Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board

SAFEGUARDING ADULT REVIEW
Gillian

2024

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1. INTRODUCTION

1.1. Gillian was a 69-year-old white British woman, who lived on her own in a flat, in a warden aided complex. She had an operation in 2014 which resulted in complications and left her unable to walk. Gillian broke her ankle and injured her neck in falls resulting in difficulty lifting her arms above her. She was confined to her bed. Gillian had a care package and required full assistance with hygiene, dressing and food for two years whilst she remained in her bed.

1.2. Gillian's sister visited her regularly, but Gillian was estranged from her only son and grandchild.

1.3. Gillian developed bed sores and she increasingly self-neglected. On 5th January 2023 Gillian was taken to hospital. She was stuck to her mattress and the ambulance crew had to cut the mattress away around her, so she could be safely transported to hospital.

1.4. Gillian died of sepsis in hospital on 9th January 2023.

2. SAFEGUARDING ADULT REVIEWS

2.1. Section 44 of the Care Act 2014 places a statutory requirement on the Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board to commission and learn from SARs (Safeguarding Adult Reviews) in specific circumstances, as laid out below, and confers on Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board the power to commission a SAR into any other case:

'A review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if –

a) there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult, and

b) the adult had died, and the SAB knows or suspects that the death resulted from abuse or neglect…, or

c) the adult is still alive, and the SAB knows or suspects that the adult has experienced serious abuse or neglect.

The SAB may also –

Arrange for there to be a review of any other case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs).

…Each member of the SAB must co-operate in and contribute to the carrying out of a review under this section with a view to –
a) identifying the lessons to be learnt from the adult's case, and
b) applying those lessons to future cases.

2.2. Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons to the future (s44(5), Care Act 2014).

2.3. The purpose and underpinning principles of this SAR are set out in **Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board Safeguarding Adult Review Enquiry Procedures.**

2.4. All Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board members and organisations involved in this SAR, and all SAR panel members, agreed to work to these aims and underpinning principles. The SAR is about identifying lessons to be learned across the partnership and not about establishing blame or culpability. In doing so, the SAR will take a broad approach to identifying causation and will reflect the current realities of practice ("tell it like it is").

2.5. A SAR referral was received from Midlands Partnership Foundation Trust (MPFT) on 4th May 2023. The case was referred to a scoping panel of the Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board and considered for a Safeguarding Adult Review at a scoping panel meeting on 20th June 2023.

2.6. The scoping panel recommended that this case met the criteria for a statutory mandatory SAR, and the Independent Chair of the Board ratified this on 11th July 2023.

2.7. The Safeguarding Adults Review was led by Patrick Hopkinson who is an Independent Consultant in Adult Safeguarding and who had no previous involvement with this case and no connection to the Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board, or its partner agencies.

2.8. **The review for Gillian**

2.9. This safeguarding adults review commenced on 26th October 2023**.**

2.10. **Scoping period for the review**

2.11. Agencies were asked to provide details of their contact with Gillian for the period 25th July 2022 to 9th January 2023 when she died.

2.12. **Key areas to be addressed by the review**

2.13. Who was Gillian and what was understood about her life experiences, including trauma and loss, and her motivations, interests and strengths?

2.14. Were there barriers to practice, for example, in taking the lead to organise multi-agency meetings and interventions, or in learning and applying lessons from previous safeguarding adults reviews, practice guidance or training when working with Gillian?

2.15. Were service responses to Gillian influenced by personal feelings about her and did preconceived ideas about Gillian influence approaches to her? Was there confirmation bias and were there assumptions in decision making about Gillian and her needs?

2.16. Did holiday times impact on service capacity and availability and on the accessibility of escalation routes?

2.17. How effective was the recognition, assessment and response to risk in Gillian's life?

2.18. How were Gillian's physical and mental health needs understood, assessed and responded to?

2.19. How was Gillian's mental capacity, and factors which might have influenced it, understood, assessed and responded to?

2.20. How was Gillian's alcohol use, malnutrition, smoking and falls understood, assessed and responded to?

2.21. How effectively did services work with Gillian's family?

2.22. How were Gillian's needs for care and support understood and met? What can we learn about the provision of care and support services to Gillian and the circumstances in which services to her were withdrawn or in which Gillian's refused services? What can we learn about support for care agencies and their staff in these circumstances?

2.23. How was supervision, reflection, case discussion etc used to support staff working with Gillian, including in commissioned services?

2.24. Are there any similarities, differences or links with the events described in and learning from the Andrew SAR?

2.25. **Methodology**

2.26. A hybrid method for this SAR was used, designed to facilitate a proportionate, fully inclusive and focussed review. Each agency provided a chronology which gave details of their involvement with Gillian within the agreed scoping period. A learning event was held where practitioners were invited to reflect on their involvement and multi-agency working in relation to the key areas to be addressed and to identify areas for improvement in safeguarding adults. Information from the learning event has been included in this report.

2.27. **Family involvement in the review**

2.28. Gillian's family was invited to provide input to the review and Gillian's sister and her husband met the review writer and the Safeguarding Board Manager to discuss the findings from the report and its recommendations. They also provided comments and further information on Gillian which have been incorporated into the report.

3. BRIEF SUMMARY OF CHRONOLOGY AND CONCERNS

3.1. The following services were involved with Gillian during the time covered by the chronology:

- West Midlands Ambulance Service (WMAS)
- Staffordshire Fire and Rescue Service (SFARS)
- Midlands Partnership Foundation Trust (MPFT) Social Care / District Nursing / Occupational Therapy / Access Team
- GP - Langton Medical Practice, Lichfield
- Staffordshire County Council – Safeguarding / Brokerage
- Housing – Pearce Court Housing Complex
- Domiciliary care agency – Secure Healthcare Solutions
- UHDB – Queen's Hospital
- Housing 21
- Staffordshire Police

MPFT provides adult social care assessment, case management and occupational therapy services on behalf of Staffordshire County Council under a Section 75 agreement.

3.2. **Who was Gillian?**

3.3. Gillian was a white British woman who was 69 years old when she died. Gillian came from a large family and was described as having been great fun to be with. Gillian married and had a son. She was hard working and had many friends. However, Gillian's husband died accidentally in 1997, which affected Gillian greatly and, according to her family, Gillian became very angry. This led Gillian to become estranged from her only son and grandchild. Gillian moved away and lost touch with her family. She lived and worked in Scotland where she had a dog who gave her unconditional love. When Gillian returned to live in England, she brought the dog's ashes with her.

3.4. In 2014 Gillian has an operation on her spinal cord which did not go well and made her condition worse. Gillian became unable to walk. Gillian fractured her right leg and her right shoulder. Gillian broke her ankle and injured her neck in falls resulting in difficulty lifting her arms above her shoulders. The order in which these falls, fractures and the operation occurred, and the timescale between them, is unclear.

3.5. Gillian lived in sheltered accommodation provided by Housing 21. The onsite Sheltered Housing Manager of the housing complex visited Gillian usually once a day and could be summoned using a buzzer system which Gillian had next to her bed. There was also an emergency button in situ within the flat to speed up assistance from

the emergency services. The housing complex is not staffed 24-hours since it is for people who can live independently with a care package in place.

3.6. Gillian was unable to walk, remained in bed 24-hours a day and was unable to access the community. She required full assistance with managing her personal hygiene; dressing and undressing; preparation of all her meals and drinks, maintaining the home environment and managing her toileting needs. Gillian smoked cigarettes and enjoyed drinking wine.

3.7. In March 2022, a social worker from MPFT Social Care visited Gillian at her home and completed an "initial assessment of Gillian's needs" and a care plan.

3.8. The care plan was sent to a care agency, Secure Health Care Solutions (SHCS), a few days before it was due to start delivering a package of care for Gillian. SHCS immediately conducted its own assessments and produced its own risk assessments and care plans.

