West Sussex Safeguarding Adults Board

Safeguarding Adults Review in respect of John

Author: Abbie Murr
Date: 31 May 2023

Version 1 | 31 May 2023

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1. Foreword

1.1. The West Sussex Safeguarding Adults Board (SAB, or the Board) has published this Safeguarding Adults Review (SAR, or Review) in relation to John.

1.2. The Board and the Independent Reviewer wish to express their sincere condolences to John's family and those who knew and worked with him. John's niece contributed to the Review by providing information about John as a person, his personality, details of his life and, a view on John's care and support at the end of his life.

1.3. Earlier on in life, John served in the military and after, held a variety of farm and factory jobs before becoming a postman, a job that he loved and took very seriously. John was an avid collector. Prior to losing his eyesight he collected Rupert Annuals and later, began to collect audio books, both of which he took great care of. John married in later life and was married for 15 years. John became his wife's main carer, before she sadly passed away from cancer.

1.4. After fracturing his hip in December 2020, John required long-term care and was initially placed, temporarily, in a Care Home. John's niece explained that John realised his need for care would be permanent, so he chose to remain in the Care Home.

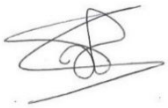
1.5. John had some difficulties with his mental health over the years and at times believed his phones were being "bugged" or that he was being covertly watched or spied on. On the 12th of June 2022, his 88th birthday, John made the decision to end his life by way of refusal of foods and fluids. 11 days later, John passed away in the early hours of the 23rd of June 2022.

1.6. Following John's death, a SAR referral was made to our Board. The SAR subgroup acknowledged there were areas where agencies involved with John could learn from, including collaborative working, the need to consider professional curiosity, determination of capacity, end-of-life care, and the involvement of agencies and care provided prior to John's decision to end his life.

1.7. It was agreed that the criteria for a SAR was met and Independent Reviewer Abbie Murr was appointed to lead this Review.

1.8. The purpose of a SAR is to identify how lessons can be learned, and services improved for those who use them, and for their families and carers. This Review looked at the circumstances prior to John's death and the actions of agencies. Recommendations made will enable lessons to be learned and contribute to service development and improvement. Although agencies have not waited for the outcome of this SAR to consider their own learning, we will ensure that they are fully engaged in taking forward, together, the Review recommendations.

1.9. The Board will monitor progress on the implementation of recommendations to reduce risks and ensure the development of systems and procedures to improve practice. The Board will also ensure that learning from this Review is widely shared and that the outcomes of the learning will lead to improved services in West Sussex.



Annie Callanan, Independent Chair

2. Introduction

2.1. The Care Act 2014, Section 44, requires that Safeguarding Adults Boards must arrange a Safeguarding Adults Review when certain criteria are met. These are:

- When an adult has died because of abuse or neglect, or has not died but experienced serious abuse or neglect, whether known or suspected, and;
- There is a concern that partner agencies could have worked more effectively to protect the adult.

2.2. Safeguarding Adults Reviews are required to reflect the six safeguarding adults' principles, as defined in the Care Act. These are empowerment, prevention, proportionality, protection, partnership, and accountability.

2.3. The aims of the Safeguarding Adults Review are to contribute to the improved safety and wellbeing of adults with care and support needs and, if possible, to provide a legacy and support family and friends.

2.4. There are clear review objectives which have been addressed to achieve these aims. Through a shared commitment to openness and reflective learning, involved agencies have sought to reach an understanding of the facts (what happened), an analysis and findings (what went wrong and what went right), the recommendations to improve services and to reduce the risk of repeat circumstances, and a shared action plan to implement these recommendations. It is not the purpose of the review to re-investigate the suspected abuse or neglect, or to apportion blame to any party.

2.5. The review process to meet these aims and objectives has followed a clear path. The Independent Reviewer has chaired an initial panel meeting to agree the review terms of reference; conducted research by critically analysing Individual Management Reports, chronologies and relevant records held by involved agencies and by interviewing representatives of agencies; culminating in a planned Safeguarding Adults Review Outcome panel meeting and presentation to the West Sussex Safeguarding Adults Board.

3. Overview of the case and circumstances leading to the review

3.1. John was an 88-year-old white man, who on the 12th of June 2022, his 88th birthday, made the decision to end his life by way of refusal of foods and fluids. John passed away in the early hours of the 23rd of June 2022, some eleven days later at Rotherlea Care Home where he had lived since the 24th of December 2020. The official cause of death has been recorded as:

- 1a. Renal failure
- 1b. Dehydration
- 1c. Frailty of old age

3.2. Between the 17th and 22nd June 2022 five adult safeguarding concerns were raised to the West Sussex County Council Adult Safeguarding Team by several agencies

involved in the care and support of John. During this same period John's mental health was assessed under the Mental Health Act 1983 (as amended, 2007) and by the Sussex Partnership Foundation Trust Older Peoples Mental Health Team. Additionally, five assessments of John's capacity were undertaken by several agencies, with differing views on whether John was capacitated or not.

3.3. The SAR subgroup acknowledged there were areas where agencies involved with John could have collaborated more effectively, as well as the need to consider professional curiosity, determination of capacity, end-of-life care, and the involvement of agencies and care provided prior to John's decision to end his life. The subgroup considered that the criteria for potential neglect by agencies was met.

