adult Review Panel (supported by the Joint Independent Chairs) and in accordance with the SAR policy/procedures and the Care Act 2014.

1.2. The criteria for this review were met as a female (hereafter known as Jayne to ensure confidentiality) was an adult with needs for care and support, who sadly died on the 26th of March 2021, age 49 years. And there is reasonable cause for concern about how professionals worked together to safeguard her.

1.3. Prior to her passing, Jayne had complex health needs. She lived with her mother who, towards the latter stages of her life became her main carer, and she had support from services within the community and the acute setting.

2. Safeguarding Adult Review Process

2.1. Methodology

2.1.1.Allison Sandiford[1] was appointed as the independent reviewer.

2.1.2.The independent reviewer and the SSAB would like to offer their condolences to Jayne's family.

2.1.3.A multi-agency review panel consisting of representation from the agencies involved[2] was established, and the panel met[3] on the 4th of February 2022 to discuss terms of reference, chronology timelines, the practitioner's reflective sessions, the learning event, and an expected date of completion.

2.1.4.It was agreed by the panel members that the review would follow a question-based learning format in place of traditional recommendations. The questions developed during this Safeguarding Adult Review process will drive SSAB and its partner agencies to develop an action plan that will respond directly to the identified learning.

2.1.5.The panel further met on the following dates to monitor the SAR process and discuss learning:

- 24th of March 2022
- 15th of June 2022
- 4th of August 2022

2.1.6.It was decided that the review ought to explore the following key lines of enquiry:

- Was Jayne's mum recognised as a carer – what support was offered to support her in the caring role, was there any recognition that she may have been an adult with her own needs and a carer who was experiencing stress.
- Potential concerns regarding domestic abuse within the home environment
- How did partners work together?
- How were safeguarding concerns managed?
- Did the Home Care provision provide a person centred, strengths-based approach?
- What impact did Covid have on how support and services were provided to Jayne and her mother?
- Throughout the period of review, there was a large amount of Government Guidance being released which impacted on how services were delivered. The review needs to ensure the guidance is referenced throughout the report.

[1] Allison Sandiford is an experienced reviewer of children's, adults', and domestic homicide reviews. She has a legal background and has gained safeguarding experience whilst working various roles for Greater Manchester Police.

[2] SSAB, Greater Manchester Police, Adult Social Care, Northern Care Alliance Salford Royal NHS Foundation Trust, Greater Manchester Mental Health Trust, Salford Clinical Commissioning Group, Community Safeguarding Partnership, Salford City Council, Salford Legal services, Community District Nurse Services, Intermediate Care Services, Tissue Viability Service, Diabetic Service, Premier Care, Gaddum Carers Centre.

[3] Covid precautions necessitated that panel meetings and the learning event be virtually attended. As such they convened using Microsoft Teams.

- Application and understanding of Making Safeguarding Personal – was Jayne's voice heard throughout all interactions?
- Explore how risks were assessed, managed and what safeguarding plans were in place.

2.1.7.The reviewer, whilst ensuring that a streamlined, proportionate approach to reviewing and learning would be taken, sought to engage as many frontline workers and their managers with the review process as possible to consider why actions and decisions had been taken.

2.1.8.A practitioner reflective session was held on the 5th of May 2022 and was attended by a variety of professionals from:

- Northern Care Alliance NHS Foundation Trust (District Nurses, Urgent Care Team, and Dietician),
- Adult Social Care
- Hospital Discharge Team
- Greater Manchester Police, and
- The SSAB

2.1.9.To accommodate the professionals unable to attend the first reflective session, a mop up session was held on the 18th of May 2022 and was attended by professionals from:

- Adult Social Care
- Salford Clinical Commissioning Group, and
- Northern Care Alliance NHS Foundation Trust (Urgent Care Team, Ward Manager), and
- The SSAB

2.1.10.Additional communications between the independent author and professionals[4] who were either unable to attend either reflective session or had minimal involvement in the care around Jayne, helped to clarify practice and shape the learning.

2.1.11.Professionals have generated positive discussion around areas of practice that could be developed and improved and have also highlighted much good practice. This feedback has formed the basis of this report.

2.1.12.Upon completion of the review report and acceptance from the SSAB, a learning event will be held to share the wider learning from this SAR.

2.2. Time Period reviewed

2.2.1. The timeline for the review was agreed to be from the 7th of February 2020 until the 31st of March 2021.

2.3. Parallel Reviews and Processes

2.3.1. The following processes and reviews have been undertaken either prior to, or parallel with, the Safeguarding Adult Review:

2.3.2. Jayne's death was reported to the Coroner. The medical cause of death is reported as Sepsis caused by Pressure Ulceration, with a background of Diabetes, Obesity and Lymphoma being contributory factors. Her Majesty's Coroner opened an inquest which concluded that Jayne died of natural causes.

2.3.3.Following the pathologist becoming concerned that the level and stages of Jayne's pressure sores could indicate sign of wilful neglect, Greater Manchester Police commenced an enquiry to determine whether there was neglect by professionals. The investigation concluded that there was no evidence of a criminal act being committed and the case was filed.

[4] Domiciliary home care providers, North West Ambulance Service, St Ann's Hospice

2.4. Family Engagement

2.4.1.Family members of Jayne were notified in person of this review by the SSAB Business Manager and invited to participate. The subjective experiences of support and services provided to the deceased, from the point of view of family members, is an important aspect of the Safeguarding Adult Review process and the independent reviewer would like to thank Jayne's mother and sibling for agreeing to meet with her. Their invaluable contribution is woven into the body of the report.

2.4.2.To ensure confidentiality, Jayne's mother is to be referred to as Anita and Jayne's sibling as Anne.

3. Overview of the Key Episodes

Key episodes are periods of intervention that are deemed to be central to understanding the work undertaken around Jayne. The episodes do not form a complete history as they are key from a practice perspective and summarise the significant professional involvements that informed the review. Professionals at panel meetings and the reflective sessions explored the following key episodes.

Key Episodes	Date
Key Events Prior to, and at the Beginning of, the Scoping Period	Pre 30.5.2020
Jayne's Admission to, and Discharge from, Hospital	30.5.2020 – 14.9.20
On-going Care Provided to Jayne at Home	14.9.2020 – 24.2.2021
Jayne's Further Admission into Hospital	24.2.2021 – 26.3.2021

3.1. Key Events Prior to the Scoping Period

3.1.1. Jayne began to experience problems with her joints when she was at secondary school, and she was subsequently diagnosed with inflammatory arthritis.

3.1.2.As an adult, Jayne suffered a number of long-term medical conditions including type 2 diabetes, asthma, hypertension, high cholesterol, migraines, gastro-oesophageal reflux disease, severe osteoarthritis of weight bearing joints and sleep apnoea. In 2011 Jayne was successfully treated for large B cell lymphoma[5] in the floor of the mouth.

3.1.3.Despite her own problematic health, Jayne continued to support her mother, who she lived with, and they would shop together and enjoy hobbies such as needlecraft. In addition, Jayne enjoyed online gaming and would regularly connect with her nieces and nephews to play with them.

3.1.4. Jayne struggled with weight management but always remained mobile at her own pace and continued to holiday, be actively involved with her extended family, and enjoy life.

3.1.5.In March 2020, the United Kingdom was placed in lockdown due to the Covid pandemic. Jayne was told to shield by her GP.

3.2. Jayne's Admission to and Discharge from Hospital

3.2.1.On the 30th of May 2020 Jayne had been shopping with her mum but later in the evening found herself unable to get out of her chair. The following day paramedics attended and transported Jayne to the Accident and Emergency department at the hospital where they raised concerns about Jayne's living conditions to hospital staff.

3.2.2.Examination of Jayne uncovered excoriated pressure sores. These were dressed and concerns were raised for recurrent lymphoma. Jayne was admitted into the hospital.

[5] A cancer of the lymphatic system of the body involving immune cells. This causes swelling of lymph nodes in neck, armpit or groin, fever, night sweats, difficulty in breathing and weight loss.

3.2.3.Hospital staff submitted a safeguarding referral to Adult Social Care outlining unkempt home conditions. Upon receipt and upon learning that Jayne was an impatient at the hospital, a practitioner at the Adult Social Care Contact Team contacted the referrer and advised that Jayne be referred to the Hospital Social Work Team.

3.2.4.Following confirmed relapse of lymphoma, Jayne remained an inpatient of the hospital and embarked upon a course of chemotherapy.

3.2.5.Because of the Covid pandemic family members were unable to visit Jayne on the ward but Anne regularly took clean clothes and personal items into the hospital. The family communicated with Jayne by telephone and Facetime.

3.2.6. Jayne was declared medically fit for discharge on the 5th of August 2020. By this time Anne and her husband had deep cleaned the home address, replaced the kitchen, and the downstairs living area had been suitably adapted to meet Jayne's needs. However, hospital discharge was delayed due to problems obtaining a bariatric ambulance.

3.2.7.A discharge planning meeting did not convene on the ward as it was thought that the numerous communications that had been had between professionals who would be supporting Jayne at the home address was sufficient and a 'contact assessment' setting out the care and support needs for Jayne had been sent to a domiciliary care agency. In addition, this review has heard that a virtual meeting had taken place with family.

3.2.8. Jayne was discharged home on the 14th of September 2020. During a phone call with the integrated care team duty the following day, Jayne said she was doing okay and as a result she was placed on the waiting list for a review of her package of care in 2-4 weeks time.

3.3. On-going Care Provided to Jayne at Home

3.3.1.Within two days of Jayne returning home, the commissioned domiciliary provider contacted the Adult Social Care Duty Care team to raise concerns over Jayne's wounds and pain. The domiciliary provider was advised to request Jayne's GP carry out a home visit and was reminded that the district nurses would be visiting. The following day the domiciliary provider submitted a safeguarding concern to Adult Social Care to allege that the district nurses had not completed wound care with Jayne. (A subsequent section 42 enquiry found this to be unsubstantiated and no further action required.)

3.3.2.The domiciliary provider continued to have the same concerns and submitted a further referral to Adult Social Care on the 29th of September 2020.

3.3.3.The community tissue viability team visited the home address on the 30th of September 2020 to review Jayne and to conduct verification of wounds.