3.9. In the last week of June 2022, (the exact date is not recorded) SHCS started to provide the care package with, as agreed, three 30-minute care calls a day (of one carer), morning, lunch and evening. On Mondays, an additional 15 minutes was allowed to change Gillian's bedding.

3.10. Gillian's sister was a regular visitor, usually weekly. She did not provide direct care but did Gillian's shopping and laundry on an informal basis.

3.11. On 25th July 2022 the SAST (Staffordshire Adult Safeguarding Team) of Staffordshire County Council received a safeguarding concern from Gillian's sister, via a Quality Assurance Officer, as Gillian had been left without care for eighteen hours. SAST and SHCS discussed the incident by telephone. SHCS gave an explanation and an assurance that it would not happen again. The safeguarding concern was closed as SAST believed there was no ongoing risk of harm. SAST recommended a "review of care", but it is not clear whether Gillian's care package was reviewed. SAST and SHCS also discussed "some of the issues [SHCS] staff [were] experiencing" in working with Gillian.

3.12. On 31st July 2022 Gillian's sister emailed MPFT Social Care raising concerns about a missed care call by SHCS, Gillian's health, her sore skin and her belief that her sister was "giving up".

3.13. On 12th August 2022 SHCS notified SAST by safeguarding "referral" that it had missed two care calls to Gillian on 6th August 2022, in the mistaken belief that Gillian had been admitted to hospital. SAST closed the safeguarding concern as SHCS gave assurances about staff training to prevent a similar situation happening again and SAST considered there was no ongoing risk of abuse or harm.

3.14. On 19th August 2022 a social care assessor and an occupational therapist made a joint visit to Gillian and discussed concerns including missed calls, the timing of calls which impacted negatively on Gillian's food intake, unsafe food hygiene and the application of non-prescribed creams on Gillian's skin. The social care assessor raised these concerns to SHCS by email. The social care assessor also noted that Gillian was

experienced a stinging sensation when urinating, however, no urine sample was requested by Gillian's GP at this time.

3.15. On 22nd August 2022 Gillian's sister advised Gillian's GP that Gillian drank six bottles of wine a week.

3.16. On 22nd September 2022 Gillian's sister reported to MPFT Social Care that Gillian had developed blisters on her body.

3.17. During September 2022 SHCS noted that Gillian refused food on three occasions and that for 45 of the care calls that month, Gillian would only eat biscuits.

3.18. On 14th October 2022 SHCS telephoned MPFT Social Care, asking to "hand back" (withdraw from the contract to provide) the care package due to Gillian being abusive to its staff and declining care.

3.19. On 21st October 2022 Staffordshire County Council Brokerage Team refused to allow SHSC to hand back the care package and instead planned for a "care review".

3.20. On 2nd November 2022 MPFT Social Care conducted a care review and a risk assessment which identified risks of malnutrition, risks to skin integrity because of Gillian's refusal of care and a risk of SHSC withdrawing care due to Gillian's verbal aggression towards carers. It was also noted that Gillian was alcohol dependent and that she had "capacity to make decisions around her care and support needs but some of these decisions can be deemed as unwise".

3.21. On 3rd November 2022 Gillian's GP made a referral to the district nursing team to visit Gillian for pressure sores and to take blood and urine samples for testing.

3.22. On 4th November 2022 a district nurse took a blood sample and asked SCHC to get a urine sample and to check pressure areas. It appears that Gillian refused to give a urine sample.

3.23. On 17th November 2022 SHCS telephoned the district nursing team to advise that Gillian's skin was coming away and that Gillian was declining support from the carers.

3.24. On 22nd November 2022 Gillian's sister telephoned Gillian's GP requesting a home visit because Gillian had "nerve pain, bed sores, no appetite, pain in hands, not eating, will drink water and then drink wine". She also told the GP that Gillian was drinking ten to twelve bottles of wine a week.

3.25. On 23rd November 2022 a NHS 111 GP visited Gillian and noted that she had "capacity", but it is not clear what decisions she had mental capacity to make.

3.26. During November 2022 SHCS's records show that Gillian refused personal care on 26 occasions and refused a change of bed linen on 37 occasions. It appears that multiple offers were and refused.

3.27. On 6th December 2022 Gillian's GP raised a safeguarding concern with the Staffordshire County Council's Staffordshire Adult Safeguarding Team (SAST). This was progressed to a Section 42 enquiry under the Self-Neglect Protocol with an instruction that a multi-disciplinary team meeting should be convened.

3.28. On 11th December 2022 a SCHS carer made a 999-call concerned that Gillian was not eating and refusing personal care. The ambulance crew assessed Gillian as having capacity to refused treatment.

3.29. On 19th December 2022 SHCS served notice to hand back the care package and were due to end care calls on 15th January 2023. Subsequently arrangements were made for a new care agency to take over from 16th January 2023.

3.30. On 21st December 2022 Gillian's sister emailed MPFT Social Care concerned that Gillian's physical health had deteriorated. A social worker noted that Gillian "still appeared to have capacity", but this needed to be explored further as "no formal mental capacity assessment had been undertaken".

3.31. During December 2022 SHCS's records show that Gillian declined food on 33 occasions and refused personal care on 12 occasions.

3.32. On 4th January 2023 NHS 111 had requested blood tests, but Gillian refused. Gillian's GP wrote to MPFT Social Care (received on 9th January) asking if Gillian had capacity to make this decision.

3.33. On 5th January 2023 Gillian was found in pain by the Sheltered Housing Manager who contacted a social worker and Gillian's sister. Gillian refused to allow an ambulance to be called. The social worker and a district nurse attended and decided to act without Gillian's consent and the Sheltered Housing Manager telephoned for an ambulance Gillian was taken to hospital. She was stuck to her mattress, which did not have a cover on it. The ambulance crew had to cut the mattress away around her so she could be safely transported to hospital.

3.34. In the early morning of 6th January 2023 Gillian refused interventions by the hospital. She was "assessed to lack capacity". During a ward round later that day, Gillian was reported to be alert, non-cooperative and to have mental capacity. There was no formal assessment of capacity at that time. In the early evening, a documented mental capacity assessment was undertaken which assessed that Gillian did not have capacity to make decisions about her care and treatment. A MPFT social worker and the ambulance crew each submitted a safeguarding concern to SAST detailing the circumstances they had faced that day. Neither concern was progressed to a Section 42 enquiry because of the already open safeguarding concern raised on 6th December 2022.

3.35. Gillian died in hospital on 9th January 2023.

3.36. Gillian died of sepsis, resulting from bed sores. The death certificate stated this was caused by self-neglect, poor care and malnutrition. Conditions contributing to Gillian's

death, but not related to the disease or condition causing it, were alcohol abuse, chronic obstructive pulmonary disease and osteoarthritis.

4. ANALYSIS

4.1. Who was Gillian and what was understood about her life experiences, including trauma and loss, and her motivations, interests and strengths?

4.2. Although practitioners were unaware, Gillian's husband had died in 1997. The had led to the breakup of her relationship with her son. Gillian's family believe that if Gillian was asked what she really wanted, she would reply that she wanted to be with her deceased husband. Gillian's recent life also appears to have been characterised by loss. According to practitioners, approximately six years prior to her death, Gillian's partner had died. This was the second time that Gillian has been bereaved by the death of a partner. Gillian's son was very close to Gillian's sister, his aunt. According to Gillian sister, Gillian was jealous of her and of her relationship with Gillian's son. Gillian's sister said her relationship with Gillian had not been a happy one. Gillian's dog had also died a few years ago.