3.4. Summaries of Involvement (SOI)/IMR's were requested from the following agencies:

Agency	Date SOI/IMR requested	Date received
South East Coast Ambulance Service	N/A	17.02.2023
Approved Mental Health Professional Service	06.03.2023	22.03.2023
West Sussex County Council	06.03.2023	03.04.2023
Integrated Care Board (Continuing Health Care Team)	06.03.2023	21.03.2023
Rotherlea Care Home	06.03.2023	06.03.2023
Rotherlea Care Home (further information requested)	31.03.2023	12.04.2023
Sussex Partnership NHS Foundation Trust	09.03.2023	14.03.2023
Sussex Partnership NHS Foundation Trust (further information requested)	31.03.2023	06.04.2023
Sussex Community NHS Foundation Trust	09.03.2023	28.03.2023
GP		17.04.2023
Niece of John (shared coroners questions/character statement)	NA	17.03.2023

3.5. The scoping period for this Review is from 1st January 2022 to 26th June 2022.

4. Literature review referencing local and national learning

4.1. The Independent Reviewer attempted to locate comparable Safeguarding Adult Reviews (SARs) in which voluntary stopping and eating drinking (VSED), of capacitated and non-capacitated adults played a significant role. After a thorough internet search, it does not appear that any SARs of this nature have been published. In addition, there is presently no nationalised information or guidance

regarding capacitated adults who chose to hasten their death by refusing food and fluids that could assist clinicians and practitioners with anticipatory care planning[1]. However, case law does exist regarding the management of symptoms in individuals who wish to hasten their death in this manner who are capacitated at the time they make the decision to end their lives via VSED[2]; this will be discussed further in section 10 (Analysis of Findings) of this report.

5. Key themes identified for this Review

5.1. The following key themes have been identified.

- Professional curiosity and defensible decision making
- Multi-agency working and professional accountability and ownership
- Agency resources and staffing capacity
- Safeguarding and self-neglect
- Mental capacity
- Voluntary stopping eating and drinking and end of life planning

5.2. These themes are reflected in the associated terms of reference:

- Professional curiosity
- Determination of capacity
- End of life care
- Multi-agency care

6. About John

6.1. John was an 88-year-old man, who was partially sighted and registered as blind. Since 2011 John had a urinary catheter because of chronic urinary retention. John was discharged to Rotherlea Care Home on the 24th of December 2020 after breaking his hip resulting in a total hip replacement. John was self-funding his care and therefore did not receive annual reviews of his placement as would be the case if he was funded by the local authority or by Continuing Health Care (via the Integrated Care Board, previously known as the Clinical Commissioning Group). In February 2022 John had a fall in his bathroom, resulting in bruises on his back and left elbow. John's niece reports that the fall negatively impacted John and he lost a lot of his confidence.

[1] Compassion in Dying [2022] 'Voluntary Stopping Eating and Drinking: A call for guidance'
[2] R (Nicklinson) v Ministry of Justice [2014] UKSC 38, para 255

6.2. John had a range of health issues, namely:

- Chronic kidney disease
- Myocardial infarction
- Benign prostatic hyperplasia
- Hereditary hemochromatosis
- Total hip replacement
- Ischemic heart disease
- Enlarged prostrate
- Macular degeneration

6.3. John served in the military for a number of years, and after departing the military, he held a variety of farm and factory jobs before becoming a postman. John cherished his position as a postman and took it very seriously, frequently exceeding his contractual hours of service.

6.4. John married later in life, and he and his wife were devoted to each other. The couple didn't have children. Sadly, John's wife's mental health deteriorated significantly, and she required full time care, resulting in John leaving his job as postman to care for his wife. During this time John's wife was also diagnosed with cancer and John nursed her until her death, the couple had been married fifteen years at the time of her death.

6.5. John was an active member of the Liberal Democrats for a number of years. John's niece recalls that she got the impression he fell out with someone, so after a few years and with his declining health and eyesight, he left. John's niece also recalls that during this time John received threatening mail from the TV Licensing authorities which John took extremely personally given he hadn't owned a television for many years.

6.6. John was an avid collector of Rupert Annuals, and most weekends would travel to antique fairs across the country to collect his beloved Rupert Annuals. However, in 2002 John was diagnosed with macular degeneration and as his eyesight declined over time John was unable to attend the antique fairs. As a result, John sold all his annuals at a loss to a local collector. However, John's love of collecting did not end there, as he then begun to collect audio books. John had a huge range of audio books, which he kept meticulous, and would often clean the covers, ensuring there were no fingerprints.

6.7. John enjoyed listening to his radio in addition to his audio books. Given his hearing impairment and aversion to headphones, he would play his audio books and radio at maximum volume. Upon moving to Rotherlea, however, staff members would enter his room and lower the volume so as not to disturb the other residents. John determined that if he couldn't listen to his audio books and radio as he desired, he would stop listening altogether. John therefore spent most of his time alone in his room because he did not wish to participate in any of the activities offered by Rotherlea.