3.3.4.On the 1st of October 2020, the care provider withdrew their care - stating that they felt unable to meet Jayne's needs. The rapid response team[6] took over with the support of the urgent care team[7].

3.3.5. Jayne continued to be nursed in bed. Because of her immobility, obesity and sores, Jayne required the assistance of four staff to change her position. Despite their care, at the end of November 2020, a full skin inspection of Jayne conducted by the tissue viability nurse concluded that whilst some sores were showing signs of improvement, others were developing.

3.3.6.A new domiciliary care provider commenced care on the 30th of November 2020. To begin with the rapid response team continued to visit to support them as the new provider did not have the capacity to pick up all the calls with immediate effect.

[6] The Rapid Response Service is provided by a multi-disciplinary team of health and social care staff. The focus is on preventing avoidable admission to acute hospital or residential care.
[7] The urgent care team work to support people in their own homes who urgently need treatment and care.

3.3.7.During the time that Jayne's care needs were being met in the community, she experienced pain to such an extent that she was sometimes unable to accept professional care.

3.3.8.On the 31st of December 2020, a tissue viability nurse advised possible infection in the wounds and a topical antibiotic and antimicrobial wash was prescribed.

3.3.9.Throughout February 2021, Jayne's wounds deteriorated, and professionals suggested that Jayne needed to go in to hospital to optimise the management of the wounds and prevent sepsis and death. However, Jayne was adamant that she did not want to. Jayne said that she had a negative experience during her last admission and felt that the hospital was to blame for the development of her bed sores.

3.3.10.Attending Jayne's wounds at home became increasing difficult as she was suffering too much pain and nausea to engage with care and medical intervention.

3.3.11. On the 22nd of February 2021, Anne raised concerns with Adult Social Care about Anita's ability to manage Jayne's deteriorating condition after she learned of an incident whereby Anita had thrown a controller at Jayne's bed. The incident had been caught on camera. The social worker informed the police who commenced enquiries.

3.3.12.On the 24th of February 2021 Anne voiced concern to a district nurse at the address that Jayne was particularly drowsy. The district nurse advised Anne that the new medication could be the cause. When Anne next returned to the address later in the day, she was advised by a nurse that an ambulance should be called. Paramedics transported Jayne to the Accident and Emergency department at the hospital with a suspected infection.

3.4. Jayne's Further Admission into Hospital

3.4.1.Upon admittance Jayne was presenting as unwell, with low grade temperature and abdominal pain.

3.4.2.On the 25th of February 2021, Jayne was re-referred to Greater Manchester Mental Health and seen by a Consultant Psychiatrist who concluded that she had delirium. The Consultant advised that a Best Interest meeting and an Independent Mental Capacity Advocate be arranged.

3.4.3.An application was triaged for a Deprivation of Liberty Safeguard and added to the waiting list for allocation when a Best Interests Assessor was available.

3.4.4.Over the next few weeks Jayne's health showed signs of improvement, and despite Jayne having said that she specifically did not wish to go back there, she was moved to the ward on which she had previously been an inpatient.

3.4.5.Within a week following a deterioration to Jayne's health, family were invited to go on to the ward to see Jayne. From thereon Anne continued to visit daily to support Jayne with food and drink.

3.4.6.Sadly, on the 26th of March 2021, Jayne was found deceased in her hospital bed at 07:15 hours.

4. Thematic Analysis

The following practice areas have been identified[8] as containing practice and organisational learning for the SSAB:

- The Care and Support of Clinically Obese Immobile Patients.
- Hospital Discharge.
- Communication Between Professionals and Significant Others
- Consideration of the Whole Family
- Safeguarding Concerns / Professionals Meetings and Risk Assessment
- Home Care Provision

[8] They have been identified from: agency reports, professional consultation, family consultation, and panel consideration of the terms of reference alongside the key episodes.

- Making Safeguarding Personal
- Pain Management
- Mental Capacity
- The Effect of the Covid Pandemic
- Equality, Diversity and Human Rights

4.1. The Care and Support of Clinically Obese Immobile Patients.

4.1.1.This review has seen no record of Jayne's body mass index during the time Jayne was in hospital, but it is recorded on the 2nd of November 2020 to be 50.6. Currently NHS guidelines define a healthy weight as a body mass index of 18.5 up to 24.9. People who are overweight have a body mass index of 25 to 29.9 and a body mass index of thirty or above is considered obese. Extreme or severe obesity is defined as forty and above[9].

4.1.2. Jayne's family have told the review that Jayne had a propensity to gain weight from childhood and had always struggled with weight issues. Whilst it is acknowledged that given her enjoyment of take away food, it is likely that environmental issues contributed to her struggles, Jayne's weight would have been affected by many factors including genetics, age, gender and underlying medical conditions.

4.1.3.GP records evidence that Jayne was offered a referral to the weight management services in 2018 but declined, and there are records of diet discussions being had with Jayne in August 2019. The GP surgery has also reassured this review that it would have been usual practice for weight management to be discussed at Jayne's annual chronic disease reviews. However, obesity has complex origins and complicated solutions, and treating Jayne's weight concerns effectively would have required a professional gaining an understanding of the drivers that contributed to her weight and an understanding of her character. There is no evidence of Jayne ever developing a long-term and trusted relationship with a health care professional who could do this. Consequently, it was a reactive referral to the weight management services that Jayne was offered in 2018 and, by this time, Jayne was experiencing obesity[10]. This review has been informed that there are no proactive weight management services available in the NHS and that it is a requirement of the weight management service that a person be clinically obese with complications such as diabetes.

4.1.4. Jayne's family have advised this review that Jayne sometimes spoke of feeling how, because she was obese, no-one saw the person inside her body. Given that fat shaming remains a common form of ridicule prevalent on social media sites and within entertainment, it is understandable why Jayne may have felt such weight bias, and consequently how, even though professionals had not ever treated her any differently because of her weight, her own self-esteem may have been a barrier to her accepting support.

4.1.5.This theory gains credibility when consideration is had of how obesity is portrayed. In the policy paper[11], *Tackling Obesity: empowering adults and children to live healthier lives*, published in July 2020, the government reported that *obesity puts pressure on our health service,* and *we owe to the NHS to move towards a healthier weight.* The report also states that *tackling obesity would reduce pressure on doctors and nurses in the NHS, and free up their time to treat other sick and vulnerable patients.* Such language enforces the bias and stigma attached to obesity and suggests that weight management is an individual's responsibility and not something that should be depleting professional resources. Until this attitude changes systemically, professionals are left in a position where they must work hard to negate the stigma an obese person may feel to encourage individuals to feel able to engage with offers of support.

Question 1 for the SSAB:
How can the SSAB learn of the current challenges professionals face when attempting to support people experiencing obesity who are at risk of harm, and how can the SSAB and their partner agencies improve or develop practice which will encourage people in their area to engage with dietetic support?

[9] What is the body mass index (BMI)? - NHS (www.nhs.uk)
[10]This practice is pre the timescale of this review but relevant as weight management may have afforded Jayne better health and improved self esteem.
[11] Tackling obesity: empowering adults and children to live healthier lives - GOV.UK (www.gov.uk)

4.1.6. Jayne's discharge from the hospital was complicated by her weight. Bariatric transport was recognised to be necessary for discharge and a bariatric ambulance[12] was booked from the hospital to Jayne's home address on seven occasions as follows:

Date	Booking	Reason for non-transportation
5.8.20	Booked as a Bariatric.	Wrong mode of transport
5.8.20	Booked as a Bariatric.	Patient not ready.
6.8.20	Booked as a Bariatric.	Appointment no longer required
1.9.20	Booked as a Bariatric requiring a scoop and a 4xlift.	Wrong mode of transport.
3.9.20	Booked as a Bariatric requiring a bariatric scoop and 4xlift.	Unable to source private vehicle with the required equipment.
7.9.20	Booked as a Bariatric requiring a bariatric scoop and 4xlift.	Patient not ready.
9.9.20	Booked as a Bariatric requiring a bariatric scoop and 4xlift.	Discharge needed to be privately sourced

4.1.7. A risk assessment conducted by a member of North West Ambulance Service operational staff on the 5th of August 2020, deemed that the Patient Transport Service could not accommodate Jayne as Jayne would require a scoop stretcher and a 4-man lift[13]. The crew attended the property to assess whether there was any other way that they could get Jayne into the property without this equipment, but none was identified. Consequently, the specific bariatric transport required for Jayne was sourced elsewhere. As is evidenced in the above table – it was sometimes problematic to co-ordinate the availability of the transport with Jayne being ready for discharge.

4.1.8. Jayne's weight and mobility was also an issue in October 2020 when owing to difficulties in transporting Jayne to the hospital, she was discharged from haematology. As a result of the discharge, Jayne was unsure of the status of her cancer and on the 2nd of December 2020 she raised concerns with a social worker that she was outstanding a scan to assess whether her cancer was in remission. Jayne said that not knowing whether she was in remission was affecting her mental health.

4.1.9.This review has been unable to evidence whether any attempts were ever made to book bariatric transport for Jayne to facilitate her attending the haematology appointments. Panel members have suggested that given the amount of pain Jayne was experiencing, it may have been decided that transporting her to hospital for an appointment was not feasible.

Question 2 for the SSAB:
How can healthcare agencies assure the SSAB of improved management of the transportation of bariatric patients to and from hospital to support timely discharge and appointment attendance?

4.1.10.It was good practice that Adult Social Care recognised that Jayne's obesity and immobility would cause a problem should she have to be evacuated from the home in the case of an emergency and asked the fire service to contact Jayne. As a result, the fire service conducted a safe and well assessment over the telephone with Jayne.

4.1.11.Whilst it has been recognised that Jayne declined further intervention, this review asked why the fire service were not contacted to conduct a safe and well assessment in September 2020 when Jayne was discharged back to her home address. The answer being that during this period, the fire service had paused their assessments due to the Covid pandemic.

4.1.12. Jayne's weight was monitored by professionals during the scoping period of this review and Jayne was referred to the dietetic team when she was a patient on the haematology ward at the hospital. A dietetic nurse

[12] A bariatric ambulance is an ambulance vehicle modified to carry obese individuals. They carry bariatric stretchers and have specialised lifting equipment.
[13] The Patient Transport Service's specialised equipment was too wide for the doorframe at the home address.

contacted the ward by telephone (all patients were remotely assessed during Covid), and it was agreed that the ward could manage Jayne's nutritional needs and did not need dietetic input. The ward would re-refer as required.

