East Sussex Safeguarding Adults Board

**Safeguarding Adults Review in respect of Gwen and Ian**

**Author: Clive Simmons**

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## Foreword

* 1. The East Sussex Safeguarding Adults Board has today published this Safeguarding Adults Review in respect of Gwen and Ian (not their real names).
  2. The purpose of a Safeguarding Adults Review is not to reinvestigate or to apportion blame but to establish where and how lessons can be learned and services improved for all those who use them and for their families and carers.

**Seona Douglas  
Interim Independent Chair, East Sussex Safeguarding Adults Board**

## 2 Introduction

* 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.
  1. The East Sussex Safeguarding Adults Board (SAB) Independent Chair in December 2022 endorsed the recommendation of the Safeguarding Adults Review Sub-Group that the criteria to undertake a Safeguarding Adults Review (SAR) was met in respect of Gwen. The Sub-Group met again in February 2023 and decided that the criteria to undertake a Safeguarding Adults Review was also met in respect of Ian. As the circumstances of Gwen and Ian and the potential learning were similar, it was decided to undertake a joint review. Both were living at home in circumstances of self-neglect and were residing with a daughter or son who were experiencing difficulty in performing caring roles. There were features of engagement difficulties experienced in limited agency involvement, as well as missed opportunities to respond to presenting needs and risks in a comprehensive and coordinated way.
  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.
  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 to the people directly affected, comfort to family and friends, and support to professionals.
  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.
  5. The review process to meet these aims and objectives has followed a clear path. The Independent Reviewer has chaired initial panel meetings to agree the review terms of reference; conducted research by critically analysing information provided by involved agencies and by interviewing representatives; culminating in presentation of this overview report to the Safeguarding Adults Board. It was initially intended to arrange a Safeguarding Adults Review workshop and, due to the limited range of actively engaged agencies, it was decided instead to focus on wider individual practitioner meetings.
  6. The Independent Reviewer has involved families and significant others in the review. For Gwen, this involved meeting with her nephew and his wife, as well as telephone contact with a neighbour. Gwen’s daughter was not contacted as part of the review, on the advice of the ASCH Mental Health Team. For Ian, this involved meeting his brother, his wife and his niece, NP. Ian’s son was contacted as part of the review and has not participated. The families contributed positively to the review and provided considerable insight into the experience of Gwen and Ian, also contributing to the agencies’ learning. Both families and significant others expressed a wish that learning from the review would lead to improved responses to needs and risk, and to a reduced risk of similar circumstances occurring for other adults at risk in the future.
  7. The Independent Reviewer met with the following representatives of relevant agencies, either face to face or online, and acknowledges that all contributed positively to the conduct and outcome of the review. They comprise both professional leads and frontline practitioners. Some participants contributed in regard to both Gwen and Ian, whilst others provided information specific to one person:
* Head of Safeguarding & Quality; Adult Social Care & Health (ASCH)
* Operations Manager; Safeguarding Development Team, ASCH
* Practice Manager; Mental Health & Substance Misuse Service North, ASCH
* Senior Practitioner; Mental Health & Substance Misuse Service North, ASCH
* Director of Safeguarding & Principal Social Worker; Sussex Partnership NHS Foundation Trust (SPFT)
* Matron; Beechwood Unit & High Weald Lewes & Havens, Specialist Older Adults Mental Health Services (SOAMHS), & Memory Assessment Service, Sussex Partnership NHS Foundation Trust
* Community Mental Health Nurse; Memory Assessment Service, SOAMHS, Sussex Partnership NHS Foundation Trust
* General Practitioner; Edenbridge Medical Practice (West Kent)
* General Practitioner; Mid Downs Medical Practice
* Practice Manager; Mid Downs Medical Practice
* Named GP for Safeguarding Adults & Children; NHS Kent & Medway Integrated Care Board (ICB)
* Assistant Director of Safeguarding; Kent Community NHS Foundation Trust
* Deputy Designated Nurse for Safeguarding Adults – pan Sussex; NHS Sussex Integrated Care Board (ICB)
* Trust Safeguarding Lead & Clinical Supervisor; South East Coast Ambulance Service (SECAmb)
* Director of Public Health; East Sussex County Council
* Designated Nurse, Adult Safeguarding; Kent and Medway ICB
* Named Nurse for Safeguarding Adults & MCA Lead, Maidstone, and Tunbridge Wells Hospitals Trust
* Lead Nurse Safeguarding Adults; University Hospitals NHS Foundation Trust
* Community Services & Corporate Safeguarding Lead; Lewes District & Eastbourne Borough Councils
* Senior Caseworker; Lewes District & Eastbourne Borough Councils
* Detective Sergeant; Sussex Police
  1. The review is independent of any other process, including any potential Coroner’s inquest. Gwen received some services in Kent and cross-border implications are considered within the review, where applicable. A Thematic Safeguarding Adults Review[[1]](#footnote-1), completed on behalf of the Kent and Medway Safeguarding Adults Board in April 2021, covers similar areas of concern and the findings and recommendations are incorporated within this report, as well as relevant learning from a similar review.