6.8. John's niece described John as 'reclusive' and said he had few acquaintances over the years, with the exception of his neighbour Frank, with whom he socialised until Frank's passing. She stated that John was always a stickler for following the rules and was extremely determined, stubborn, and obstinate. John's niece explained that John "had never been a happy person" and "once someone annoyed him there would be no renewing of friendship". She stated that John was "incredibly stubborn" and that "everything had to be done by the book." She described John as a "bit of an oddball" and provided an example of a group of young people who would arbitrarily call his name as he walked by. However, John's niece stated that he may have misunderstood due to his hearing impairment.

6.9. After fracturing his hip in December 2020, John required long-term care and was initially placed temporarily at the Rotherlea Care Home. John's niece explained that John realised his need for care would be permanent, so he chose to remain at Rotherlea. She stated that although John was unhappy at Rotherlea, he did not feel like he was constantly being "tested" as he did when he was in hospital and was able to accept his situation. She also mentioned that John had a particularly strong rapport with one carer.

6.10. **Mental health over the years**

6.11. After Frank's death and the arrival of new neighbours, John began to change, according to John's niece, and this occurred approximately twenty years ago. She explained that John began to suspect that his house and phone were being "bugged" and that his neighbours were to blame. He believed that taxi drivers were police officers operating covertly. She further stated that whenever John was hospitalised, he believed that the nurses were "playing games with his head". She also stated that John frequently accused her of "spying" on him and attempting to "make him mental." In her coroner's character statement, she also provided an example of John's paranoid ideation while he was hospitalised, describing how he was convinced that hospital staff had intentionally swapped his electric razor despite her numerous attempts to convince him otherwise. Additionally, she states, "this behaviour seemed strange as he was mentally alert with other aspects of life, and he always came across as a law-abiding person".

6.12. John consulted his doctor in 2017 and 2018 about "funny things" that were occurring. However, John was determined to be "functioning normally" and no diagnosis or referral to the Older Persons Community Mental Health Team was made. John reported to his doctor in 2020 that he was "being bugged" and "interrogated" during a recent emergency catheter insertion at A&E. The doctor found John to be "suspicious and paranoid," but knew where he was, what time it was and who he was. The doctor had recorded that the plan was to "watch and wait." In 2021, John visited his doctor with low mood, disinterested in life, and had the desire to end his life but no plans to do so. John was prescribed an antidepressant called Mirtazapine.

6.13. John's niece believes that receiving a birthday card from his cousin triggered John's decision to end his life by ceasing eating and drinking. She explained that when she visited John on June 16, 2022, John "thrust" a birthday card at her. In the card, John's cousin explained that she had taken a DNA test and discovered that they had unknown relatives on their grandmother's side of the family. She explained that this appeared to alarm John, and he questioned whether his cousin

had questioned her paternity. John's niece asserted that he did not comprehend that it was merely a popular trend of the present day. Although John's niece debated with him at length about the innocuousness of the situation and attempted to convince him to change his opinion, she acknowledged that her efforts were futile. Although John's niece was shocked by his decision to end his life by not eating and drinking, she wasn't entirely surprised because he had stated a few months earlier that he 'could always stop eating'. John's niece explained that he may have committed a minor infraction in the past, which led him to believe he was being spied on and monitored by various agents of the state, and the mention of DNA testing in his disoriented state caused him great distress and ultimately led to his decision to take his own life.

7. Engagement with family

7.1. The Independent Reviewer spoke with John's niece to ensure that the family's perspective was fully comprehended and reflected in this report. This narrative not only provided a comprehensive overview of John as a person, his personality, and the situations he had encountered throughout his life, but also provided context for the information received from the agencies involved in John's care and support at the end of his life.

7.2. In the event that John lost mental capacity, his niece explained that she had the authority to make health and care decisions for him as she held power of attorney. She explained that she had promised John that no one would ever do anything she knew he would not want. She then provided an illustration of how she knew John would not want to be admitted to hospital based on his previous negative experiences. John’s niece described the extremely difficult and emotional situation she found herself in when John decided to end his life by voluntarily stopping eating and drinking, and how professionals wanted to admit John to hospital, but she knew this would have been against John's wishes and it was ultimately her decision to make on John's behalf. She explained that on June 21 2022, John's GP contacted her to inquire about her views on hospitalisation, and she informed him that she needed additional time to consider. The following day, however (22 June 2022), she notified John's GP that hospitalisation was not in accordance with her uncle's wishes and that she believed it would be in his best interests to remain at Rotherlea as long as his comfort could be adequately maintained there.

8. Summarised chronology

8.1. The review focuses on the events preceding John's death, during which there were a number of opportunities to gather information that could have aided in decision-making regarding the mental health assessment, Mental Health Act assessment, assessments of capacity, and safeguarding adults’ concerns. Additionally, several opportunities that could have promoted greater partnership working have also been identified.

Date	Concern/activity	Outcome
19.02.2022	John has fall in his bathroom, sustained bruises on his back and left elbow.	John loses confidence as a result of fall.