4.1.13.A dietician at the reflective session confirmed that Jayne had a 17% weight loss during her first hospital admission but remarked that this weight loss may have been masked by fluid and may not have been immediately noticeable on Jayne. However, this weight loss may have been an indication of Jayne suffering malnutrition.

4.1.14.Malnutrition occurs due to an insufficient supply or an incorrect absorption of essential nutrients, which impairs the body's functions. Although Jayne was obese, she was still at risk of malnutrition, when she was hospitalised. The World Health Organization classifies malnutrition as the biggest threat to public health worldwide, and the condition is observed in 20–60% of hospitalised patients.

4.1.15.Screening Jayne to identify malnutrition was particularly important because there is clear evidence from a large number of studies that nutrition support significantly improves the outcomes for medical patients[14]. And as malnutrition affects the function and recovery of every organ system and the immune system, it could increase Jayne's risk of infection and delay wound healing.

4.1.16.Screening is undertaken using the Malnutrition Universal Screening Tool which is a five step nationally recognised screening tool to identify adults who are at risk of malnutrition. The initial steps of the Malnutrition Universal Screening Tool include obtaining the person's height, weight, and body mass index.

4.1.17.Significant and unintentional weight loss was identified for Jayne on two occasions; the first occasion was on the 21st of September 2020 when community dieticians conducted a telephone assessment[15]. As a result of this assessment the dietitian prescribed supplement drinks for Jayne and kept her under review[16].

4.1.18.The second occasion was when Jayne was in hospital and was, on the 4th of March 2021, re-referred to dietetics for dietary advice for wound healing and care of an obese patient. A dietician started Jayne on Ensure Compact Milkshakes[17] the following day. (These were later changed to chocolate Ensure Plus Milkshakes upon Jayne's request).

4.1.19.It is documented that following use of the Malnutrition Universal Screening Tool on the 8th of March 2021, evidencing a 28% weight loss in less than six months, dietetics met with the medical team to discuss the prospect of Nasogastric feeding. The medical team reported a few days later that Jayne had declined the intervention. (This is discussed further at paragraph 4.9.4 of the report.) On the 25th of March 2021, the sister on the ward rediscussed the possibility of Nasogastric feeding with the dietician as further weight loss had been noted. The dietician again discussed this with the medical team, but Jayne was now too unwell to tolerate a tube.

4.2. Hospital Discharge

4.2.1.Planning for a patient's discharge from hospital is a significant aspect of effective care. Jayne's hospital discharge was led by a patient pathway manager and a social worker based in the hospital. Jayne was discharged from the ward on the 14th of September 2020, but discharge planning had been ongoing for a period by means of consulting with the family and professionals to prepare and adapt the home address for Jayne's return.

4.2.2.The social worker had consulted with Anne to improve home conditions and adaptions had been made to a downstairs room to ensure that Jayne's needs could be met. Also, because it had been recognised that Anita had health care needs of her own, a referral had been made for Anita in her own right and as a result, Anita had been allocated her own social worker.

[14] Elia M, Russell CA, editors. on behalf of BAPEN and collaborators. *The 'MUST' Report. Nutritional screening for adults: a multidisciplinary responsibility. Development and use of the 'Malnutrition Universal Screening Tool' (MUST) for adults*. A report by the Malnutrition Advisory Group of the British Association for Parenteral and Enteral Nutrition, 2003.

[15] Neither Jayne's height nor weight could be measured when she was immobile at home, but estimated measurements were used. The scores recorded whilst Jayne was in the community are recorded as zero, meaning that Jayne was deemed to be at low risk of malnutrition.

[16] The community dieticians reviewed Jayne on the 2nd of November 2020 and again on the 20th of January 2021.

[17] Complete, high energy, high protein milkshakes designed for people suffering involuntary weight loss.

4.2.3. Jayne's ongoing care in the community post hospital discharge was complex as it involved the use of specialised equipment in the home, daily support from carers, and regular visits from nurses to administer care and medication. A discharge planning meeting did not convene on the ward because the social worker had been consulting with individual staff and agencies to ensure that the care was in place and had also had conversations with Jayne and with family members. Telephone conversations with family members were had with Anne, as Anita experiences poor hearing.

4.2.4.Professionals at the reflective sessions discussed how not having conversations with Anita directly about the care Jayne would require at home, inadvertently risked Anita not getting the information she needed. It also prevented communication from being a two-way process as it hampered Anita's opportunity to ask questions. Whilst it was agreed by Anita that Anne would relay the information to her, it is the responsibility of the practitioner to ensure clear communication with patients and significant others.

4.2.5.There is nothing to suggest that Jayne's discharge was unsafe but when the number of professionals involved in Jayne's care and the complexity of her situation (for example, previous safeguarding concerns, mother's own health needs, Jayne's weight management) is taken into consideration, the benefits of a thorough discharge planning meeting are appreciated.

4.2.6.Anita has told this review of the confusion she experienced regarding who was coming into her home to do what. Discussions established that a list of the professionals who were to be involved, along with their roles and contact numbers would have been helpful for the family and for Jayne. In addition, it would have been useful to have a key professional contact with whom conversations could have been had as any problems arose. Although providing such documentation is not current standard procedure, a discharge planning meeting would have afforded an opportunity to do this, and the provision of a contact list is something that could be considered in the future.

4.2.7.A discharge meeting would have also been a good opportunity to acknowledge any anxieties that Jayne or her family were experiencing and to establish, in the presence of all the professionals, how much care the family felt able to provide and how they wished to be included. It is particularly important for professionals working in the community to make the effort to build a rapport with a service-user and a service-user's carers, whose homes they are going to frequent - a discharge meeting would have provided introductions and conversations which may have paved the way for better relationships in the future.

4.2.8.In summary, although a safe discharge was had, a professional's discharge meeting would have provided an opportunity for multi disciplinary detailed discussions regarding the care and support being put in place, and an occasion to additionally consider the needs and any required support for Anita and Anne who were both significant to Jayne's care. Consideration could also have been had to facilitating a section 27[18] of the Care Act 2014 – review of care and support plan.

4.3. Communication Between Professionals, Jayne, and Significant Others

4.3.1.When Jayne was admitted to hospital in June 2020, family were not allowed to visit her due to the Covid-19 pandemic. This made communication between professionals and 'significant others' harder to have, as it removed opportunistic conversation and resulted in professional contact only being had on a pre-arranged basis.

4.3.2.Also owing to Covid, any meetings between family and professionals were conducted by video conference but this presented challenges for Anita given her hearing difficulties - mixed sound quality and background noise can make virtual meetings difficult to follow and, when there are many people, it is sometimes hard to tell who is speaking.

4.3.3.Possibly because of no face-to-face contact being had between family and professionals whilst Jayne was in hospital, both Anita and Anne have expressed their frustrations to this review regarding how they do not feel that

[18] This section requires the local authority to ensure the care and support plan (or support plan) remains an accurate, up-to-date reflection of the person's needs and the outcomes they wish to achieve

they were given enough information about the severity of Jayne's health condition upon hospital discharge. Both parties understand that Jayne had the right to ask that professionals did not share all her information with them, and recognise that this may have been the case, but expressed concern about their ability to care without having more understanding of the issues.

4.3.4.The second domiciliary care provider has confirmed that Jayne did not ever ask their staff to withhold any information from Anita and/or Anne, and there is nothing documented within the records of the hospital ward on which Jayne spent her final days to suggest that she had. However, some professionals who have contributed to this review were under the impression that Jayne had not consented to sharing her information. If this were the case, it was Jayne's right and whilst Jayne had mental capacity, her wishes could only be overridden in certain circumstances whereby not sharing the information would put herself, or others at risk of serious harm.

Question 3 for the SSAB:
How can the SSAB guide professionals from all agencies and organisations to ensure that all professionals supporting a person are clear about whether a person is consenting to their information being shared with loved ones, and understand concerns when consent may need to be overridden?

4.3.5.However, any reluctance on Jayne's behalf to share all her information with her family did not prevent professionals from being able to discuss general information about Jayne's condition with Anita and Anne. And professionals were still able to share information about Jayne's medication, treatment, and side effects as this was essential information about Jayne's care.

4.3.6.Opinion is divided between professionals and family as to whether this was done effectively - Anita and Anne have told this review that they advised professionals that they did not feel that they had enough information.

4.3.7.In January 2021, following concerns being raised from a carer about Jayne's deteriorating health, Anita's social worker suggested a meeting with Anne, Anita, Jayne's social worker and team managers to discuss family concerns and try and establish how best to help Jayne. Anne has said that despite her taking the opportunity at this meeting to raise her concerns about not knowing the true extent of Jayne's health, in hers and her mother's opinion nothing was resolved.

4.3.8.This meeting provided an opportunity for professionals to explain to Anita and Anne the level of information sharing that had been agreed with Jayne and to reconsider the facts that were already known. It would have been helpful to remind both Anita and Anne of the professionals involved in Jayne's care, explain their roles, provide contact details and to ensure that Anita knew who to contact with any concerns, worries or information. A lead professional could have been identified as a point of contact.

4.3.9.Besides offering Jayne and the family a single point of contact, a lead professional would have been useful to help Jayne and the family to navigate the number of different services involved in Jayne's support package

4.3.10. Jayne had been allocated a social worker on the 12th of October 2020 and this social worker was well placed to be the lead professional. However, the first visit to see Jayne in her home was not undertaken until the 26th of November 2020 and consequently, neither Jayne, or her family built a trusted relationship with the worker or was confident that she had a good enough knowledge of Jayne's circumstances. In the absence of a trusted relationship having been established, family favoured Anita's social worker for support.

4.3.11.This review has established that the delay in Jayne's Social Worker visiting her at home was in line with the Covid policy at the time, which instructed that face-to-face assessment was only undertaken in an emergency. Jayne's social worker had contacted Jayne by telephone at the end of October 2020 and had been liaising with district nurses and other professionals prior to the visit in November, to ensure that support was in place.

4.3.12.When Jayne was admitted to hospital in February 2021, professional communication with family reverted to telephone conversations with Anne because of Anita's aforementioned hearing difficulties.