4.3. The loss in Gillian's life was not just in relationships. Gillian had worked all her adult life. Latterly, she had lived and worked as a retail manager in Scotland for 15 years, which she had enjoyed. It is not recorded why and by whom, but Gillian had been advised to have a back operation. Gillian had initially refused this, despite having been told of the consequences of doing so. By the time the operation took place, it was apparently too late to be effective, and Gillian was left unable to walk. Gillian was frustrated and angry about this. It is not clear whether Gillian moved from Scotland to Staffordshire before or after her back operation.

4.4. Consequently, Gillian had experienced the loss of close personal relationships, her career, her mobility and independence. Gillian would appear to have been affected emotionally by these losses, which are likely to have led to trauma. Gillian's persistent anger after the untimely death of her husband might have been a sign of this. Bereavement and the loss of relationships are strongly associated with self-neglect. This is demonstrated in Safeguarding Adults Reviews (for example, "Andrew", Staffordshire and Stoke, 2022) and also in research and guidance.

4.5. It is not clear when Gillian started to self-neglect, but from August 2022 onwards there were clear signs of self-neglect in Gillian's reduced food intake; refusal of personal care; not allowing bed linen to be changed, despite her poor skin integrity, and refusal of medical investigations and treatment. The table below has been compiled using data provided by SHCS from its care records. SCHS has acknowledged that the care records are incomplete. The figures shown here may underrepresent the number of incidents and events (Table 1)

Table 1: Incidents of Self-neglect

	Number of visits / number of recordings during the month. At least:				
Month	**August**	**September**	**October**	**November**	**December**
Refused food	10	3	3	"Sharp increase"	33
Biscuits only food intake		45	Most of time		18
Refused change bed linen				37	
Refused personal care / pad change				26	12
Record of poor skin integrity	Some (exact figure unknown)		9	Some (exact figure unknown)	7 Gillian in pain noted 17 times

4.6. It is unclear how many of the occasions of self-neglect were reported to senior SHCS staff and what actions were taken in response to all of them. However, SHCS did raise some concerns with other agencies. For example, on 14th October 2022 SHCS telephoned MPFT social care asking to "hand back" the care package since Gillian was being abusive and was declining support. On 5th December 2022 a carer from SHCS telephoned the "out of hours service" requesting a visit from a district nurse due to signs of further breakdown of Gillian's skin integrity and of an infection.

4.7. In addition to the incidences of self-neglect shown in the table above, during the scoping period for this review, Gillian refused medical tests. Gillian also refused treatment by an ambulance crew, and to be taken to hospital on two occasions and she declined the offer of medication for her low mood from her GP.

4.8. During November 2022, Gillian's GP tried without success to coordinate a visit to Gillian when her sister would be with her. In response, on 5th December 2022 the GP requested that a safeguarding enquiry be made. On 14th December MPFT Social Care noted this under the self-neglect protocol and that a MDT (Multi-Disciplinary Team) self-neglect meeting would be arranged. The GP was told that this meeting would be arranged in the New Year, but there is no record that the GP was invited and it appears that no MDT meeting took place before Gillian died. In hindsight practitioners believe that an MDT meeting should have been arranged earlier. This is consistent with the findings from other SARs (for example Andrew, Staffordshire and Stoke-on-Trent, 2022; Zahra, Surrey 2023) which suggest that MDT approaches are essential when working with people who self-neglect. Despite this, escalation to multi-disciplinary discussion and coordinated interventions is often too late to be effective.

4.9. **Terms of Reference: How were Gillian's physical and mental health needs understood, assessed and responded to? And; How were Gillian's needs for care and support understood and met? What can we learn about the provision of care and support services to Gillian and the circumstances in which services to her were withdrawn or in which Gillian's refused services? What can we learn about support for care agencies and their staff in these circumstances?**

4.10. **Responses to self-neglect**

4.11. Self-neglect can be defined as, "*the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecter and perhaps even to their community*" (Gibbons et al, 2006, p.16). Of especial relevance to Gillian, who was bereaved by the loss of two partners and a dog, the loss of a loved-one is one of the two most common experiences cited by individuals who self-neglect (the other is being a victim of violence) (Lien et al, 2016). Self-neglect is one of the ten categories of abuse and neglect specified in the adult safeguarding sections of the Care Act statutory guidance.

4.12. Extensive research into, and guidance on, working with people who self-neglect is that practice with people who self-neglect is more effective where practitioners:

Table 2: Practice ideas for working with people who self-neglect
Seek to understand the meaning and significance of the self-neglect, taking account of the individual's life experience
Work patiently at the pace of the individual, but know when to make the most of moments of motivation to secure changes
Keep constantly in view the question of the individual's mental capacity to make self-care decisions
Communicate about risks and options with honesty and openness, particularly where coercive action is a possibility
Ensure that options for intervention are rooted in a sound understanding of legal powers and duties
Think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks
Work proactively to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals.

4.13. From August 2022 Gillian had begun to refuse food, as well as medication. Gillian's mental capacity was not assessed until 2nd November 2022. Consequently Gillian's mental capacity to make self-care decisions was not kept constantly in view.

4.14. SHCS telephoned MPFT Social Care on 14th October 2022 advising that Gillian was refusing care, however the self-neglect protocol was not initiated until 14th

December 2022 and no multi-agency meeting was held nor a multi-agency response made to Gillian before she died.

4.15. There appeared to be little effort to understand Gillian and the significance of self-neglect for her. There is little evidence that practitioners explored her reasons for refusing medical intervention and care and support.

4.16. **Trauma Informed Practice**

4.17. A trauma-informed approach by agencies may have established better trust between Gillian and individual practitioners, including SHCS carers. Trauma is a term used to describe the challenging emotional consequences that living through a distressing event can have for an individual. Gillian had lost a dog and two partners. She had lost the ability to walk. As a result, Gillian experienced grief, loss and trauma. Trauma-informed practice gives attention to how practitioners engage with individuals. Further information about trauma informed practice is available at https://www.plymouth.gov.uk/trauma-informed-practice.

4.18. In conclusion, there was no comprehensive understanding of all of Gillian's needs for medical intervention, care and support as her mental health and some of her physical health symptoms were not assessed and explored. Even where her needs were understood they were not always met. There were a variety of reasons for this, including failures by SHSC, lack of trauma informed approaches, Gillian's refusal of care, insufficient attention given, and too late, to Gillian's reasons for self-neglect and a lack of joined-up multi-agency interventions. As a result, responses to Gillian's needs were largely ineffectual.

4.19. **Physical health issues**

4.20. On 19th August 2022 MPFT Social Care noted that Gillian experienced a stinging sensation when urinating. This could have be a sign that Gillian may have had a urinary tract infection (UTI). Three days later a GP visited Gillian. It is not clear what prompted the visit and whether a UTI had been suspected. The GP recorded, however, that Gillian had no problems with her urination. As a result, no urine sample (which might have identified an infection) appears to have been requested or taken at this stage. It is possible that a UTI may have affected Gillian's mood and her behaviour towards others. In older people a UTI can induce changes in behaviour such as agitation or confusion https://www.nhs.uk/conditions/urinary-tract-infections-utis/. A greater awareness of UTIs by non-medical staff and may have led to a more specific investigations.

4.21. Blood test results in November 2022 showed that Gillian's folate level was low. Folate deficiency is common in people who have generally unbalanced and unhealthy diets and in people who regularly use alcohol. Folate deficiency is associated with thickening or hardening of the arteries (atherosclerotic disease). Gillian's GP prescribed medication for Gillian's low folate level and on 8th November 2022 sent a text message asking Gillian to collect the medication from the pharmacy. Gillian was bed-bound and it is not clear whether anyone else was asked to collect it for her.