## Circumstances leading to the review.

* 1. Safeguarding Adults Review (SAR) referrals for Gwen and Ian were submitted by Adult Social Care and Health (ASCH) teams to the Safeguarding Adults Board in March 2022 and January 2023, respectively.
  2. Gwen was a 95-year-old woman who lived with her daughter and received limited services. She had not seen her GP since a home visit in April 2018, or a Community Nurse after the following month. A neighbour contacted ASCH in September 2020 to report concerns about how Gwen and her daughter were managing. Gwen was prescribed regular medication, but her prescriptions had not been collected since January 2021. Following a rapid decline in her physical health, she was admitted to hospital in October 2021 and died on the following day.
  3. Ian was a 67-year-old man who lived with his son and received limited services. He experienced a range of traumatic events and had not arranged repeat anti-depressant medication over many months. Some professionals had intended to report concerns about how Ian and his son were managing, without timely referrals being made. Following a rapid decline in Ian’s mental and physical health, he was admitted to hospital in September 2022 and died in the following month.
  4. The scoping period for this review is from April 2018, when involved agencies experienced issues in trying to contact Gwen, to October 2022, when Ian died in hospital. The Independent Reviewer has also considered contextual historical information, to support an understanding of Gwen and Ian’s lived experience.

## Key Themes identified for the review.

* 1. As an overriding theme, the review considers how health and social care agencies can better meet the needs of adults at risk who have limited interaction with services, when there are concerns about self-neglect and carers needs.
  2. Examples of positive practice are also highlighted in the course of the report.
  3. The following specific key themes are identified in the terms of reference and form a thread through the analysis and recommendations within the review:
* How effective was multi-agency needs and risk assessment; with a consideration of responding to disengagement, needs assessments, carers assessments, and multi-agency risk assessments and management involving professional curiosity?
* How effective was decision-making in response to safeguarding concerns, when raised by a member of the public, family member or agency?
* How effective was the consideration of mental health, mental capacity, and personalisation?
* How did resources and environmental factors impact on care?
* How compliant were agencies with legislation, policies, procedures, and practice guidance?

## Pen picture of Gwen

* 1. Safeguarding Adults Reviews (SARs) should provide a window into the lived experience of adults at risk.
  2. Gwen lived in a privately-owned house with her daughter who had resided with her mother since birth. They had a close relationship. Her daughter had a history of experiencing mental health concerns. The house is in an isolated location, built by Gwen’s husband, and she had laid the first brick. Both Gwen and her daughter were very attached to their home.
  3. Gwen’s family describe her as a lovely person, who had experienced rough times in the course of her life. She had worked as a hairdresser. Her husband was in the Merchant Navy and died at a young age. Gwen’s nephew had been supportive in helping with shopping and collecting prescriptions but was unable to continue for the final few years when his health declined. Gwen’s daughter then relied on taxis and, at times, accepted the help of a neighbour. Gwen’s nephew feels that both Gwen and her daughter had been reluctant to accept visitors to their home and her daughter was resistant to support for her mother and herself, when offered.