4.3.13.Still unable to visit her sister in hospital due to Covid, Anne contacted the hospital several times a day to enquire about Jayne's wellbeing. Anne has said that the staff were persistently vague about Jayne's condition and would only tell her that Jayne was 'settled'. Anne has said that she was constantly promised by ward clerks that a nurse or doctor would get in touch with her to discuss Jayne and her condition, but this didn't happen until, approximately two weeks after Jayne had been admitted when Anne was contacted by a nurse who said that she was concerned by Jayne's deterioration and that Anita and Anne should come and visit.

4.3.14.Throughout this time Jayne had not answered her personal mobile phone or responded to family texts and it was only at this visit that the family discovered that Jayne's phone was out of her reach and uncharged. This was a huge concern for the family as not only had they been struggling to get any information from professionals, but they also now realised that Jayne had not been in a position herself to pass any information.

4.3.15.Upon visiting Jayne, Anne became genuinely concerned for the care that Jayne was receiving as she felt that Jayne was not in receipt of adequate support with her food, hygiene, and basic care needs. Anne recalls a telephone conversation she had with a member of staff at the hospital during which she expressed some of her concerns, but Anne has said that overall, she was reluctant to complain in case the care afforded to Jayne deteriorated as a result. In particular, Anne was concerned that if she complained, her permission to visit Jayne could be withdrawn.

4.3.16.In 2013, the Care Quality Commission commissioned the ICM[19] Government and Social Research team to undertake research into the fear of raising concerns about care[20]. Their report echoes Anne's sentiment - it found that the main barrier to making a complaint was not wanting to be seen as a trouble maker (26% of people said that was the main factor that would prevent them from making a complaint). In addition, 11% of people said that the single main reason they would not complain was worry that care would get worse as a result. Enablers to complaints were found to be anonymity and having an advocate or third party.

4.3.17.This review has been informed that patients used to be given admission leaflets which included helpline numbers and details of the Patient Advice and Liaison Service (this service can give you information on the NHS complaints procedure and how to get independent help if you wish to make a complaint). These admission leaflets were stopped during Covid but the helpline information and the process to contact the Patient Advice and Liaison Service was displayed for patients in the hospital. Patients and relatives are encouraged to discuss any concerns with the ward manger/matron first.

4.3.18.It is recognised that, at this time Jayne was very poorly and therefore likely unable to raise concerns for herself, but Jayne had also previously voiced concerns about her care in hospital. Following a safeguarding concern being raised by the first domiciliary care provider regarding wound care afforded by the district nurses, a Section 42 enquiry was completed. Within the enquiry, Adult Social Care visited Jayne to obtain her views. Jayne said she had no concerns with the district nurses but did raise concerns about the care she had received whilst an inpatient at the hospital. It is documented that she did not wish to take any action or have any issues raised on her behalf, but her reasons remain unknown.

4.3.19.In March 2021, a doctor from the hospital requested that family attend a meeting. This is the only meeting that family had with professionals during Jayne's five week stay at the hospital and this convened the day prior to her passing. Family consider that this meeting was 'too little too late' and would have appreciated being involved more in Jayne's care.

4.3.20.Research has shown that healthcare professional and family collaboration in acute care settings leads to positive outcomes of recovery and satisfaction with care[21]. This real collaboration between families and healthcare professionals is known as 'relational practice' and requires healthcare professionals to consistently work with families and to acknowledge that family members hold the expertise on their loved one.

[19] When ICM was initially established the initialism represented 'Independent Communications and Marketing'. However the full name was never used in practice.
[20] 201304_fear_of_raising_complaints_icm_care_research_report_final.pdf (cqc.org.uk)
[21] Real-time patient experience surveys of hospitalized medical patients - PubMed (nih.gov)

4.3.21.Considering the positive outcomes of family and healthcare collaboration in reviewed studies, a scoping review[22] published in 2022 has recommended ongoing training and education to capacitate healthcare professionals to work relationally. Consequently promoting relational practice with families.

Question 4 for the SSAB:
How can the SSAB be reassured that partner agencies are working and developing their collaboration with a service users' family, and within that practice, supporting individuals to raise concerns about either their own or another's care?

4.4. Consideration of the Whole Family

4.4.1.It was clear that given Jayne's immobility, Jayne would be dependant on her family for much of her care. For this reason, it was important that practitioners explored how Jayne's health and her required care, could impact the whole family.

4.4.2.The SSAB hosts a seven-minute briefing summarising carers and the support available[23] on their website. It advises professionals how they can request a carer's assessment using an online portal or by contacting Gaddum. Gaddum is a service available to young people and adults in Salford who identify as being a carer.

4.4.3.Adult Social Care case notes evidence that a referral was made to the Gaddum centre on the 22nd of July 2020 for Anita. A call was made to Anita the following day to discuss any support needed. Due to her hearing difficulties, Anita passed the phone to Anne and a zoom call was arranged for the 4th of August. Following the initial zoom meeting, a needs assessment took place and Anita was later, on the day that Jayne was discharged home from hospital, offered a carer's assessment. Case notes state that Anita declined and said that no further support was needed. This is disputed by Anita who does not recall being offered a carer's assessment and has said that she would have liked to have known what support, if any, was available to her.

4.4.4.On the 8th of October 2020, a carer's assessment was completed with Anne as it had become apparent that she was caring for both her sister and her mother. The outcome was the provision of a personal budget to help Anne to purchase a Nintendo Switch which would enable her to play games with Jayne, and to use the exercising game to improve her own health.

4.4.5.There is no evidence of either Anne or Anita being offered or requesting further assessment under the Care Act 2014 as Jayne's health deteriorated. Anne has informed this review that had she wanted further advice or assessment she would have approached her mother's social worker.

4.4.6.On the 8th of June 2022, the SSAB held a Bite Size briefing on Carers which was presented by staff from the Gaddum Carer's Service. Unfortunately, only forty-two professionals attended which was a much lower figure than expected. Upon investigation it was established that the SSAB mailing list was not up to date and did not reflect a change of email addresses for all Northern Care Alliance staff. Upon identification of this error, and in in attempt to circulate the briefing wider, a recording of the briefing has been sent to Adult Social Care, Northern Care Alliance (Health) and the Clinical Commissioning Group with a request that it be circulated and promoted to their respective workforces including GPs.

4.4.7.To compliment, or in any absence of, any direct professional advice for carers, information[24] is available to the public on the Gaddum website, Salford Council website and the SSAB website. This is supportive but who can access this information is dependant upon the availability of the internet to a prospective carer and his or her ability to search for information.

[22] In-hospital interventions to promote relational practice with families in acute care settings: A scoping review - PMC (nih.gov)
[23] 7-min-briefing-carers-mar-2022.pdf (salford.gov.uk)
[24] Information for Carers | Salford Safeguarding Adults Board

4.4.8.The SSAB has run a report using Google Analytics to the carers page on their website and has recognised that the figures are extremely low in comparison to other pages on their website. For the period of the 1st of October 2020 until the 30th of September 2021, which encompasses the time that Anita was caring for Jayne, the page had eighty-two visitors.

4.4.9.Web statistics evidence that the Salford Council and Gaddum webpages for carers have stronger footfalls[25] but a local survey conducted with Salford carers undertaken to support Salford in developing an Integrated All Age Carers Strategy[26], has reflected those members of the community caring for another, want *"Better communication and information as not everyone can access the internet".*

Question 5 for the SSAB:
How can the SSAB ensure that information and advice for carers reaches everyone, including individuals who are not confident with a computer?

4.4.10.Whether having a caring role or not, the emotional and physical effects on other individuals living in the home of a person who is to be extensively visited and supported by professionals, should always be given consideration. In Jayne's case the first consideration to be had was how the adaptations that were made to the downstairs room would impact Anita. Anita has told this review that she found it uncomfortable when professionals entered her home and started to move things around.

4.4.11.Whilst a professional is entering the home to get a job done and might see rearranging furniture or moving items around as a necessity, the owner of the property may feel distress as things are re arranged. It is important to collaborate openly with the owner of the property, which is to be moved, and not to take-over their space.

4.4.12.Moving forward professionals need to be mindful that the home they are entering to care for their service user, is also the home of the other occupants. Anita knew that Jayne needed the care that was being provided from the professionals, but she recalls how bombarded she felt by so many strangers entering her home. Anita has told this review of how Jayne needed to be coaxed to eat some of her meals and when people came during meal times, Jayne would then be unable to eat. She recalled how professionals would turn up at unexpected times and how she would have to abandon meals as a result. Anita said that she felt that it would have helped if the visits had maintained more structure.

4.4.13.Professionals partaking in this review recognised upon reflection how frustrating this must have been for Anita and added that this problem was not unique to Anita and Jayne's circumstances. Staff explained how delays often occur due to traffic conditions and other work commitments. They put forward how more could be done to try and learn of a family's routines and therefore avoid for example, mealtimes. In the event of disruption being unavoidable, better communication could reduce tension.

4.4.14.The learning for professionals is that they need to remember that whilst they are attending an address to do their job, the place they are entering is also someone's home.

4.4.15.A further consideration to be had was how caring for Jayne and watching Jayne suffer might affect Anita. Caring for someone you love and watching them in extreme pain must be one of the hardest things to do and it is important that a family carer does not care at the expense of his or her own health. Anita had her own health problems, and these would affect her energy levels[27] but clearly, she wanted to care for her daughter. Professionals entering the family home, whilst focusing on the needs of Jayne, needed to remember to look out for Anita too, particularly as prior to Jayne's health deteriorating, Anita had been supported by Jayne regarding her health problems.

[25] Overall users of www.gaddum.org.uk/carers - January 2022 - 166, February 2022 – 171, March 2022 – 172, April 2022 – 134, May 2022 – 63, June 2022 (up to 15th) - 92

[26] The Integrated All Age Carers Strategy sets out Salford's vision to create a 'carer friendly' Salford by placing carers at the centre of decisions about them. It is being produced in collaboration with carers, key partners and professionals supporting carers.

[27] This review has been informed that not all the professionals working around Jayne were aware of Anita's health issues.

4.4.16.Staff at the second domiciliary care provider demonstrated good practice by always ensuring that Anita, as well as Jayne, did not need anything more before they left the address. The review has been informed of how staff would always make Anita a cup of tea and of how they took the time to build a relationship with Anita in recognition of the fact that they were attending her home address two and latterly, three times a day.