21.02.2022	John diagnosed with a catheter associated urinary tract infection. John had to have re catheterisation by District Nurse.	Commenced antibiotics
01.03.2023	Reported by District Nurse that both John's buttocks are sore, red/purple in appearance.	Proshield being applied and currently no open areas. Profiling cushion and pump mattress in situ.
06.04.2022	John complained of a pain in his hip.	Painkiller prescribed
04.05.2022	John has swollen and red leg, diagnosed as led oedema with some infection.	Commenced antibiotics and a diuretic
07.06.2022	John had become confused over 2-3 days; a urine dipstick test was suggestive of a urine infection.	Commenced antibiotics
10.06.2022	John developed infection around his foreskin.	Commenced antibiotics and antifungal cream
12 +13.06.2022	John declined food and fluids (John's Birthday on the 12th June)	Not unusual for John to decline food and fluids on occasion.
14.06.2022	John declined food and fluids as no longer wants to live.	Concerns escalated; MDT arranged next day
15.06.2022	MDT - GP, community admissions avoidance matron, community matron, Rotherlea's manager and deputy manager. Referral to OPMHT for urgent 4hr response assessment.	Urgent 4-hr response assessment from Sussex Partnership Foundation Trust Older Peoples Mental Health Team (OPMHT). OPMHT unable to attend due to critical staffing levels – assessment agreed for following day.

16.06.2022	Niece (LPA) visits John.	Niece reports John had received birthday card from his cousin on the 12th where she had written that after a DNA test, she has found family related to them. Niece reports John was distressed by this, and distress seemed to be linked with ongoing long term paranoid ideation John regularly voiced. Niece is of the opinion that John's decision to end his life was linked to receiving the birthday card and John's paranoid ideation.
16.06.2022	Rotherlea escalate need for urgent assessment with OPMHT	OPMHT unable to attend due to critical staffing levels
17.06.2022	Assessed by OPMH	No evidence of mental illness and **mental capacity intact**.
17.06.2022	Rotherlea request Mental Health Act Assessment (MHAA)	Due to 'stretched resources' date/time of MHAA could not be provided by AMHP Service.
17+18.06.2022	Safeguarding Concern Raised by Rotherlea	Recorded by safeguarding team that criteria for safeguarding not met and that the MHAA was the most appropriate course of action (reviewed on the 18th June 2022).
19.06.2022	MHAA at 23:00hrs	MHAA Report states '**lacking capacity'** in relation to John's refusal of food, fluids and medication and that a "best interest decision meeting and assessment of capacity required". AMHP t/c to ambulance for admission to hospital due to physical health and lack of capacity. Rotherlea case notes state that from handover from assessing MHAA team John *'has capacity to make his own decisions but concerned about his physical health'*

19.06.2022	Ambulance attends	John refuses to attend hospital, paramedics assess John **to have capacity** to refuse being taken to hospital, John left at Rotherlea.
20.06.2022	GP assessment of capacity	GP assessed John as **lacking capacity** to make an informed choice regarding whether he should be admitted to hospital or not. Decision made for John to remain at Rotherlea until the end of his life and that he would have access to end of life supporting medications if needed. This decision was made by the assessing GP and by John's niece who held LPA for health and welfare.
21.06.2022	GP seeks legal advice re prescription of end-of-life medications to someone that is choosing to end their life.	Legal advice given that prescription would not be appropriate as it could be perceived that they were assisting John to end his own life.

21.06.2022	Best Interest Meeting and MDT - AMHP (leaves before "pre-emptive" BI discussions), GP, Rotherlea Management/Nurse, clinical nurse practitioner and care co-ordinator from GP surgery. GP T/C to John's Niece (LPA)	**Discrepancy in information provided by agencies regarding outcome of best interests meeting.** **Rotherlea chronology** states there were "pre-emptive discussions re BI after AMHP left meeting and that decision on discussion between GP and John's niece was for John to remain at Rotherlea even after possibly becoming unconscious and only be admitted to hospital if staff at Rotherlea believed him to be distressed or in any pain. **GP Statement** states John's niece felt that an admission to hospital would cause him enormous stress. She also felt that he had been very clear in stating his wishes to end his life in this manner when he was found to have capacity, but that she needed more time to think. GP concludes that it is in John's best interests that he remains at Rotherlea with a focus on comfort-based care. **AMHP Case notes** state arrangements to intervene based on best interest due to lack of capacity to make decisions regarding his own care and treatment. Independent Reviewer notes that these arrangements were not recorded.
21.06.2022	John asks staff to roll him onto his stomach so he can suffocate himself using pillow.	Regular staffing checks implemented.

21.06.2022	Rotherlea contact Court of Protection for advice.	Advised by CoP that referral to the court would need to be made by a solicitor and unless capacity became compromised and there were concerns about John's niece and LPA making appropriate decisions it was unlikely that the court of protection would have a role to play.
21+23.06.2022	Safeguarding Concern Raised by Petworth Surgery	Recorded by safeguarding team that criteria for safeguarding not met (reviewed on the 23rd NB. John had passed away at the point the safeguarding concern was reviewed).
22.06.2022	John attempts to strangle himself with his call button flex cord.	Ambulance called by Rotherlea, John refuses admission and paramedics state John had capacity. John left at Rotherlea.
22.06.2022	Rotherlea call 999 for ambulance	Following a mental capacity assessment by the ambulance crew they deemed him **to have capacity** and as such would not be taking him to hospital. Paramedics had telephone conversation with John's GP.
22.06.2022	GP attempts to arrange referral to Court of Protection	GP leaves message with CCG vulnerable adults team explaining situation and that advice is required.
22.06.2022	GP T/C to John's niece	John's niece clear that an admission to hospital was not in accordance with her uncle's wishes. She also reported that she felt his best interests were served by him remaining at Rotherlea so long as his comfort could be adequately maintained there.