4.22. **Mental health needs**

4.23. On 31st July 2022 Gillian's sister emailed MPFT Social Care writing that she felt that Gillian was "giving up". According to practitioners, Gillian was noticed to be unwell in August 2022 and there were concerns for her mental wellbeing. When Gillian was advised to eat better or to look after herself, she said that she did not care. During this review practitioners commented that over time Gillian's alcohol consumption increased and this, together with her physical pain, often resulted in low mood.

4.24. On 22nd August 2022 Gillian's GP offered Gillian medication to improve her mood. Gillian refused this and asked for dog therapy instead. There is no record that dog therapy was explored or followed up further. There is empirical evidence for the effectiveness of dog-assisted therapy for depression and anxiety in institutional settings (for example, Ambrosi et al, 2019) and for reducing loneliness (Vrbanac, 2013). The therapeutic process appears to be mediated by dogs acting as facilitators of social interaction, leading to increased interaction with their handlers. Given Gillian's isolation, this may have been a useful approach to not only improve her mood but to stimulate conversation with her about her life and her hopes and fears. Significantly, since Gillian had requested dog-therapy whilst refusing other interventions, it could have been an opportunity to form a therapeutic alliance with her and to work with her strengths. Identifying and responding to moments of motivation is an essential factor in effective intervention in self-neglect and this appears to have been such a moment.

4.25. Gillian's family said that Gillian felt that there was a complete lack of respect for her and for her circumstances. She had been fit and healthy until her failed back operation and had become completely reliant on strangers, particularly for personal care. Gillian was proud and independent and would not talk about how she felt but she wanted to be understood by the people trying to support her. Gillian became increasingly frustrated. Gillian had a huge fear of going into a care home. Following one of her falls, Gillian had moved briefly into a care home which she not disliked intensely. According to her family, Gillian found not being in control very difficult. Approaches which empowered Gillian, involved her and gave her a sense of agency might have been more effective.

4.26. Gillian's family believed that Gillian was depressed. Gillian, however, was not open to mental health services and any underlying mental health issues were therefore not explored. During this review SCHS stated that it approached mental health services, which attended six weeks later and said there was nothing they could do.

4.27. Assessment by mental health professionals to better understand Gillian's refusal to engage with the support offered to her, to explore the reasons for her alcohol consumption or to determine her understanding of the consequences of her decisions, may have been helpful. Long-term trauma and alcohol and substance use can causes frontal lobe brain damage which can impact negatively on cognitive ability and especially on executive brain function (which includes working memory, mental flexibility, and self-control and regulation) which in turn can impact on mental capacity. People with frontal lobe damage caused by alcohol use and traumatic

experiences might have the mental capacity to predict what might happen but are less likely to be able to take action to prevent it from happening. Consequently, close attention to mental capacity when working with people who have a history of trauma and alcohol and substance use is required.

4.28. **Pain**

4.29. Gillian was in pain and this may have affected the way in which she related to others. Gillian's GP increased the dose of Gillian's pain relief patch, but it appears that Gillian continued to experience considerable discomfort and in December 2022 SHSC staff noted on 17 occasions that Gillian was in pain. Gillian's sister wanted Gillian's pain to be better managed and on 3rd January 2023, Gillian's GP made a referral for Gillian to a specialist pain management review service. This was however only six days before Gillian died.

4.30. **Care and support package**

4.31. In the last week of June 2022 SHCS was contracted to provide three thirty-minute care calls to Gillian's home each day, with one carer for each call. The purpose of these calls appeared to be predominantly to meet Gillian's physical needs for personal care, food and drink and for changing Gillian's bedding.

4.32. There were however some concerns about SHCS not attending to Gillian's needs. On 25th July 2022 Gillian's sister raised a safeguarding concern with SAST that SHSC had missed care calls which had left Gillian for 18 hours without food, drink and a change of incontinence pad. After seeking assurances from SHCS that the situation had been rectified, the safeguarding concern was closed since there was no ongoing abuse or neglect.

4.33. On 19th August 2022 a social care assessor from MPFT submitted a safeguarding referral to SAST for a missed care call by SHCS. The concern did not meet the threshold for a s42 Care Act 2014 enquiry. The social care assessor instead sent an email to SHCS to address concerns. These concerns also included quality matters. Carers applied non-prescribed creams for dry skin and lunch care calls were too late and evening calls were too early. This impacted on Gillian's nutritional intake and support with incontinence care / skin integrity. In addition food preparation was unhygienic, which impacted on Gillian's confidence to accept food from carers. SAST asked for Gillian's package of care to be reviewed. It is not clear If this was done.

4.34. On 14th September 2022 SHCS responded to the social care assessor's email addressing each of the concerns. SHCS also commented that its staff struggled to support Gillian, who was very challenging due to her use of alcohol.

4.35. The Sheltered Housing Manager employed by Housing 21, who visited Gillian regularly, felt that some of the SHCS carers were excellent while others provided poor care and failed to record and escalate concerns. However, these concerns were not raised with SHCS

4.36. **Mobility**

4.37. On 5th August 2022 MPFT Social Care discussed occupational therapy involvement with Gillian "in the hope that she would be able to get out of bed". On 19th August 2022, MPFT Social Care and an occupational therapist visited Gillian and discussed the use of a hoist to assist her. Gillian declined as she did not feel confident in the ability of care workers from SHCS to use the equipment with her. A further referral to occupational therapy would be made once Gillian had carers that she had confidence in. In order to "enable Gillian to choose her own carer" direct payments were discussed and information provided but it is not clear why this option was not pursued any further.

4.38. **How effective was the recognition, assessment and response to risk in Gillian's life?**

4.39. Gillian developed both pressure ulcers and moisture legions. According to Gillian's GP practice, skin breakdown would not have been identified by the GP during telephone consultations with Gillian. It also appears that skin breakdown was not always identified and reported by SHCS when Gillian would have been mobilised for change of incontinence pad or bed linen. Gillian, however, did not always want to move because of pain. She also refused to allow district nurses to assess her wounds on several occasions.

4.40. Attempts to meet Gillian's pressure care needs do not appear to have been turned from plans into action. For example, on 6th August 2022 a district nurse ordered a pressure relieving "repose" mattress topper for Gillian. On 27th September 2022 a district nurse (it is not clear if it was the same district nurse), on visiting Gillian, noted that the mattress topper was still in its box and arranged to have it returned unused. Gillian was bed-bound, and there are no notes to suggest what help, if any, had been arranged to unpack and fit the mattress topper.

4.41. On 2nd November 2022 a review and risk assessment was conducted by MPFT Social Care in response to SHCS's request to withdraw from their contract to provide services to Gillian.

4.42. Representatives from SHCS were present as was the Sheltered Housing Manager and Gillian's sister. Gillian had risks of malnutrition and alcohol dependency and to her skin integrity. SHCS felt unable to meet Gillian's needs as she refused care and SHCS was unable to mitigate the risks to its staff, as Gillian was verbally and physically abusive to them. The outcome of the review meeting was that SHCS would prepare snacks and provide additional drinks at lunchtime calls for Gillian and on Mondays would provide a carer who was accepted by Gillian so that she would agree to have her bed linen changed. MPFT Social Care would contact Gillian's GP about her level of pain, low mood, skin integrity and poor dietary intake. MPFT Social Care would also contact occupational therapy for an air mattress. In addition, MPFT Social Care would signpost Gillian's sister to alcohol advice for Gillian and to Carers UK. It appears that no air mattress was provided. Given Gillian's history of service and care refusal, and the guidance on, and evidence basis for, working with people who self-neglect, planning for Gillian's refusals of help or assessment might have been appropriate.

4.43. Instead, the GP referred Gillian to district nursing for a home visit. The district nurses then asked Gillian's carers to check her skin and report any concerns to them. One of reasons for the review on 2nd November 2022 was that Gillian would not accept support from SHCS carers so it is not clear how they would have checked Gillian's skin. In addition, the carers are unlikely to have been sufficiently qualified to assess and report back meaningfully on Gillian's skin.