4.4.17.Some professionals reported a strained relationship with Anita but when you hear Anita's voice, one can gain an understanding of how tensions arose. Both professionals and Anita have told this review of an incident when Anita threatened to call the police if professionals did not leave. On the surface this sounds to be an extreme reaction, but Anita has explained how on that day she returned home and could hear Jayne's screams from outside the address. When she entered her lounge, she found eight people looking at Jayne. She recalled that four were observing and four were caring. Given how Jayne had told her that she often felt 'like a piece of meat', she was immediately concerned for her daughter's dignity and for how her daughter would feel with so many people present whilst she had personal care.

4.4.18.This is a situation that would upset any mother and it is understandable why Anita felt protective. Professionals may have viewed Anita as a carer, but Anita had not labelled her role. Anita loved Jayne and was simply being a 'mum'.

4.4.19.This is a sentiment echoed in the aforementioned 'Salford All Age Carer's Strategy' whose *engagement with Salford carers suggested that some carers did not perceive themselves as a carer because they primarily saw themselves in other roles such as Mum or Dad. This made them reluctant to access the support they could have, as they did not identify as a carer.*

4.4.20.Regardless, whether in the role of 'mum' or the role of 'carer', and even with the help of domiciliary carers and nurses, Anita was under enormous strain caring for Jayne. The psychological effect of:

1. managing her own health needs,
2. coping with the intrusion of a stream of professionals coming into her home,
3. worry for Jayne's health, and
4. watching her daughter in extreme pain,

should not be underestimated. And possibly because of an accumulation of Anita's worries, stresses and frustrations, an incident eventually occurred during which Anita threw a remote at Jayne's bed in anger.

4.4.21.Upon learning of this incident, Anne became concerned for both her sister's deterioration in health, and her mother's ability to cope. Anne discussed her concerns with her mother's social worker who then informed the police. The police concluded that whilst throwing the item at the bed where Jayne was, could have been seen as reckless (as it could have been foreseen that it might hit Jayne) there was no malice in the action. No further police action was taken.

4.4.22.However, whilst system response was of a punitive nature, the incident could instead have been viewed as an indicator of how Anita required additional emotional support whilst caring for Jayne.

4.5. Safeguarding Concerns / Professionals Meetings and Risk Assessment

4.5.1.Given the safeguarding concerns[28] and the considerable number of professionals involved in Jayne's care, teamwork was crucial. Central to achieving effective teamwork is good multi-agency and inter-agency communication and information sharing procedures between the professionals.

4.5.2.A professional team began to support Jayne following their attention being brought to a potential deterioration of Jayne's circumstances when the Accident and Emergency department submitted a safeguarding enquiry on the 1st of June 2020. The social worker at the contact team requested that the referral be passed to the hospital social work

[28] Appendix 1

team. This review has been assured that this decision was of sound rationale as the hospital team would visit Jayne face-to-face and communicate with her. The contact team would not have seen Jayne face-to-face as they are a screening service who would make onward referrals.

4.5.3.Whilst it was clearly more appropriate for the hospital social work team to deal with the enquiry, professionals at the reflective sessions ruminated that better practice may have been for the contact team to communicate directly with the nurse in charge and ensure a thorough handover. This review would ask Adult Social Care to consider if this is something that could be incorporated into future practice.

4.5.4.Following a team of professionals becoming involved in the care and support of Jayne, many opportunities to convene multi-agency discussions and meetings were exercised. For example, the review has seen evidence of a series of professional meetings being convened following safeguarding concerns being raised in February 2021 and during the investigation into Anita throwing a remote on to Jayne's bed.

4.5.5.On the 13th of January 2021, records document that the domiciliary care provider contacted Anita's social worker to express concerns that Jayne was refusing personal care due to pain, had open wounds and a smell from the wound at her groin. The social worker advised the care provider that rapid response would be contacted, and an urgent professional meeting arranged. However, professionals engaging with this review have been unable to locate any evidence in case notes of this meeting convening, and the care co-ordinator does not recall ever having been invited to, or attending, a multi-agency meeting concerning Jayne's care. This meeting not going ahead resulted in a missed opportunity to discuss Jayne's pain management multi-agency.

4.5.6.With the benefit of reflection that has been provided through this detailed review, professionals have highlighted other times when a professional meeting would have benefitted the care and support offered to Jayne. The most obvious missed opportunity being as previously mentioned, a discharge planning meeting at the hospital. Other opportunities professionals have highlighted are.

1. In June 2020, the consultant met with Jayne, Anita, and Anne whilst Jayne was in hospital. The meeting was held in Jayne's room and Anita and Anne attended via social media video. Professionals at the reflective sessions contemplated that no therapy or other multi-disciplinary practitioners were present and that this may have been useful to ensure that everyone involved in Jayne's care understood her treatment options and preferences.
2. When the first domiciliary care provider withdrew their care, particularly as there appeared to be some mis-communication which left the urgent care team not knowing that the care provider had stopped visiting.
3. On the 20th of January 2021, a GP and a nurse attended Jayne's address to discuss a Do Not Resuscitate order[29]. The form was not signed on this occasion as per Jayne's wishes but a meeting to discuss the result of this contact would have been particularly helpful, particularly as the domiciliary care provider has told this review of the distress and anger Jayne was left processing following this visit[30].
4. In February 2021, concerns were raised from the district nurses that Jayne was end of life and a GP review was requested. On GP review, Jayne was not thought to be end of life. A more co-ordinated approach at this time, may have clarified the concerns that had been raised, and feedback from the GP review could have been shared in a timelier manner. (Jayne was discussed within the monthly Gold Standard Framework Palliative Care practice meetings but on reviewing the notes, these discussions were not always transferred onto the patient's records. It would have been helpful if this information had been shared as it would have helped to record Jayne's deterioration over a period.)

Question 6 for the SSAB:
How can the SSAB explore whether partner agencies are maximising opportunities to convene multi-agency professionals' meetings, and how can partner agencies assure the SSAB of robust managerial oversight to support the incorporation of such meetings within practice?

[29] A Do Not Resuscitate form is a document issued and signed by a doctor which informs the medical team not to attempt cardiopulmonary resuscitation. It is not a legally binding document but helps a patient to communicate with healthcare professionals involved in their care. The form only covers cardiopulmonary resuscitation, all other types of treatment for a condition and/or to ensure that a patient is comfortable and pain free, will still be given.
[30] The GP issued a Do Not Attempt Resuscitation form on the 12th of February 2021. This was not completed in the presence of Jayne.

4.5.7.It is imperative that opportunities for professional meetings, such as these identified, are optimised to allow professionals to merge their observations, expertise, and decision-making. Effective information sharing within meetings was essential to Jayne's care to minimise mis-communication within the core team, and any misunderstanding of other roles and responsibilities.

4.6. Home Care Provision

4.6.1.Anita has told this review that she found staff from the homecare providers to be friendly and personable. She spoke of one carer going above and beyond and bringing Jayne crafts that she could enjoy doing whilst she was immobile. This is an excellent example of how against the backdrop of Jayne's health problems and pain, homecare provision needed to be creative to make Jayne's safeguarding personal.

4.6.2.Sadly, the care provider who initially supported Jayne in her home post hospital discharge in September 2020 has not responded to the requests of the SSAB to engage with the review. However, the Independent Reviewer has met virtually with the care co-ordinator from the latter home care provider who provided care for Jayne from the end of November 2020 until she was admitted into hospital in February 2021.

4.6.3.It was clear from conversations that staff knew Jayne well and built a good relationship with both Jayne and Anita. The care co-ordinator was able to explain in detail what Jayne liked to do, watch on television, and eat. She spoke of much conversation with Jayne which included light hearted 'banter' as well as discussions about her health and care. The resulting trust that developed between Jayne and her carers is demonstrated by how the care co-ordinator was able to shed some light on Jayne's experiences of the hospital ward and disclosed that Jayne had cited falling out of bed on the ward as a reason she did not want to return to the hospital.

4.6.4.The co-ordinator explained to the review that their role was one of attending to Jayne's personal care needs. This included changing sheets, washing Jayne, and changing her nightclothes. Four staff members would attend Jayne, initially twice a day (10:00am and again around lunchtime) and in time, three times daily. Four staff carers were necessary to ensure safe handling of Jayne when turning her which was difficult because Jayne was unable to lie straight and would struggle to breathe in certain positions.

4.6.5.Often the carer would have to redress Jayne's wounds because either her dressing had become unstuck, or Anita had cut off bandages at Jayne's request. The care co-ordinator has told this review that it is very unusual that they be asked to dress such severe wounds but that all the carers agreed that it had to be done. However, such was the carers' unease for Jayne, her pain, and her wounds, that most days, the provider would contact the rapid response team by telephone to report concerns.

4.6.6.The care co-ordinator spoke of how staff were not always sure whether medical professionals had attended Jayne since their last visit or not. The district nurses keep records at the home of the people that they visit which the carers have access to, but carers report that in the case of Jayne, only phone numbers were recorded, and they found no detail of any district nurse visits.

4.6.7.There is a clear need for professional teams around people like Jayne to include domiciliary care providers within their communications as often the domiciliary care staff are the key professionals who spend the most time with the person and build trusted relationships.

4.6.8.The care provider has a hand written book in which staff document every visit. This book is always left with the person and the care co-ordinator wondered whether it would be possible for all professionals to document visits within this book. Such practice would have been beneficial to Jayne's care and would have supported care staff who otherwise only received information about Jayne's care either through telephone calls which they initiated, or through the occasional joint visit which had been arranged by nurses when they needed the carers support to turn Jayne.

Question 7 for the SSAB:

How can the SSAB support and encourage partner agencies to share information with domiciliary care providers which will improve the quality of care offered to a service-user without breaching privacy and data protection?

4.7. Making Safeguarding Personal

4.7.1.On their website the SSAB describe making safeguarding personal as an approach to safeguarding that is outcome focused and engages with the person through the process to ensure they are empowered, involved in decision making as much as possible and their views and wishes would inform what happens[31]. In other words, making safeguarding personal is about recognising people as 'experts in their own lives' and collaborating with them.