22+23.06.2022	Safeguarding Concern Raised by Rural North Chichester Primary Care Network (PCN) (Sussex Community Foundation Trust) as John had tied ligature around his neck with call bell cord.	Chronology from safeguarding team states that safeguarding concern reviewed on 23rd (NB John had passed away at the point the safeguarding concern was reviewed).
22+23.06.2022	Safeguarding Concern Raised by GP (Coastal West Sussex CCG) – GP explains complex situation and referral to court of protection required, requesting support from safeguarding team to raise CoP referral.	Chronology from safeguarding team states that safeguarding concern reviewed on 23rd (NB John had passed away at the point the safeguarding concern was reviewed). Safeguarding Team do not make contact with GP.
22+23.06.2022	Safeguarding Concern Raised by Community Nursing Team (Sussex Community Foundation Trust)	Chronology from safeguarding team states that safeguarding concern reviewed on 23rd (NB John had passed away at the point the safeguarding concern was reviewed).
22.06.2022	NHS Sussex designated adults safeguarding nurse emails WSCC safeguarding team advising John attempted to strangle himself.	Recorded in GP chronology that safeguarding nurse reported to GP that safeguarding team manager was happy with plan that was in place and did not feel it necessary to speak with GP. WSCC safeguarding team chronology states that they advised safeguarding nurse that MHAA was arranged for that evening.

22.06.2022	MHAA not undertaken	Recorded in SCFT chronology that MHAA refused by AMHP Service as *"allegedly stated that even if he was assessed as needing to be sectioned there was no bed available and that there where 22 people currently waiting for a OPMH acute bed".* The AMHP service however have stated that the assessment could not be conducted as there were no available section 12 doctors.
23.06.2022	John passed away in the early hours of the 23rd.	

9. Key findings

- **Professional curiosity:** Limited evidence of professional curiosity resulting in significant information not being known by professionals which could have changed decision making and outcomes.
- **Defensible decision making:** As there was a lack of professional curiosity defensible decision making may come into question
- **The voice of families:** John's niece, was not contacted by professionals as part of their assessment process or triaging of safeguarding concerns (raised in previous SAR Beverley February 2023)
- **Multi-agency working:** Lost opportunities identified where agencies could have jointly assessed risk, John's capacity and developed/implemented a coordinated care plan and risk management approach (raised in previous SAR MT September 2022 & Jean August 2019)
- **Silo working and professional accountability and ownership:** Although Rotherlea Care Home and the GP surgery worked closely together there was limited evidence of professional accountability and ownership by other involved agencies who appeared to be working in silo and not supporting each other as a wider safeguarding and care planning system (raised in previous SAR Beverley February 2023)
- **Self-neglect and safeguarding:** Sussex Safeguarding Adults Policy and Procedures regarding Self-Neglect not initiated or followed
- **Agency resources:** Limited staffing created unnecessary delays for assessments and timely sharing of information across system partners
- **Mental capacity:** A multi-agency agreement of John's capacity status, especially in relation to his executive functioning was never reached

10. Analysis of findings

10.1. Professional curiosity and defensible decision making

10.2. John's niece described an approximate twenty-year history of John voicing paranoid thoughts and persecutory delusional beliefs. Additionally, John reported symptoms of paranoid ideation to his GP on three separate occasions (2017, 2018 and in 2020). John's niece is of the opinion that the decision to end his life was as a direct result of receiving a birthday card from his cousin which appeared to distress John and link directly into his paranoid thoughts and persecutory delusional beliefs.

10.3. There appears to have been a lack of professional curiosity given that John's niece, who could have shared her observations of John's behaviour in relation to his paranoid thoughts and ideas, was never contacted, despite the presence of references to paranoid ideation in John's medical records. The complexity of John's situation required professionals to explore and triangulate information from multiple sources by asking proactive questions of those who knew John well. Although John's GP contacted John's niece this concerned her role as power of attorney over health and care decisions. If these discussions had occurred, different questions may have been asked during the mental health assessment, Mental Health Act assessment and capacity assessments and alternative outcomes may have been reached.

10.4. Where there is a lack of professional curiosity questions may arise concerning how robust decision making was by professionals. As professionals when we make a decision, we don't have the benefit of hindsight. We do not know what will happen. We may, in the light of later events or evidence, have made a decision that had an untoward outcome. However, it will be a defensible decision if we can justify our decision-making by demonstrating an evaluation of all available information has taken place, which includes information gathered from family members, professionals, and other teams involved in the care and support of that person.

10.5. Professional curiosity is a concept which has been recognised as important in the area of safeguarding children for many years. More recently however, Safeguarding Adult Reviews (SARs) have highlighted a similar need for professional curiosity in safeguarding adults with care and support needs.[3] Professional curiosity is about exploring and understanding what is happening with an adult. It is about enquiring deeper and using proactive questioning and challenge. It is about understanding one's own professional responsibility and knowing when to act, rather than making assumptions, or taking things at face value. Professional curiosity means not taking a single source of information and accepting it at face value. It means triangulating information from different sources to gain a better understanding.