4.44. The actions following this do not appear to have been particularly effective. On 16th November 2022, Gillian's sister asked the district nursing team to visit Gillian. On 17th November 2022 SHCS telephoned the district nursing team to advise that skin was detaching from Gillian's body. On 24th November 2022, the District Nurses visited Gillian, but she would not allow them to assess her skin. At the next visit on 1st December 2022, Gillian was verbally abusive to the district nurses and again refused to allow her skin to be assessed. On 5th December 2022, an SHCS care worker contacted the MPFT social work out of hours service to report that Gillian's skin integrity had deteriorated further and there were signs of infection.

4.45. Gillian's GP raised a safeguarding concern about Gillian by letter to Gillian's allocated social worker on 5th December 2022. According to Gillian's GP surgery the social worker replied that "safeguarding referrals could not be made by letter" and that "the GP or a clinician must telephone" the safeguarding team. According to MPFT the social worker asked the GP to redirect the concern "to the contact centre either by email or telephone call". The GP contacted the District Nurses on 6th December 2022 for information on Gillian's pressure sores. The District Nurses replied that Gillian had not consented to an examination. These refusals could have been anticipated and planned for since they were the reasons for the concerns about Gillian.

4.46. On 8th December 2022, the district nurses appear to have examined Gillian and noted that her skin condition had worsened. The District Nurse advised that the SHCS carers use a different kind of cream. On 20th December 2022, Gillian was assessed by District Nurses, using the Malnutrition Universal Screening Tool to be at high risk of malnutrition. Gillian was also found to be at high risk of developing pressure sores using the Walsall Community Risk Score Calculator. These tests do not appear to have prompted any further attention or action despite their results. There is no evidence that the results were shared. It appears no further district nursing visits were made. Gillian continued to receive support from SHCS but this was not able to manage her deteriorating condition. Instead, the pattern of raising concerns about Gillian was repeated. On 21st December 2022, Gillian's sister raised concerns with MPFT Social Care about Gillian, who was deteriorating. MPFT Social Care in turn requested that the GP ask the district nurses to visit. On 3rd January 2023, the GP asked Gillian's sister to ask the district nurses to visit. Gillian was admitted to hospital on 5th January 2023 and died on 9th January 2023.

4.47. This cycle and silo working might have been prevented by an approach that involved all the agencies working with Gillian and those that might have role in supporting her. Involving the district nurses in planning and sharing concerns about Gillian might have prepared them for Gillian's predictable refusal of the services. It might have

also provided a context in which Gillian's high risks of malnutrition and pressure sores could be responded to on a multi-agency basis.

4.48. **Were service responses to Gillian influenced by personal feelings about her and did preconceived ideas about Gillian influence approaches to her? Was there confirmation bias and were there assumptions in decision making about Gillian and her needs?**

4.49. Agencies struggled to engage with Gillian. Gillian became angry and could be physically and verbally aggressive. Prior to SHCS's involvement, several other care agencies had withdrawn their services and it is possible that this was as a result of Gillian's refusal of care and behaviour towards them.

4.50. SHCS's daily notes recorded eight incidents of verbal abuse and/or aggression towards its staff in September, five in October and fifteen in December 2022. The number in November 2022 is not clear, but according to SHCS it was becoming increasingly difficult to persuade staff to attend the contracted care calls to Gillian since they were scared of her. Some of the care staff did not have English as a first language. Gillian may have had difficulty understanding them and became agitated. These factors appear to have impacted on the quality of the service.

4.51. "Thwarted Belongingness" refers to a person's feelings of wanting to be, but not being, accepted by others and socially connected with them. Research studies have identified the role of thwarted belongingness in suicide (Van Orden et al, 2012) and also in hoarding (Edwards, 2022)[1], eating disorders (Trujillo et al, 2019) and social exclusion (Albanese et al, 2021). Gillian would appear to have experienced at least two of these. There appear to have been no studies of the connection between feelings of thwarted belongingness and self-neglect. It would, however, seem that one is likely given its association with related factors. Consequently, and consistent with self-neglect practice guidance, approaches which focus on increasing feelings of involvement, acceptance and connection with others might be effective when working with people who self-neglect. Approaches that do not do this are likely to be ineffective and are also likely to reinforce the problem.

4.52. The Housing 21 Sheltered Housing Manager had a good relationship with Gillian and regarded her as a "lovely person once you got to know her". The relationship was not without problems, but the Sheltered Housing Manager was tell Gillian that her behaviour was not appropriate and leave her. SHCS staff may have not felt confident or able to do this. Whilst the Sheltered Housing Manager felt that the service provided by some of the SHCS carers was excellent, she had concerns that some workers tried to avoid Gillian and minimise the time they spent with her. These concerns were not raised with SHCS so that they could be addressed.

4.53. In order to better understand and learn from this situation, the process of "malignant alienation" was considered during this review. The phrase "malignant alienation" was coined by Morgan (1979) to describe the process by which empathy and sympathy are

[1] In fact, thwarted belongingness is a distinguishing factor between people who hoard and people who have obsessive compulsive disorder. People who hoard experience feelings of thwarted belonging. People with OCD do not.

lost and members of staff tend to construe the behaviours of a person who uses services as provocative and unreasonable (Watts and Morgan, 1994). This process is termed malignant since it grows and is associated with fatal outcomes.

4.54. Malignant alienation was first identified in services which support people with personality disorders who self-harm or attempt suicide. The concept also applies to other situations too (Hadfield et al, 2009). General methods for resisting the development of malignant alienation include recognising it and that the difficulties are mutual rather than located in the person receiving services; exploring the reasons for, and functions of, the behaviours; recognising that these are shared problems not misbehaviours; assessing for treatable mental health conditions including depression; and using boundaried engagement approaches which moderate expectations, acknowledge limitations and establish rules of behaviour (see for example, https://cdn.mdedge.com/files/s3fs-public/Document/September-2017/0807CP_Cases.pdf). It would appear that an active approach to mitigate against malignant alienation is more effective than a passive one.

4.55. One of the persistent lessons from Safeguarding Adults Reviews, research and practice guidance is that difficulties with engagement, resistance and service refusal are components of self-neglect. Consequently, they should be expected, planned for and addressed. They should not be considered separately from self-neglect and should not lead to, for example, discharge for lack of adherence to treatment, failure to attend appointments or the rejection of service offers.

4.56. There is a need to consider how to support agencies and staff to manage relationships with people who are hard to engage, to build up trust and to meet their complex needs. This will involve developing skills across the provider and commissioning workforce to recognise and respond to the challenges of service refusal and of unacceptable behaviour. This requires the ability to distinguish self-neglect from other forms of refusal, the resilience to depersonalise aggressive outbursts and insults and the skill to recognise them as indications of the need for services. This must be supported by management supervision and the formulation and testing of behaviour management strategies.

4.57. **How was Gillian's alcohol use, malnutrition, smoking and falls understood, assessed and responded to?**

4.58. Gillian was immobile, bed-bound, smoked 100 cigarettes a day and drank an often-unrecorded quantity of alcohol. Whilst once socially acceptable, the combination of smoking and drinking presents significant health and safety risks. For example, smoking kills more dependent drinkers than alcoholic liver disease does. Smoking worsens diseases associated with alcohol use including oral cancers, coronary heart disease and liver disease. Smoking increases fire risk and fifty percent of domestic fires in England are alcohol related. In this context, good practice was shown by MPFT which made a referral to SFRS (Staffordshire Fire and Rescue Service) on 9th May 2022. SFRS visited Gillian and provided advice and support, including fire retardant bedding. Additionally, on 23rd November 2022 an NHS 111 GP, who been asked to visit Gillian by her GP practice following concerns raised by Gillian's sister about nerve pain, bed

sores and not eating, suggested to Gillian that she should stop smoking. Gillian said that she was too old to do this.