4.7.2.The fundamental practice to this approach is to help a person to feel in control, comfortable in their environment, and free from unnecessary anxieties. There are numerous factors that can increase a person's anxiety, the most obvious being: worries about health and life, isolation from family and/or friends, unfamiliar surroundings, lack of privacy, and feeling physically uncomfortable.

4.7.3.To limit any of the above factors affecting Jayne and to help Jayne feel involved and in control of her circumstances, health and social care professionals needed to endeavour to learn what Jayne was experiencing whilst in their care and what she wanted to happen. This could only be done by having regular conversations with Jayne to keep her involved in her care and to allow her to make choices.

4.7.4.When Jayne was admitted to a ward in hospital in 2020, she was allocated a side room. This was because of her support needs and bariatric care requirements. Because of the Covid pandemic, staff had to put on the personal protection equipment to protect both themselves and Jayne before entering the room. Hence, at a time when family and friends were restricted from visiting, staff also, were unable to just 'pop in' and have a conversation. Consequently, alongside a time when Jayne was at risk of feeling lonely, the ability for staff to build a positive relationship with Jayne was immediately hindered. Jayne was provided with a television, magazines, and her mobile phone, but such things do not replace human face-to-face contact, particularly with family.

4.7.5.The effect of Jayne not having face-to-face contact with family must not be taken lightly and this is considered further in section 4.10 of this report; The Effects of the Covid Pandemic.

4.7.6.On the 1st of September 2020 Jayne discussed with a Consultant Psychiatrist from Greater Manchester Mental Health team how the most important thing for her was to return home to live with her mother as they looked after each other. Jayne also voiced that she was bored on the ward and upset by 'lying around' as she usually enjoyed crafts. Sadly, none of the conversation content was subsequently explored via the occupational therapist to alleviate Jayne's boredom. Better practice would have seen Jayne's voice being responded to and an outcome being delivered.

4.7.7.Boredom is common in hospitals; Hyland (1996) reported that 86% of inpatients with cancer indicated that they had 'time on their hands' and 50% said that they were bored. Likewise, Hardy & West (1994) found that 70% of patients they surveyed had 'not enough to do in hospital'. An observational study of activity found that patients were passive for 87% of the time (Nolan 1995). Whilst boredom can not always be avoided it must be remembered that chronic boredom can negatively affect a person's health and has been associated with poor diet, depression, and anxiety. Disease is an 'abnormality of the structure and function of the body' but 'the illness experience and sickness are not always caused by the disease; they depend on psychosocial factors as well'[32] Accordingly, as it is important to consider a person's health in a more holistic manner, and incorporate psychosocial considerations, the British Medical Association has recommended that measures be put in place to allow in people to participate in recreational and creative therapies[33].

[31] Making Safeguarding Personal | Salford Safeguarding Adults Board
[32] Handbook Of Health Research Methods: Investigation, Measurement And Analysis. Chapter 1, Research on health and health care Paul Dieppe
[33] BMA Science & Education (2011) The Psychological and Social Needs of Patients.

4.7.8. Jayne was in hospital for a number of months; hence it was particularly important that staff be aware of the presence of boredom and approach Jayne's treatment holistically. Especially because Jayne was an inpatient when, due to Covid[34], hospital visiting was restricted, and wards were affected with staff shortages.

4.7.9.During the time that Jayne was being cared for in her home address, her isolation and boredom improved, and she benefitted from being back in familiar surroundings, but Jayne's pain heightened to the point where she was unable to engage with most of her care. This is discussed in detail in the next section of the report but understanding Jayne's pain and not just 'walking away' when Jayne refused treatment was fundamental to making her safeguarding personal.

4.7.10.There is an example of the extent of the pain Jayne was experiencing dating from the 14th of January 2021. The tissue viability nurse visited Jayne at home and Anita informed her that Jayne did not want her to be involved in any physical care due to the previous visit being too painful. Anita explained that Jayne was happy for the nurse to review the wounds from the doorway to the room. The nurse respected Jayne's wishes and advised Jayne that the Rapid Response staff would continue treatment for the wounds and offered an offloading device which would assist with turning Jayne. The nurse suggested Jayne feel the device prior to use and Jayne acknowledged that she was happy to try it. Before leaving Jayne, the nurse asked Jayne if she was comfortable, and Jayne replied that she was. This was good practice. Despite Jayne pushing the nurse away because of the amount of pain she was experiencing, the nurse found a way to engage with Jayne.

4.7.11.Whilst being cared for at home, Jayne made it very clear to her GP that she did not want to be re-admitted into hospital. This was discussed on at least three separate occasions, and she was always deemed to have the capacity to make these decisions. The GP attempted to try and understand her refusal for admission by talking with Jayne and established that Jayne's previous experience in hospital had not been good. Jayne felt that her sores were developed in hospital and that she was not treated correctly. These concerns were echoed by Anita. The GP explored with Jayne whether admission to a different hospital would be acceptable or the avoidance of specific wards and advised Jayne and Anita how they could raise a formal complaint with the hospital via the patient advice and liaison service if they wished to pursue their concerns further.

4.7.12.These conversations were documented within the GP records but in the absence of a multi-agency meeting were not shared further. Hospital staff are not always able to view all the GP notes and therefore in the event of Jayne's unplanned admission this information was likely not available.

4.7.13.These conversations were good practice and demonstrated the GP making safeguarding personal by trying to find out about Jayne's experiences and why she felt that way about hospital admission. Such conversations build up trust with a patient. Unfortunately, when Jayne was re-admitted to hospital, it was to the same hospital and eventually, on to the same ward, suggesting either that admission to the ward was unavoidable or that there had been a breakdown in professional communication post the GP hearing Jayne's voice.

4.7.14.A further example of professionals making Jayne's safeguarding personal can be found when Jayne was admitted in to hospital in February 2021. She was suffering from delirium and the Greater Manchester Mental Health team advised staff at the hospital to refer for an advocate and consider a best interest meeting. Referral to an advocate was to ensure that Jayne had a voice at this time.

4.7.15.When Jayne was moved to the ward, she was again isolated in a side room, but this was now exacerbated by her immobility. Anne has questioned how personal the care Jayne received at this time was.

4.7.16.The ward has reported that staff were aware of Jayne's feeding struggles and that consequently Jayne had the red tray system in place which meant that she was supported and encouraged with food and that her bedside table was kept next to the bed within Jayne's access. Also, that a call bell was in place near Jayne's hand for her to call if she needed attention.

[34] Discussed further at 4.10 of the report

4.7.17. In contrast, Anne considers that Jayne was no longer consistently able to reach her bedside table for drink or food, or able to feed herself at all. Staff had been given Jayne's mobile phone to pass to Jayne, but Anne has noted that Jayne was unable to reach it or keep it charged. Anne and Anita both consider that staff at the hospital did not learn enough of what Jayne needed at this time and that as a result the care Jayne received was not personal and/or tailored to her requirements.
4.7.18.However, it is important to acknowledge that, at this time, due to Covid and skill mix[35] changes, ward staffing levels were not as high as usual and, also that the voluntary services[36] had been suspended.

4.7.19.In summary, there are clear examples of some professionals around Jayne making safeguarding personal but there appears to be a problem with the wishes and feelings of Jayne, revealed during this good practice, being shared, and acted upon.

4.7.20.This review has been assured that Salford Adult Social Care are now focussing on an approach which ensures that people feel empowered and included in their care as they are currently working with the National Development Team for Inclusion to implement a Community Led Support model of strengths-based working. This model focusses on having good conversations with people and aims to achieve peoples wishes, feelings and outcomes.

4.8. Pain Management

4.8.1.The GP, the urgent care team and the palliative care team were all involved in Jayne's pain management. But despite the medication prescribed, Jayne's pain management has clearly been an ongoing concern as:

1. Anita has told this review of occasions when she had been outside of the house and had heard Jayne screaming in pain from inside whilst carers were attending to her.
2. Professionals have noted that the most significant barriers to supporting Jayne were because of Jayne's refusal of appropriate care for her wounds and that on further questioning, pain appeared to be the reason.

4.8.2.In January 2021, a nurse from the rapid response team made a referral to the community specialist palliative care team for help with symptom control, specifically pain management, and for advanced care planning discussions in view of Jayne's deteriorating condition. As a result, a Speciality Doctor in Palliative Medicine employed by St Ann's Hospice attended the home address to see Jayne on the 29th of January 2021. Anita recalls that this doctor spent considerable time talking to Jayne. Jayne reported pain from her pressure ulcers that was an issue during movement, particularly during care and when being dressed. Jayne said that pain lasted 2-3 hours post-dressing but said that she was relatively comfortable afterwards. As a result of the visit the doctor reviewed and amended Jayne's medicine.

4.8.3.The hospice had four further contacts with Jayne before she was admitted to hospital: three by telephone and one in person.

4.8.4.A representative from the hospice has informed this review that in their opinion the referral to their service was timely and appropriate. A sooner referral to the service would not have significantly improved the situation for Jayne as she did not have an underlying palliative care diagnosis. Jayne's situation became palliative because of her non-healing pressure ulcers.

4.8.5.Nevertheless, it is clear from conversations had with professionals during this review that there was much confusion by many professionals regarding who was lead, and what could be done to support Jayne to manage her pain.

Question 8 for the SSAB:
How can the SSAB work with partner agencies to support the development of a 'pain management in the community' pathway?

[35] Skill mix refers to the number and educational experience of nurses working in clinical settings.
[36] The Trust have voluntary services in place to support inpatients with eating and drinking.

4.8.6.Consultations with the self-neglect assessment tool[37] evidence that as suggested by the tissue viability nurse, when professionals became concerned for Jayne refusing their care early in 2021, the self-neglect policy could have been followed.

4.8.7.Consideration of:

- Jayne's health being affected by her refusal to engage with some services,
- Jayne's deterioration, and
- Jayne's struggles with hygiene,

would have placed Jayne within the high-risk category. This would have claimed a multi-agency response and resulted in comprehensive assessment which would have identified that whilst there may have been other causes contributing to Jayne's self-neglect, pain was a prominent factor. Although it is recognised that there are limitations to pain management within the community, use of the self neglect pathway would have encouraged multi-agency assessment, intervention, and planning.