## Pen picture of Ian

* 1. Ian was the youngest of nine children and lived in a council flat with hisson who was 20 years old when his father died. Ian’s sondid not have care needs in his own right, but did have needs as a carer, withoutreceiving statutory support. Their flat was in an isolated location and, without a car, his son relied on public transport to access college, work, and shopping.

After Ian was divorced in 2006, he retained custody of his son (then aged 10) and they shared a close relationship. He experienced a range of other traumatic events in the final years of his life.

Ian had been employed as a supervisor in a company selling bricks and later as a gardener on a farm, working alongside his brother every weekday. He was made redundant  in October 2021, although his family feel that this was not a traumatic event, as he continued to work until the following January and should have been financially comfortable at that point. Ian experienced episodes of depression and, by early 2022, was spending much of his day asleep in bed.

* 1. Ian is described by his family as a soft spoken, very thoughtful and kind person; a much-loved ‘cool uncle’ and an integral part of a close family network. He took pleasure in life and had an uncomplicated personality. Ian was a well-known and popular character in the local community, where he grew up, and he had a close association with a local pub, winning many darts and other competitions and raising funds for charitable causes. He was also interested in horse racing and loved animals. Ian’s family feel that he gave up due to a number of factors, including his dementia diagnosis and his isolation.

## 7. Summarised Chronology - Gwen

## April to July 2018

* 1. In April 2018, the GP rang Gwen’s daughter, who said that mother was too frail to attend a surgery appointment. Therefore, Community Nurses visited to take blood samples and to check her blood pressure. The GP made further phone calls to Gwen’s daughter in late April and early May 2018. In a final visit to Gwen on 30/04/18, the GP reviewed her medication. Gwen had a diagnosis of temporal arteritis, which had been causing headachesand were now resolved with steroid medication. She also had medication for high blood pressure, painkillers for back pain and she had a swollen ankle. There were further Community Nursing visits in May 2018, with afinal visit on 22/05/18.
  2. Gwen did not attend a heart scan appointment in June 2018 and the GP rang, without reply. A further referral was made to Community Nursing for blood samples and, following two failed visits in late June and early July 2018, the GP Practice was informed. The GP wrote to Gwen, encouraging her to visit the practice for an important health test. There was no further intervention by primary health care.

**September 2020 to January 2021**

* 1. A neighbour submitted an online referral form to the Adult Social Care and Health (ASCH), Health & Social Care Connect (HSCC) duty team on 24/09/20. He reported his concern about Gwen’s daughter’s deteriorating mental health and distrust of others; the reliance of Gwen on her daughter for medication and care and that she was not managing as a carer; and the condition of the property, in disrepair, with damp and mould. The neighbour had not seen Gwen at any time and no person outside the household had seen her in over two years. An HSCC duty worker rang the neighbour on the following day to confirm the details of his concern. The referral was passed to the safeguarding adults triage system in HSCC, with a focus on Gwen’s daughter’s mental health. The neighbour recalls that the house had smelt of damp since around 2015; there was mould on the ceilings and walls; there were piles of magazines, papers, and boxes of materials, some about waist high and with space to walk in between; the living room was less cluttered; and the house was generally unclean and dusty.
  2. His concern was emailed by ASCH to the GP Practice on 28/09/20, to triage and review as necessary, without any specific request or plan. ASCH did not take any further action and the information was held in Gwen’s daughter’s notes, with no file created for Gwen. The GP did not take any action and there were no medical notes for Gwen between September 2020 and October 2021.
  3. The last prescription for Gwen was collected from the dispensary attached to the GP Practice in January 2021, with no follow-up at this time or when further prescriptions were not collected.
  4. There was no contact by agencies with Gwen or her daughter after May 2018 until October 2021, a period of over two years.