[3] Preston-Shoot, M [2017] 'What difference does legislation make? Adult safeguarding through the lens of serious case reviews and safeguarding adult reviews'

10.6. **Multi-agency working and agency accountability and ownership**

10.7. From the information and chronologies provided by agencies involved in John's care and support prior to his death, it appears that there were lost opportunities for all agencies to collaborate, which could have resulted in a multi-agency risk management and care plan.

10.8. The reviewer acknowledges that there is currently no nationalised information or guidance regarding capacitated adults that choose to end their life by voluntary stopping eating and drinking (VSED) that could have assisted clinicians and practitioners/agencies with anticipatory care planning if deemed John had capacity. However, Sussex Safeguarding Adults Policy and Procedures, edition 4 provides information and guidance on those adults who self-neglect (Sussex Multi-agency Procedures to Support Adults who Self-neglect 2.8 of the Sussex Safeguarding Adults Policy and Procedures). This will be discussed further on in the report.

10.9. From June 12 to June 23, 2022, there were no multidisciplinary meetings in which all involved agencies participated. A multi-agency meeting would have afforded agencies the opportunity to discuss discrepancies concerning John's capacity and the chance to implement a multi-agency care plan and risk management strategy. Given the complexity of the situation, close coordination between agencies and their legal departments would have been required.

10.10. A multi-disciplinary team meeting was held on 15 June 2022, with the GP, Community Nursing Team staff, and Rotherlea Care Home management in attendance. However, the older persons community mental health team, West Sussex's Councils Safeguarding Team, Approved Mental Health Professionals Service, and Council, ICB, and NHS legal team representatives were not invited.

10.11. On June 21, 2022, nine days after John stopped eating and drinking, a second meeting was convened. The meeting was both a best interest decision meeting and a multi-disciplinary team meeting. The meeting was attended by the assessing AMHP who had conducted the Mental Health Act assessment on the evening of 19 June 2022 (although they only stayed for the beginning of the meeting), the GP from Petworth Surgery, Rotherlea Management/Nurse, the clinical nurse practitioner, and the GP surgery care coordinator. As with the meeting on the 15th June 2022 a number of significant agencies were not invited to the meeting (Sussex Partnership Foundation Trust Sussex Partnership Foundation Trust Older Peoples Mental Health Team, the Councils and NHS Safeguarding Teams and the Councils, NHS, and ICB legal teams). At this meeting neither a multi-agency care plan nor a plan for risk management were developed.

10.12. There is also evidence of contradictory approaches that ought to have been adopted if John were to experience distress or pain. Rotherlea had documented that John would be admitted to hospital, whilst the GP had noted that it was in John's best interests to remain at Rotherlea with a focus on comfort-based care, and that John's niece had made it clear that hospitalisation would cause John "enormous stress".

10.13. It did not appear that a comprehensive system-wide approach to safeguarding and/or care planning had been reached or implemented. Instead of functioning as part of a safeguarding or multi-agency care planning system, it appeared that

agencies were predominantly operating in isolation. This can be seen in the divergent opinions of agencies regarding the necessity of a Court of Protection application; John's GP believed an application was necessary, whereas the Council's Safeguarding Team felt that the most appropriate course of action was a further Mental Health Act assessment.

10.14. Similarly, a number of agencies believed that John's circumstances merited the raising of safeguarding concerns (five safeguarding concerns were raised between June 17 and June 22, 2022), but the Safeguarding Team did not believe that John's circumstances met the legal threshold for safeguarding interventions. Both the AMHP Service and the Sussex Partnership Foundation Trust Older Peoples Mental Health Team believed that they had no role to perform because there was no evidence of mental illness, and in the case of SPFT, a clinical determination was that John had mental capacity to decide whether to eat or drink. Given the divergent opinions and complexity of the situation, an urgent multi-agency meeting that included John's niece and all involved agencies was required. At this meeting, a consensus could have been reached regarding a shared action plan, the agency best suited to lead and coordinate the plan, and whether legal departments of agencies were also required to be involved.

10.15. **Agency resources, staffing capacity, and timely sharing of information**

10.16. Clearly, this was a complex and high-risk situation that demanded prompt interventions from all involved professionals. However, due to staffing constraints in both the Sussex Partnership Foundation Trust Older Peoples Mental Health Team and the AMHP Service, delays in assessments were experienced.

10.17. At a multi-agency disciplinary meeting held on 15 June 2022, it was decided that Rotherlea Care Home would request an urgent four-hour assessment from the Sussex Partnership Foundation Trust Older Peoples Mental Health Team. However, due to "critical staffing levels," this assessment was not conducted until June 17, 2022, five days after John had refused all sustenance and drink. The assessment determined that there was no evidence of mental illness, and that John possessed the mental capacity to withdraw from food and fluids as well as prescribed medication.

10.18. On the 17th June 2022, Rotherlea Care Home requested an urgent Mental Health Act assessment via West Sussex's County Councils AMHP Service. Due to staffing pressures the assessment did not take place until the 19th June 2022. The assessment was conducted at 23:00 hours, and John had been in bed several hours and had to be awoken to participate in the assessment.