4.9. Mental Capacity

4.9.1.There are a number of occasions throughout the timeline of this review when Jayne's mental capacity has been critical to her decision-making regarding her decline of medical assessment, care, and hospital admission. Documentations evidence that professionals consistently considered Jayne's capacity to make such decisions and concluded that she had the capacity to do so. Such recurrent consideration of capacity is good practice as capacity is not a permanent condition and as such assessment should be time-specific and decision-specific.

4.9.2.Professionals must and did always start with the assumption that Jayne had the capacity to make her own decisions, unless and until that assumption was proved wrong, but under the Mental Capacity Act 2005 the true test[38] to deciding whether Jayne lacked mental capacity was to confirm whether she was able:

- to understand the information relevant to the decision,
- to retain that information,
- to use or weigh that information as part of the process of making the decision, or
- to communicate her decision.

4.9.3.Only on one occasion when Jayne was seen by a Locum Consultant Psychiatrist in hospital did Jayne demonstrate that she was unable to do this. On that occasion she was deemed to lack the capacity to make decisions regarding surgical treatments and the Consultant recorded that Jayne would require a formal capacity test completed by the surgical team prior to any surgical treatment. The Consultant added that the team should decide how urgent surgical intervention was and consider the risks versus the benefits and decide whether there was time to have a Best Interests Meeting preferably with an Independent Mental Capacity Advocate, or whether there needed an urgent Best Interest decision to be made within the next 24 hours.

4.9.4.Around the 15th of March 2021 a member of the medical team is reported to have discussed the possibility of a feeding tube with Jayne. This was a major decision for Jayne, and it was crucial that she had capacity to understand the procedure, its potential consequences, and its potential benefits, and make an informed decision. Unfortunately, due to Covid[39], this discussion has not been documented. Hence this review has been unable to consider whether Jayne's capacity was appropriately assessed at this time.

4.9.5.Throughout the rest of the review timeline there is clear documentation evidencing that health professionals, carers and social workers all had conversations with Jayne during which she was able to converse with them and

[37] appendix-3-self-neglect-assessment-tool.pdf (salford.gov.uk)
[38] Section 3(1) Mental Capacity Act 2005
[39] This is discussed further at paragraph 4.10.17

answer their questions coherently. Consequently, apart from the one aforementioned occasion, Jayne was consistently deemed to have capacity and the right to make her own decisions about her healthcare.

4.10. The Effect of the Covid Pandemic

4.10.1.In December 2019, a coronavirus emerged which was swiftly labelled a pandemic. Every Country was advised to take urgent action, and major disruption followed.

4.10.2.The United Kingdom saw the Prime Minister announce a lockdown on the 23rd of March 2020. As a result, professionals had to rapidly adapt to new working conditions. The second phase of a UK wide study[40] exploring the impact of the Covid-19 pandemic on health and social care has highlighted that social work and nursing were the most impacted occupational groups.

4.10.3.Amongst the confusion of the new conditions, professionals, whilst concerned for the safety of those around them, were understandably also concerned for their own safety. Everyone worked hard to maintain service and continuity for their patients and service users, but no one could escape the emotional distraction that the pandemic introduced.

4.10.4.Over time, practices and communications within the new working conditions have become more effective and the ability of staff to adapt is praiseworthy, but this review must look at the resulting quality of care that was afforded to Jayne when she needed it.

4.10.5.At the beginning of the lockdown Jayne lost her regular face-to-face contact with Anne and Anne's children, who she frequently spent time with. But Anita and Anne have told this review that the major issue for Jayne regarding the pandemic, and the most significant, appears to have been its personal effects when she was admitted into hospital in June 2020. Hospitals, with a prominent focus on how they were going to protect patients, visitors, and staff, highly restricted the numbers of visitors and visiting periods in hospitals, and consequently during her admission to hospital between May and September 2020, Jayne was not allowed to have any visitors. She reported to family that she was lonely and missing them.

4.10.6.In November 2020, a study[41] was undertaken to look at the impact of visitor regulation on the post operative experience of Covid 19 negative patients. Whilst the study was looking at patients undergoing surgery in particular, its conclusions and findings can be applied to Jayne's circumstances post chemotherapy. The study noted that *family members, friends, and caregivers serve an important role in the recovery process of patients in the hospital and are thought to be important mediators for ensuring patient-centered care and preparing for transitions to the post-discharge setting.* It concluded that a lack of visitors adversely affected patient's psychosocial wellbeing and that patient without visitors were less likely to have their preferences addressed upon discharge. These findings highlight the need for innovative strategies to improve the experience of hospitalised patients during this time of visitor restriction.

4.10.7.And it was not just Jayne's emotional health that would have been affected by the visiting restrictions, it was family members too. A study[42] has found *that 'not being physically present for their hospitalized family member created worries, anxiety, sadness and a need for more information and updates on the family member's condition.'* Not being allowed to be present in the hospital created moral concerns and a feeling of failing to support and protect their loved ones among family members of intensive care patients who were not infected with Covid-19 (Creutzfeldt et al., 2020).

[40] HSC Workforce Study
[41] Impact of visitor restriction rules on the postoperative experience of COVID-19 negative patients undergoing surgery - PMC (nih.gov)
[42] Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review - PMC (nih.gov)

4.10.8.The worry and anxiety felt by Anne is apparent by her daily calls to the ward when Jayne was in hospital in 2021. Such need for information and regular updates when a family member is unable to visit a loved one, is understandable and it has been reported that because of restricted visiting, health professionals have been expected to provide more detailed and frequent communications with family members throughout the pandemic.
4.10.9.In addition, to reduce the risk of transmission of the coronavirus, the national lockdown in March 2020 saw many professionals who worked in safeguarding organisations being required to leave the office and work from home. As a result, face-to-face communication with other professionals, both within organisations and out, was affected and was replaced with virtual communication. Platforms such as Zoom and Microsoft Teams started to be used but at first, different sectors used different virtual platforms, and this stilted multi-agency discussions. Professionals at the reflective sessions spoke of further problems inter-agency as, initially, not everyone had access to computer stations or all the equipment that they needed. They explained that rollout of equipment took time and those that did have equipment were not always familiar with the communication tools and had to rapidly learn how to use them.

4.10.10.Another major problem for professionals was that to reduce the risk of transmission of the coronavirus, the pandemic saw many professionals being restricted from visiting members of the community in their own homes. It is to the professionals' credit that this does not seem to have hindered the care and support that Jayne was offered. She was visited at home by care staff, nursing staff from many community teams, the GP, social worker, and the hospice.

4.10.11.The GP surgery has told this review that during the pandemic, an assessment was always made as to whether Jayne needed seeing face to face. This assessment would consider whether a face-to-face consultation was needed to complete a safe consultation, whilst balancing the risk of contact to both Jayne and the professional. If it was deemed that a home visit was required, this was arranged.

4.10.12.Similarly, Adult Social Care still undertook home visits throughout the pandemic, although as mentioned in paragraph 4.3.11, some contact was affected.

4.10.13.These professionals not working continuously from home were at risk of contracting the disease. Hand in hand with the contamination risks came low staffing levels:

1. Staff who had been exposed to the virus had to self-isolate
2. Staff who had been unfortunate enough to contract Covid-19 were off work

4.10.14.This is particularly true for staff working within hospital settings and it is good practice that although the Greater Manchester Mental Health team had less staff based within the Acute Trust due to Covid restrictions, Jayne was still seen face-to-face by their consultant.

4.10.15. Some professionals presumed that the reason that a discharge planning meeting did not convene was due to the Covid restrictions, but this has not been cited as the reason by the staff in charge of the discharge. However, discussions around Jayne's discharge reflected that, had a meeting convened it would have been virtual - as were professional's meetings and strategy meeting. Whilst virtual meetings were not always favoured pre-Covid, this review has been told of advantages, as once professionals had become accustomed and were in receipt of the technology, virtual meetings proved to attract better attendance, likely because they are so accessible.

4.10.16.A further consideration for discharge is the pressure that was put on services to discharge people from hospital and to transition to community teams. Government guidance was for discharge to be had within three hours of a patient becoming medically optimised. This was because the focus was upon the availability of beds to allow the hospital to respond to the demands of Covid. This did not happen in the case of Jayne because she required bariatric transport, but it does example the pressures that staff were under.

4.10.17.The aforementioned low staffing levels resulted in an increased pressure of work on those still able to attend. As a result, much documentation was paused, the rationale being less documentation – more time to care. The decreased recording did not affect the level of care provided to a service user at the time but has influenced the

ability of professionals to look back and consider previous interactions between professionals and service users, and in the case of Safeguarding Adult Reviews such as this one, analyse and learn from previous practice.

4.10.18.Anita and Anne have told this review that the bereavement care provided by the hospital made Jayne's passing harder to manage. Anne spoke of unclear advice and of being made to feel like a criminal because she unknowingly had not dealt with Jayne's financial affairs as she should have. Upon hearing this, professionals have explained how the bereavement team at the hospital was extremely overwhelmed during the Covid pandemic in terms of supporting people following the death of a loved one, and had to recruit more staff. Unfortunately, during the time of crisis, the inexperienced staff were not trained as well as they should have been, and this may have affected the quality of support on offer.

4.10.19.The amount of death in the hospitals was also having a significant effect on staff and extra support had to be brought in to help them manage the significant emotional impact.

4.10.20.During the Covid 19 Pandemic, two additional bereavement offers were commissioned for Salford residents. From April 2020, the Greater Manchester Suicide Bereavement service (operated by Six Degrees) extended its remit to include all forms of bereavement providing information, advice, and support via phone. And in addition, Six Degrees were commissioned to provide a bereavement counselling service for Salford residents from November 2020. Both services are now recurrently funded. However, because of the wider Covid related pressures on all services, it is now realised that their pathways with the bereavement services at the hospital took time to develop.

4.11. Equality, Diversity and Human Rights

4.11.1.The Equality Act 2010 replaced previous anti-discrimination laws, bringing them together under one piece of legislation. This includes the Disability Discrimination Act which was originally written in 1995 to stop discrimination against disabled people.