4.59. There was no record of Gillian's alcohol consumption in the care plan provided by MPFT to SHCS, other than that Gillian enjoyed a glass of wine. There appears to have been insufficient attention to the extent of Gillian's alcohol consumption, which may have been underestimated as a result. According to the SHCS, during August 2022, care staff poured two to three beakers (size unknown) of wine for Gillian at every care call.

4.60. In August 2022, Gillian's sister believed that Gillian was drinking five bottles of wine a week. On 19th August 2022, a MPFT social care assessor spoke with Gillian about her alcohol intake. Gillian was unimpressed and responded, "I don't give a monkey's" and "What else do I have to do?".

4.61. During September 2022, Gillian was given two beakers of wine at every care call and left a bottle of wine in reach to pour for herself. By November 2022 Gillian's sister reported that Gillian was drinking twelve bottles a week.

4.62. Gillian received seven to ten bottles of wine in her weekly shopping and her carers bought up to five bottles per week for her. The SHCS office was surprised to find that carers had been buying alcohol for Gillian. It is not clear when the SHCS office found out.

4.63. Gillian's alcohol use seems to have impacted upon her. Practitioners believed that Gillian lost her appetite due to her alcohol consumption. This is likely to have further exacerbated the effects of alcohol.

4.64. According to the Sheltered Housing Manager, Gillian had limited use of her hands and Gillian's sister reported nerve pain to Gillian's GP. It is possible that this may have been peripheral neuropathy (damage to the nerves in the body's extremities) which can be caused by excessive alcohol intake or diabetes. There is no evidence in the chronologies that this condition was explored, diagnosed or treated.

4.65. Gillian had also fallen a number of times, leading to injuries to her ankle and neck, and fractures to her right leg and right shoulder. These may also have been alcohol related but there is no evidence that a connection was explored. Additionally, there is no evidence in the chronologies that Gillian's risk of falls was considered, although since she was in bed this was, probably intuitively, believed to be low.

4.66. Gillian's alcohol consumption also impacted on Gillian's SHCS support staff who believed that alcohol intake contributed to Gillian's aggression towards them.

4.67. Gillian's GP offered Gillian medication to improve her mood, but she declined. Gillian's alcohol use may have partly been a form of self-medication to manage both physical and emotional pain. It does not appear that this was considered.

4.68. Given Gillian's situation, recent history and pain, her alcohol consumption could have been a coping mechanism for trauma, loss and discomfort. On 2nd November 2022 a

risk assessment undertaken by MPFT noted that Gillian was at risk as she was "alcohol dependent". On the same day MPFT signposted Gillian's sister to the website "Bottled-Up" for "problem drinkers" and their families. Apart from this there is no evidence of any other type of intervention with Gillian for her alcohol consumption.

4.69. **How was Gillian's mental capacity, and factors which might have influenced it, understood, assessed and responded to?**

4.70. Gillian's mental capacity to refuse social and health care services does not appear to have been considered until 2nd November 2022, when MPFT conducted a review following SHCS's request to "hand back" the care package. This was despite Gillian's previous and persistent refusals to accept care and her alcohol consumption.

4.71. The risk assessment that "Gillian has capacity to make decisions around her care and support needs but some of these decisions can be deemed as unwise". The term "unwise" is often misunderstood in the context of mental capacity. Principle 3 of the Mental Capacity Act 2005/2007 states that a person should not be treated as lacking capacity merely because they make a decision that others deem "unwise". However, where there is a pattern of unwise decisions, or when the decisions seem to place the person at great risk, as was the case with Gillian, it may be appropriate to at least consider if the person is unable to make the decision.

4.72. Prior to Gillian's admission to hospital on 5th January 2023 there were two further occasions when Gillian's capacity was questioned, but no formal mental capacity assessment was undertaken. These were on 21st December 2022 (queried by a social worker) and 4th January 2023 (queried by a GP). There were also two more occasions (23rd November and 11th December 2022) prior to Gillian's admission to hospital where she was deemed or possibly formally assessed (it is not clear) to have capacity.

4.73. Although there is little information about the content of any mental capacity assessments, there does not appear to have been any consideration of whether Gillian's alcohol consumption, the trauma she suffered through loss, mental ill health (depression) or pain, led to an impairment or disturbance in the functioning of her mind or brain. There does not appear to have consideration of alcohol related brain damage, separate from intoxication, and its impact on capacity. A very detailed mental capacity assessment is necessary as confabulation and dysexecutive functioning can be features. See for example, Alcohol-related brain damage - quick guide for professionals | Alcohol Change UK and Issues in the Support and Management of ARBD | Alcohol Change UK.

4.74. Gillian was assessed to have the mental capacity to refuse care even though this meant that her physical health condition would be likely to deteriorate and she would be in pain. Gillian's sister had already said that Gillian was "giving up" in July 2022. There does not appear to have been any consideration that Gillian's pain, depression and isolation led to or exacerbated her self-neglect. If Gillian had made a decision that she no longer wanted to live, there does not appear to have been consideration of how Gillian could be supported with the consequences of this decision. Instead, Gillian continued to deteriorate.

4.75. On 5th January 2023, Gillian had not eaten for ten days. She was crying out in pain. A social worker, a district nurse and the Supported Housing Manager had been with Gillian all day. Gillian would not give consent for an ambulance to be called but an ambulance was called. The ambulance crew assessed Gillian as having capacity to decide not to go to hospital, but remained worried about Gillian, whom they could see needed care. The crew explained during the practitioners' session that due to Gillian's condition, they wanted to explore every avenue before leaving her. They felt that Gillian would have died sooner if they had left her. Gillian's sister was very grateful for their persistence.

4.76. Consequently, the crew escalated to a more senior supervisor who attended and repeated the capacity assessment. On this occasion Gillian did not recall the information necessary to make a decision to refuse to go to hospital. On this basis, the crew made a Bests Interests decision to take Gillian to hospital. The ambulance crew suspected that Gillian had become tired during the second mental capacity assessment and therefore did not answer the questions.

4.77. Gillian was conveyed to the emergency department on 5th January 2023. Gillian was laying on a mattress without a sheet. She was stuck to the mattress and the ambulance crew had to cut the mattress around her to safely convey her to hospital.

4.78. Gillian refused interventions by the hospital on 6th January 2023 and was "assessed to lack capacity". During a ward round, Gillian was reported to be alert, non-cooperative and to have capacity. There is no evidence of a formal assessment of capacity at this time but later in the day, Gillian was assessed to lack mental capacity to make decisions about her care and treatment.

4.79. There is a need for practitioners to consider mental capacity at an early stage when someone is self-neglecting. This should include the impact of trauma, depression, alcohol misuse or other factors which may have led to an impairment of or disturbance in the functioning of the mind or brain. Where someone is concluded to be making a capacitous decision that may lead to their death, then they could be offered information, options, the right to change their mind and palliative care.

4.80. **How effectively did services work with Gillian's family?**

4.81. Gillian's sister often initiated contact with agencies to raise her concerns about Gillian. Gillian's sister was an active family member, with whom agencies could have worked in partnership to support Gillian. Apart from her participation in a review meeting on 2nd November 2022, there do not appear to have been attempts to use Gillian's sister's knowledge of, or relationship with Gillian to find a way to approach her reluctance to receive care and support. Gillian's sister considered that the different organisations working with Gillian had not involved her or Gillian sufficiently.