10.19. The Mental Health Act 1983 (as amended, 2007) places a legal duty on local authorities to ensure they have sufficient AMHPs to carry out their statutory functions so that significant delays are not experienced[4]. It is important to note that nationally there continues to be a significant shortage of AMHP's and a national increase in Mental Health Act assessments[5].

[4] Mental Health Act Code of Practice 2015, para 14:35

[5] Community Care, Samuel, M [2022] 'AMHP numbers shrink by 3% amid increase in detentions and plans to expand role'

10.20. With regards to the Mental Health Act assessment AMHPs must ensure that the person is interviewed "in a suitable manner"[6]. On the AMHPs Report under "were there any problems for the AMHP in interviewing the customer in a suitable manner?" the AMHP has ticked yes, given that John had to be awoken and was drowsy and found it difficult to talk as his mouth was dry. The independent reviewer raises the question as to how appropriate it was to assess John who was 88 years was old at the time of assessment at 23:00 hours after he had been asleep for several hours and whether this could be classed as interviewing in a "suitable manner".

10.21. Finally, John's niece, who was also his nearest relative under the meaning of the Mental Health Act was not contacted by the assessing team. John's niece has clearly voiced her views that John's decision to end his life was a direct result of receiving a birthday card from his cousin which appeared to distress him and link directly into his paranoid thoughts and persecutory delusional beliefs.

10.22. Although under section 2 of the Mental Health Act the AMHP does not need to legally consult with the nearest relative as they do with section 3, section 13 (1) (b) of the Mental Health Act states that AMHPs should *"having regard to any wishes expressed by relatives of the patient or any other relevant circumstances".* If this conversation had taken place, it may have resulted in a different set of questions being asked of John to ascertain whether there was a direct linkage to his decision to end his life and the paranoid thoughts described by his niece.

10.23. **Safeguarding and self-neglect**

10.24. From the 17th to the 22nd of June 2022, various agencies raised five safeguarding concerns regarding John's situation of self-neglect (it should be noted that three of the safeguarding concerns were raised the day before John passed away). West Sussex Council Safeguarding Team determined that the safeguarding concern received on the 17th June did not meet the statutory criteria because there was no evidence of abuse or neglect warranting safeguarding interventions and that John's mental capacity appeared to be fluctuating. The remaining four safeguarding concerns (raised on the 21st and 22nd June) were triaged on the 23rd June after John had passed away.

10.25. Under the Care Act (2014), self-neglect falls under the definition of causes to make safeguarding enquiries if the adult has care and support needs and cannot protect themselves. Self-neglect covers a wide range of behaviour such as neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding. The Care and Support Statutory Guidance[7] states that self-neglect may not necessarily prompt a section 42 enquiry and that assessment should be made on a case-by-case basis. The guidance advises that a decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour and that there may come a point when the adult is no longer able to do this, without external support.

[6] Mental Health Act 1983 (as amended, 2007) section 13(2)

[7] Care Act 2014, Statutory Guidance Section 14 Safeguarding

10.26. Sussex Safeguarding Adults Policy and Procedures, edition 4[8] provides information and guidance on those adults who self-neglect (Sussex Multi-agency Procedures to Support Adults who Self-neglect 2.8 of the Sussex Safeguarding Adults Policy and Procedures). The procedures state they *"set out a framework for collaborative multi-agency working within Sussex to provide a clear pathway for all agencies to follow when working with adults who are self-neglecting. The aim of these procedures is to prevent death and serious harm to self-neglecting adults by ensuring:*

- Adults who are self-neglecting are empowered, as far as possible, to understand the implications of their self-neglecting behaviours.
- A shared, multi-agency understanding, and recognition of the issues involved in working with adults who self-neglect.
- Effective multi-agency working and practice, whether this falls within a Section 42 safeguarding enquiry or outside of this.
- Agencies and organisations uphold their duties of care".

10.27. The procedures provide 'indicators of significant risk' which state *"would warrant consideration under safeguarding procedures and/or consideration of other legal remedies"*. With regards to John's circumstances these are as follows:

- Fluctuating capacity
- High levels of multi-agency referrals
- Unpredictable or chronic health conditions due to non-compliance of treatment (John's refusal to eat or drink and take medication)

10.28. In such circumstances as John's, the procedures advise that a multi-agency meeting should be convened under self-neglect, as *"multi-agency meetings are often the best way to ensure effective information sharing and communication, and a shared responsibility for assessing risks and agreeing an action plan"*. This meeting however did not take place. If this meeting had of happened the multi-agency team would have:

- Reviewed John's views and wishes as far as they are known.
- Reviewed information, actions, and approaches to date.
- Completed a multi-agency risk assessment
- Identify an ongoing lead professional or agency
- Developed an action plan and evaluate considered approaches.

[8] Sussex Safeguarding Adults Policy and Procedures, Section 2.8 Sussex Multi-agency Procedures to Support Adults who Self-neglect

- Review all assessments or discussions regarding the adult's mental capacity up to that point.

10.29. **Mental capacity**

10.30. Between the 17th and 22nd June 2022 John's capacity was assessed on five separate occasions by a range of professionals.