4.11.2.A disability under the Equality Act is a physical or mental impairment that affects a person's ability to conduct normal day-to-day activities[43] (the adverse effect must be substantial and long term). Examples include '*shopping, reading and writing, having a conversation or using the telephone, watching television, getting washed and dressed, preparing and eating food, carrying out household tasks, walking and travelling by various forms of transport, and taking part in social activities*[44]*.'*

4.11.3.The concept of discrimination arising from disability occurs where an individual is treated unfavourably because of something arising in consequence of their disability, and it cannot be shown that such treatment is a proportionate means of achieving a legitimate aim.

4.11.4.The Equality Act introduces a duty to the service provider to make reasonable adjustments to ensure that anyone with a disability can use the service in the same way as any person without a disability and is not placed at a substantial disadvantage (compared with a person who is not disabled) by:

- A service provider's provision, criterion, or practice.
- A physical feature of the service provider's premises.
- A service provider's failure to provide an auxiliary aid.

4.11.5.And where the duty arises, the service provider is required to take such steps, as it is reasonable to have to take, to avoid the disadvantage[45].

4.11.6.Given the extent and effect of Jayne's obesity, it can be considered a disability. As can some of the other conditions that Jayne lived with, such as diabetes and cancer.

[43] Section 6(1), Equality Act 2010
[44] Paragraph D3, Guidance on matters to be taken into account in determining questions relating to the definition of disability (Equality Act 2010 Guidance).
[45] Section 20 and paragraph 2, Schedule 2, Equality Act 2010.

4.11.7.Therefore, this review will now consider whether Jayne, with her disabilities, experienced equal access to rights, opportunities, and services, and was protected from discrimination.

4.11.8.There are two occasions that have been brought to this review's attention whereby Jayne has not been able to access services because of her obesity:

1. In October 2020 Jayne was discharged from haematology owing to difficulties in getting Jayne to the hospital for further blood tests. A letter sent to Jayne's GP surgery instructed a re referral when Jayne's mobility improved.
2. Similarly, in October 2021 Jayne received an appointment for urology which she clearly could not attend due to her mobility. Jayne's GP emailed explaining that Jayne required a home visit, but this review has seen no evidence of this home visit ever being undertaken.

4.11.9.Clearly on both occasions, the service provider was unable to provide Jayne with the service it would have provided to a non-disabled person as Jayne would have attended the appointments. Therefore, both provisions unintentionally placed Jayne at a disadvantage which was important to her health.

4.11.10.In the case of haematology, this review has seen no evidence of any reasonable steps being taken by the service provider to deliver the provision to Jayne as offering a re-referral when her mobility improved can be compared to offering her the service when and if her disability improved. There is no evidence of any consideration of whether any amendment to usual practice being considered.

4.11.11.With regards to the urology appointment, it is possible that they sent Jayne the appointment unaware of the extent of her mobility issues and it is good practice that the GP wrote on behalf of Jayne to explain. The GP's request of a home visit sounds reasonable as even in the event of home visits not being usual practice, given Jayne's disability, such an exception should have been considered. However, this review has been informed that there is no record of this correspondence in any case files.

4.12. Good Practice

There is evidence of much good practice within several agencies who supported Jayne and it is equally important to develop learning from this good practice as it is from any shortcomings:

4.12.1.Professionals at the reflective session noted that the community tissue viability nurse lead had provided excellent and continuous support to others with reablement.

4.12.2.Carers from the second domiciliary care provider have evidenced that they built good relationships with both Jayne and Anita and their reflections demonstrated good appreciation of how Anita may have felt caring for her daughter and losing privacy in her own home.

4.12.3.Good collaborative working between the tissue viability and district nurses.

4.12.4.District nurses and urgent care worked well together when the domiciliary care provider terminated care.

4.12.5.Good practice identified from staff in the Accident and Emergency ward who recognised the safeguarding concerns.

4.12.6.Nurses have told this review that the second domiciliary care provider worked well with them.

5. Improving Systems and Practice

5.1. Developments since the Scoping Period of this Review

Since the scoping period of this review, agencies have already made some important amendments to practice. Some have been included in the body of this report. Other developments include:

5.1.1.The Greater Manchester Mental Health has recently reviewed and strengthened both its Safeguarding Adults at Risk Policy, Procedures and Guidance documents and Training Packages in the following areas:

- Self-neglect
- Mental capacity and executive capacity
- Mental capacity five principles, which includes Best Interest, Least Restrictive
- Strengths-Based Approach
- Key sections of the Care Act
- Reference to Salford's Self-Neglect Protocol i.e., High Risk Advisory Panel

5.1.2.The tissue viability team leader has since commenced a piece of work to look at alternative bariatric equipment that could be used as an alternative to the standard equipment currently supplied. This will enable patients in the community to be managed in their own homes with a variety of equipment to meet their needs, which may prevent hospital admission.

5.2. Conclusion

5.2.1. Jayne, a much-loved daughter, sister, and aunt, battled with weight management and experienced many health problems including a cancer of the lymphatic system.

5.2.2.Family have informed this review of Jayne's frustrations and low self esteem borne from perceived weight prejudice and have described the loss of dignity Jayne felt requiring bariatric equipment and care when she became immobile and dependent on others.

5.2.3. Jayne was discharged from hospital in September 2020 needing specialised equipment, daily support from carers and medication and care administered by community nurses. Anita has illustrated the intrusion both her and Jayne felt as multiple professionals entered their home daily and the confusion regarding the separate roles and remits of those involved. Whilst Jayne's discharge from hospital was safe, the omission of a discharge planning meeting between family, and the professionals who were to support Jayne in the community, ensued a missed opportunity to clarify the care Jayne would need and who would provide it.

5.2.4.Despite her own health problems, Anita with much support from Anne, became Jayne's main carer. Both Anita and Anne have told this review that they do not feel that professionals imparted enough information about Jayne's health and prognosis to support them in their role as carers. Similarly, the domiciliary carers report confusion regarding which professionals had visited in their absence and what care had been provided. Communication between everyone involved in supporting a person of ill health in their own home, must improve.

5.2.5. Jayne's immobility and bariatric needs left her unable to attend hospital appointments and as a result she was left without urology care, and discharged from haematology whilst outstanding a scan. In addition, Jayne's experience of the hospital ward had rendered her adamant that she would not return - even when suffering intense pain. Professionals who had built a trusted relationship with Jayne were rewarded with some insight into this decision, but it is not known if Jayne chose to keep some of her experiences to herself. Jayne's intensifying pain resulted in an increasing refusal to accept professional care at home. Developing a 'pain management in the community pathway' could help professionals to navigate pain control.

5.2.6.Anita's subsequent protection and defence of Jayne was sometimes seen as uncooperative, but Anita was fundamentally Jayne's mother and was doing what came naturally to her. Anita did not label herself 'Jayne's carer,' but professionals must ensure that family members understand, recognise, and know how to seek support should they need it.

5.2.7.Safeguarding concerns were raised for Jayne on four occasions within the scoping period of this review. Most resulted in multi agency meetings, but other key episodes within Jayne's care (for example, when discussing treatment options, treatment preferences and/or gaps in care) would have benefitted from further multi agency meetings. Such meetings would have afforded professionals the opportunity to merge their expertise, observations, and decision-making.

5.2.8. Jayne's experience of being an inpatient in hospital was heavily affected by the Covid pandemic. The loss of visitors and volunteer services whilst on the ward resulted in boredom, isolation, a lack of physical and emotional support from those who knew her best, and decreased relational practice between health professionals and Jayne's significant others.

5.2.9.The unprecedented pressure on the hospital bereavement service developing from the Covid pandemic, also resulted in a less professional support provision for family after Jayne had sadly been found deceased in her hospital bed on the 26th of March 2021.

5.3. Questions for the SSAB

The review would ask the SSAB to deliberate the following questions. It is the responsibility of the SSAB to use the ensuing debate to model an action plan to support improvements to systems and practice.

Question 1 for the SSAB: How can the SSAB learn of the current challenges professionals face when attempting to support people experiencing obesity who are at risk of harm, and how can the SSAB and their partner agencies improve or develop practice which will encourage people in their area to engage with dietetic support?

Question 2 for the SSAB: How can healthcare agencies assure the SSAB of improved management of the transportation of bariatric patients to and from hospital to support timely discharge and appointment attendance?

Question 3 for the SSAB: How can the SSAB guide professionals from all agencies and organisations to ensure that all professionals supporting a person are clear about whether a person is consenting to their information being shared with loved ones, and understand concerns when consent may need to be overridden?

Question 4 for the SSAB: How can the SSAB be reassured that partner agencies are working and developing their collaboration with a service users' family, and within that practice, supporting individuals to raise concerns about either their own or another's care?

Question 5 for the SSAB: How can the SSAB ensure that information and advice for carers reaches everyone, including individuals who are not confident with a computer?

Question 6 for the SSAB: How can the SSAB explore whether partner agencies are maximising opportunities to convene multi-agency professionals' meetings, and how can partner agencies assure the SSAB of robust managerial oversight to support the incorporation of such meetings within practice?

Question 7 for the SSAB: How can the SSAB support and encourage partner agencies to share information with domiciliary care providers which will improve the quality of care offered to a service-user without breaching privacy and data protection?

Question 8 for the SSAB: How can the SSAB work with partner agencies to support the development of a 'pain management in the community' pathway?

Appendix 1

Date	Referrer	Concern	Outcome
1.6.20	Accident and Emergency Department	The concerns were around Jayne's living environment when ambulance crews brought her into hospital.	Adult Social Care spoke to the referrer and upon determining that Jayne was an inpatient at the hospital, advised the referrer to refer Jayne to the Hospital Social Work Team. The information was recorded within a contact assessment and closed at the contact team.

18.9.20 and 29.9.20	Premier Care	Concerns that the District Nurses had not completed wound care with Jayne, and that she was crying out in pain.	A Section 42 enquiry found this to be unsubstantiated and concluded no further action required as wound care had been provided - on one occasion Jayne had declined.
11.2.21	District Nurses	Concerns in relation to Jayne self-neglecting, and a significant risk of death if wounds worsen. Also, concerns around a poor diet which would increase Jayne's weight and impact pressure areas.	A series of professional meetings and strategy meetings convened. Sadly, Jayne was too poorly to converse.
22.2.21	NF	Reported that Jayne's mother had thrown a remote at Jayne.	Police investigation - Jayne was too poorly to converse and mother was not spoken to due to her own significant medical issues and circumstances.