4.82. **How was supervision, reflection, case discussion etc used to support staff working with Gillian, including in commissioned services?**

4.83. According to SHCS there were 55 opportunities to escalate Gillian's self-neglect to managers at SHCS, but these were infrequently raised with the SHCS office. SHSC

explained that its staff complete paper records, which are sent to the SHSC office at the end of each month. These are reviewed by more senior staff, but this process can only identify concerns monthly, it cannot respond to more rapid changes.

4.84. SCHS has since increased its number of "field workers" so that senior supervisors visit clients once a month to make sure that services are being delivered appropriately and that self-neglect, and any other areas for concern are identified.

4.85. **Did holiday times impact on service capacity and availability and on the accessibility of escalation routes?**

4.86. On 14th December 2022, SAST started a safeguarding enquiry using the self-neglect protocol, in response to Gillian's GP. It is not clear what was done to progress this enquiry between 14th and 22nd December 2002, when MPFT Social Care advised the GP that a MDT meeting would be arranged. There is no evidence that an MDT meeting was arranged and although an MDT meeting would not usually take place between Christmas and the New Year, one could have been arranged before or afterwards.

4.87. On 30th December 2022 MPFT Social Care notified the GP practice by email that the Sheltered Housing Manager had reported a further physical deterioration in Gillian. Gillian was not eating, was losing physical strength and could not now grip items. Social Care advised that Gillian's condition was concerning and invited the GP's input and opinion. The GP was to attend an online professionals meeting. During this review, the GP practice commented that the GP may have been waiting for the online professionals meeting before taking any action. A GP home visit may not have been possible because it was the week between Christmas and New Year and it is likely that there would have been minimal staffing.

4.88. **Are there any similarities, differences or links with the events described in and learning from the Andrew SAR?**

4.89. **Were there barriers to practice, for example, in taking the lead to organise multi-agency meetings and interventions, or in learning and applying lessons from previous safeguarding adults reviews, practice guidance or training when working with Gillian?**

4.90. During this review, practitioners stated that agencies were working, to some degree, in isolation, although there was contact between Gillian's GP and MPFT Social Care, and between Gillian's GP and district nurses. No professional took the lead to initiate and coordinate multi-agency responses until mid-to-late December 2022, when a decision was reached that a MDT meeting was needed, which should include a mental health professional. This meeting did not take place before Gillian died.

4.91. An MDT meeting at an earlier date, soon after 2nd November 2022, may have resulted in the identification of new multi-agency approaches and interventions to meet Gillian's needs, build up trust, and manage or possibly avoid Gillian's refusal of help. There seems to have been a slow recognition that Gillian was self-neglecting. Instead, she was a reluctant and difficult person to provide services to who made unwise

decisions. The first use of the self-neglect protocol was from 14th December 2022, but was not implemented quickly. The components of the lack of recognition that Gillian was self-neglecting would appear to include (table 4):

Table 4: components in the lack of recognition of self-neglect
Gillian had a history of service provider change, although SHCS had not be told of this.
Gillian's reluctance to receive support from SHCS was interpreted as a response to poor quality care. It is possible for someone to self-neglect and to also receive, for various reasons, inappropriate and poor quality support. They may be intertwined but are distinct from each other.
Details of the extent of Gillian's self-neglect (for example, food and alcohol intake; refusal of care) were not shared between agencies. SHCS was not in direct contact with commissioners or adult safeguarding services.
The impact of Gillian's self-neglect (for example, skin integrity, risk of pressure sores and malnutrition; potential neuropathy) was not shared between agencies.
The extent of Gillian's alcohol intake was underestimated or not known. Gillian was supported to drink alcohol as part of her package of care. Support with alcohol use has to be consensual. Gillian drank wine rather than spirits or not-for-consumption-alcohol.
Gillian had a physical reason (an unsuccessful spinal operation) for remaining in her bed.

4.92. The "Andrew" SAR found that the coordination of activity to understand and respond to needs should be improved and this would appear to be a feature of the work with Gillian. Unlike "Andrew", where for example, safeguarding concerns were closed with no further action, each component in the lack of recognition of Gillian's self-neglect was dealt with discreetly. Gillian's care needs were recognised; a package of support was commissioned; problems in provision were identified and responded to as quality problems; the deterioration in Gillian's skin integrity and her malnutrition were assessed and rated; Gillian's alcohol consumption was incorporated into her support package and she was advised to stop smoking. This approach, however, missed the bigger picture of how these components combined.

4.93. An approach which understood them all might have been more effective. There was no multi-agency understanding of Gillian's situation in which different perspectives and information could be shared and approaches discussed and coordinated. There was an opportunity for this following the review on 2nd November 2022 and from 14th December 2022 when the self-neglect protocol was invoked. These, however, led to either a circular process of referrals and Gillian's refusal of help or to no action before she died.

4.94. The "Andrew" SAR also identified a need to increase attention to mental capacity and choice and the exploration of personal circumstances. Similarly, Gillian's mental capacity was not assessed until November 2022 when she was found to have the mental capacity to make decisions about her care and treatment. The first principle of the Mental Capacity Act 2005/2007 is the presumption of capacity to make a decision. Practitioners struggle to identify the situations in which to question this presumption.

There would appear to be a need to emphasise the circumstances in which it is appropriate to question a person's mental capacity when for example, the make a series of what appear to be unwise decisions or when they make decisions that will lead them to harm.

4.95. Gillian's recent background was quite well understood. Despite this, the impact of the combined loss of a number of significant parts of her life does not appear to have been understood and considered in the context of her self-neglect.

4.96. **Good practice**

4.97. The ambulance crew showed great persistence with Gillian on 5th January 2023, which led to her admission to hospital. Where it is clear that someone's life may be at risk, but they appear to have capacity to refuse treatment or intervention, the learning from this is to be tenacious. Escalating concerns to the attention of others, staying with the person and revisiting mental capacity assessment may help to overcome resistance.

4.98. MPFT Social Care involved Gillian's sister in its review meeting following SHCS's application to withdraw for the contract to provide services to Gillian.

4.99. Good practice was shown by MPFT which made a referral to SFRS for a fire safety visit.

5. CONCLUSIONS

5.1. **Gillian's life does not appear to have been understood.**

5.2. Gillian's life would appear to have been characterised by loss, which appears to have been traumatic and contributed to her self-neglect and refusal of support. She is also likely to have been in pain, decreasing her tolerance, increasing her frustration and exacerbating her refusal of services. According to her family, Gillian wanted the losses she had experienced to be understood and for those trying to support her to show empathy towards her. Approaches which try to understand the reasons for self-neglect and refusal of help, identify and work with strengths and interests and coordinate multi-agency activity are the most likely to be effective when working with people who self-neglect. There does not appear to have been a shared recognition that Gillian was self-neglecting and instead she seems to have been considered to be a somewhat difficult refuser of services. Consequently, the self-neglect procedures were not instigated until a referral by Gillian's GP in December 2022. The process then did not work rapidly and whilst an MDT meeting was to be arranged, this did not happen before Gillian's death.

5.3. **Recognition of risks in Gillian's life.**

5.4. There were few formal risk assessments despite the extent of Gillian's needs. The review and risk assessment on 2nd November 2022 was an appropriate response and involved SHCS and Gillian's sister. It might have been more effective if it had also involved Gillian's GP and the district nurses and had planned for Gillian's inevitable refusals of help. On 5th December 2022, a safeguarding referral was made by Gillian's

GP which was delayed because it was sent to a social worker rather than the "contact centre". The time taken to point this out to the GP might have been better employed on making arrangements for an MDT meeting.

5.5. The process for assessing and potentially treating Gillian's pressure sores became caught in an unproductive cycle of delegated referrals and Gillian's refusal of help. Despite multiple concerns received by different agencies and the assessment that Gillian was at high risk of malnutrition and pressure sores, there appears to have been no sense of urgency or of ensuring that actions were undertaken. It appears that the process for identifying and responding to risks in Gillian's life was half completed and a fully multi-disciplinary approach from 2nd November 2022 might have been more effective.