No.	Date/time	Agency/professional	Outcome of capacity assessment
1.	17.06.2022	Sussex Partnership Foundation Trust Older Peoples Mental Health Team	Has Capacity
2.	19.06.2022 at 23:00hrs	Mental Health Act Assessing Team	Lacks Capacity However, Rotherlea Team Leaders case notes state the Mental Health Act Team passed on that John *"has capacity to make his own decisions but concerned about his physical health".*
3.	19.06.2022 at 23:35hrs	Paramedics	Has Capacity
4.	20.06.2022	GP	Lacks Capacity
5.	22.06.2022	Paramedics	Has Capacity

10.31. Agencies needed to assess whether at the point John made the decision to stop eating and drinking to end his he life he had capacity and secondly whether John had capacity to refuse hospital admission. However, at the time of these assessments, professionals were unaware that John's niece believed there to be a direct correlation between his decision to end his life and the paranoid thoughts he had exhibited for around twenty years.

10.32. Given the differing opinions in assessment of John's capacity, a multi-agency agreement of John's capacity status, especially in relation to his executive functioning was required to determine the most appropriate course of action. This should have involved John's niece to gather as much information as possible about John. The Sussex Multi-Agency Procedures to Support Adults who Self-neglect state that *"when assessing the mental capacity of an adult who is self-neglecting, it is good practice to consider carrying out joint capacity assessments, for example, involving an occupational therapist who can assist with assessing the adult's functional ability and executive capacity".* Once John's capacity status had been agreed by the multi-agency team, dependent on John's capacity status several options would have been available.

- If deemed John lacked capacity at the point, he made the decision to stop eating and drinking a referral to the Court of Protection could have been made by West Sussex's Councils legal team or Sussex Partnership Foundation Trusts legal team. Discussions would have been required with John's niece given she held power of attorney over his health and care and was of the opinion that he had capacity and would not have wanted to be admitted to hospital.

- Consideration of section of 2 of the Mental Health Act 1983 (as amended, 2007) could also have been considered if the team believed that John was suffering with a mental disorder which was of a nature or degree which warranted his detention in hospital for assessment and he ought to be detained in the interests of his own health or safety or with a view to the protection of other persons.

- If deemed John had capacity the law regarding the refusal of food and water for those capacitated adults is clear and was set out in the 2014 Supreme Court decision in the Nicklinson, Lamb and Martin[9] case which ruled that:

    - A person who is mentally competent is entitled to refuse food and water, and to reject any invasive treatment, even though it will lead to their death. Medical practitioners must comply with such refusals.

    - The doctor is in no danger of incurring criminal liability simply because they agree in advance to manage any pain or discomfort that may arise.

10.33. In 2015 the General Medical Council published guidance on patients seeking advice or information about assistance to die. The guidance explained that, where patients ask for information that might encourage or assist them in ending their lives, doctors should be prepared to listen and to discuss the reasons for the patient's request and to limit any advice or information in response to objective advice about the lawful clinical options (such as sedation and other palliative care) which would be available if a patient were to reach a settled decision to end their life. The guidance went on to say "For avoidance of doubt, this does not prevent a doctor from agreeing in advance to palliate the pain and discomfort involved for such a patient should the need arise for such symptom management.[10]"

11. Recommendations

11.1. **Recommendation 1: Professional curiosity and defensible decision making**

11.2. The SAB to assure themselves that not only are partners and their workforces fully apprised of the importance of professional curiosity and defensible decision making in complex situations such as the case of John, but also that clinicians and practitioners are aware of how to implement professional curiosity in practice.

[9] R (Nicklinson) v Ministry of Justice [2014] UKSC 38, para 255

[10] General Medical Council, Patients seeking advice or information about assistance to die, June 2015

11.3. **Recommendation 2: Self-neglect procedures**

11.4. The SAB should seek assurance on how agencies have promoted the Sussex Multi-agency Procedures to Support Adults who Self-neglect, (especially where there are discrepancies regarding mental capacity) and how these have been implemented within their respective organisations.

11.5. The SAB should seek assurance that any single agency training on Self-Neglect includes the Sussex Multi-agency Procedures to Support Adults who Self-neglect.

11.6. The SAB should further promote the Sussex Multi-agency Procedures to Support Adults who Self-neglect across all safeguarding system partners.

11.7. The SAB should audit the use of its guidance on self-neglect, escalation, adult safeguarding concerns, and multi-agency meetings by agencies across the Partnership.

11.8. The SAB to seek assurance that clinicians and practitioners and those with supervisory responsibilities across all partner agencies understand the need to initiate multiagency review in cases of high-risk self-neglect (as in the case of John), that pathways for doing so are clear and that they are being used effectively.

11.9. **Recommendation 3: Agency resources**

11.10. WSCC should provide assurance to the SAB that it is aware of the risks arising from AMHP service pressures, has processes in place to manage these risks, and is working to achieve an AMHP service that can meet demand in line with statutory requirements.

11.11. **Recommendation 4: The voice of carers and families**

11.12. The SAB to assure themselves all partnership agencies promote the importance of the voice of carers, families and those who know the adult well when undertaking assessments of capacity and a person's mental health.

11.13. **Recommendation 5: Mental capacity**

11.14. The SAB to raise with agencies learning from this case on mental capacity practice in cases of self-neglect, with particular attention to consideration of executive function and fluctuating capacity, and the need to take measures to strengthen practice through training, guidance or supervisory practice where indicated.