5.6. **Agencies struggled to meet Gillian's needs.**

5.7. There was a lack of information sharing about the challenges of meeting Gillian's needs. CHCS was commissioned to provide a package of care to Gillian but was not informed that other previous support arrangements by other agencies had broken down. CHCS was also not notified about the extent of Gillian's alcohol use and how to approach this. Gillian had multiple health and social care needs, which with support from district nurses, Gillian's GP and mental health services, could be met.

5.8. CHCS carers however, found it very difficult to meet Gillian's needs because of her behaviour towards them. District nurses similarly found Gillian resistant to their attempts to support her. CHCS tried to hand back the care package but this was refused by Staffordshire County Council Commissioning, which instead required a review. When a care agency is struggling to provide a package of care in these circumstances a support process could be used to overcome barriers and resistance. This could involve the application trauma informed approaches that recognise and respond to the formation of malignant alienation and thwarted belongingness. The review did not lead to these types of approaches being suggested or implemented. Alternatively, a more suitable specialist care agency equipped to work in this way could be found.

5.9. It is likely that there is a need to develop the care market and the skills available to meet the needs of people who self-neglect. The reasons for frequent changes of care provider should also be explored and could prompt a multi-agency meeting to consider how needs can be met and what support, reporting and alerting system are required to enable care staff to deliver care.

5.10. **Gillian's alcohol use, malnutrition, smoking and falls were not well understood, assessed or responded to.**

5.11. Gillian was immobile, bed-bound, smoked 100 cigarettes a day and drank, what was discovered through this review to be a large quantity of alcohol. Alcohol consumption is often underestimated and where concerns about its extent develop then it is important to record the quantity consumed as accurately as possible. Whilst there was a fire safety response to Gillian's smoking, her alcohol consumption appears to have become normalised. She was regularly given alcohol on care visits and CHCS carers appear to have bought alcohol for Gillian in order to placate her and

to try to improve their relationship with her. This seems to have turned attention away from the role that alcohol may have played in Gillian's life as physical and emotional pain killer. Consequently, there does not appear to have been exploration of the physical and mental health impacts of Gillian's alcohol consumption and its potential role in the reduced use of her hands or her falls. In November 2022 there was a recognition that Gillian may be alcohol dependent but this only led to sign-posting her sister to a website. According to Gillian's family, towards the end of her life, Gillian's alcohol consumption decreased because she was unable to lift her arms.

5.12. **More attention to Gillian's mental capacity was required.**

5.13. Gillian's mental capacity to make decisions about how her care and health needs should be met was not regularly considered. The first recorded mental capacity assessment was in November 2022, when Gillian was found to have capacity to make decisions about how her care and health needs should be met but was noted to make unwise decisions. The Mental Capacity Act 2005/ 2007 does not give people the right to make unwise decisions and instead, if there is a pattern of unwise decisions, or when the decisions seem place the person at great risk, as was the case with Gillian, it may be appropriate to at least consider if they are unable to make a decision.

5.14. In certain circumstances, people may refuse care and treatment and neglect themselves for religious and political or because of their assessment of the quality of their life against the quantity of it. Examples of these include refusals of blood transfusions, hunger strikes, and refusal of life prolonging treatments for cancer or kidney failure. Especially in the latter situations, a process which includes mental health assessments and treatment, offers of alternative approaches, exploration of options and palliative care is used. An approach like this could be considered for people who, after other methods have been tried, are mentally capacitous, self-neglect, refuse help and have made a decision about the quality of their life.

5.15. **How effectively did services work with Gillian's family.**

5.16. Apart from her participation in a review meeting on 2nd November 2022, there was little evidence of joint working with Gillian's sister to support Gillian. There do not appear to have been attempts to use Gillian's sister's knowledge of, or relationship with Gillian, to find a way to approach Gillian's reluctance to receive care and support.

5.17. **Service monitoring and support was not effective in responding to Gillian's needs.**

5.18. The SHCS monitoring processes were not frequent enough to respond to and support care staff when they were struggling to work with Gillian. SCHS has improved its "field" supervision but there appears to be a need across agencies to take a trauma informed approach with people who self-neglect. This should be supported by supervision and management approaches that assist practitioners to recognise self-neglect and to accept that disengagement and refusal are needs. Multi-agency escalation should be required as should the use of strengths-based approaches aimed at exploring why someone is self-neglecting. These approaches

may assist in locating problems with providing services to people who self-neglect within a framework of understanding.

5.19. **Did holiday times impact on service capacity and availability and on the accessibility of escalation routes?**

5.20. There was a delay in setting up an MDT meeting during December 2022 and January 2023. There is no evidence that an MDT meeting was arranged before or after Christmas and New Year.

5.21. **Are there any similarities, differences or links with the events described in and learning from the Andrew SAR? And were there barriers to practice, for example, in taking the lead to organise multi-agency meetings and interventions, or in learning and applying lessons from previous safeguarding adults reviews, practice guidance or training when working with Gillian?**

5.22. During this review, practitioners stated that agencies were working, to some degree, in isolation, although there was contact between Gillian's GP and MPFT Social Care, and between Gillian's GP and district nurses. No professional took the lead to initiate and coordinate multi-agency responses until mid-to-late December 2022 when a decision was reached that an MDT meeting was needed, which should include a mental health professional. This meeting did not take place before Gillian died. An earlier MDT meeting may have resulted in new approaches and interventions to meeting Gillian's needs, building up trust, and to manage or possibly avoid Gillian's refusal of medical help.

5.23. There were similarities with the findings from "Andrew" SAR in recognition of and response to self-neglect, in coordination of activity, attention to mental capacity and exploration of Gillian's personal circumstances. Unlike "Andrew", however, action was taken in response to different components of Gillian's situation but these were not combined into a whole. An approach which understood them all might have been more effective. There was no multi-agency understanding of Gillian's situation in which different perspectives and information could be shared and approaches discussed and coordinated. There was an opportunity for this following the review on 2nd November 2022 and from 14th December 2022 when the self-neglect protocol was invoked. These, however, led to a circular process of referrals, Gillian's continued refusal of help and, apart from the events of 6th January 2023 when Gillian was taken to hospital, little effective action before she died.

6. RECOMMENDATIONS

6.1. Recommendation 1: The Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board (SSASPB) should seek assurance that partner agencies use training sessions, learning events and one-to-one management meetings to support their staff to recognise self-neglect, especially when someone is receiving care and support services, and to use the self-neglect process, including holding MDT meetings.

6.2. Recommendation 2: The SSASPB should seek assurance from partner agencies that where interventions are planned for an individual who has a history of service refusal, relevant professionals are involved in planning for how they might avoid, minimise or otherwise respond to, future refusals.

6.3. Recommendation 3: The SSASPB should seek assurance from partner agencies that they listen to the needs of people who self-neglect and support and facilitate access to interventions they want and are willing to receive even if these are outside the traditional remit of services.

6.4. Recommendation 4: The SSASPB should assess whether the local care market and housing support has the skills available to meet the needs of people who self-neglect, and if it falls short, consider how the care market may be encouraged and supported to develop such skills in sufficient quantities.

6.5. Recommendation 5: The SSASPB should seek assurance from partner agencies that, where appropriate, mental capacity assessments of people who self-neglect are made jointly with someone who knows them, has a relationship with them and also has an understanding of alcohol related brain damage and its impact on mental capacity.

6.6. Recommendation 6: The SSASPB should consider how people can best be supported in circumstances where they are mentally capacitous, self-neglect, refuse help and have made a decision about the quality of their life.

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