**October 2021**

* 1. Gwen was conveyed to Pembury Hospital by the Ambulance Service on 21/10/21. She had fallen between her bed and commode at about 17.45 pm, sustaining injuries. Her daughter rang Gwen’s nephew, to request that he visit and support her in lifting her mother back into bed. Instead, his family dialled 999 for an emergency ambulance at 17.55 pm, which arrived at 18.28 pm.
  2. The Paramedics reported that Gwen was malnourished; had new and older injuries to her body and showed visible physical signs of self-neglect. The home was also reported to be in a neglected state. Gwen’s daughter said that her mother did not wish to be admitted to hospital. Gwen had a significantly reduced level of consciousness and the Paramedics assessed (not a full Mental Capacity Assessment) that she did not have the capacity to decide on admission for palliative care.
  3. Her daughter accepted the decision to admit her mother to hospital and the Paramedics also considered that she lacked mental capacity related to her mother’s need for admission, although a formal assessment was not completed.
  4. Gwen died in hospital on 22/10/21, the day after her admission. The primary cause of death was recorded as pneumonia, with secondary causes recorded as emphysema and coronary artery disease. A referral was not made to Sussex Police, under the pan-Sussex Adult Death Protocol[[2]](#footnote-2), as she had been admitted to a hospital in Kent.
  5. The Ambulance Service raised a Safeguarding Adults Concern with ASCH on 24/10/21, due to suspected long-term neglect. The concern also included Gwen’s daughter, due to a lack of awareness and the condition of the house.
  6. A Safeguarding Adults Enquiry from October 2021 to March 2022 found that there had been missed opportunities by ASCH, HSCC to raise a Safeguarding Adults Concern and consider a social care assessment in September 2021; and by the GP Practice to raise a Safeguarding Adults Concern in January 2021, when Gwen’s regular prescription was no longer collected.

## Summarised Chronology - Ian

**June 2021 to January 2022**

* 1. Ian lived with his son in a council flat. He attended GP appointments in June and July 2021, due to low mood and depressive symptoms that had been recurrent over some years, restarting anti-depressant medication. After these two months, he did not request a further prescription. Ian was made redundant in October 2021 and continued working for a few months, after which he lost this connection.
  2. By December 2021, it seems that he was experiencing depression, sleeping a lot during the day, and neglecting his personal hygiene. There was some contact by Local Authority Housing Officers about finances between October 2021 and October 2022, but there had been no concerns raised to warrant a welfare home visit. A rapid decline in Ian’s mental and physical health was evident from the early months of 2022.

**March to July 2022**

* 1. In a GP telephone consultation on 14/03/22, Ian’s son expressed concern about his father’s memory loss. When Ian did not attend subsequent medical reviews, the GP completed a final home visit on 20/04/22. He noted that Ian was lying in bed during daytime hours; was experiencing memory impairment and poor nutrition (although tests showed no nutrient deficiency or urinary tract infection); and his flat was untidy. On 27/04/22, he referred Ian to the SPFT Memory Assessment Service (MAS) for a routine dementia assessment; noting gradual confusion over two years, as indicated by Ian’s son, and that he was spending much of his day in bed. An intended referral on the same day to the ASCH, Health & Social Care Connect (HSCC), and for possible onward referral to Dementia Support Services, was not sent due to an administrative error. This contained brief information on advanced dementia, a cluttered and unclean flat, his son being the main carer, and that both required support. The unsent referral was not followed up.
  2. In May 2022, Ian’s brother developed an eye condition and contact from this point was limited to phone calls, which further increased Ian’s isolation.
  3. The MAS accepted the GP referral on 10/05/22 and later in the month forwarded an advisory letter to Ian about their involvement. This was followed by an appointment letter on 29/06/22 for an assessment on 09/08/22. A CT scan was completed in July 2022, which showed some abnormalities consistent with dementia, and the GP Practice was notified. In the same month, Ian became more isolated by no longer answering phone calls from his brother.

**August to October 2022**

* 1. A Community Psychiatric Nurse (CPN) from the MAS visited Ian at home on 09/08/22 to undertake an assessment. She found that he was experiencing significant memory loss, with a difficulty in engaging, and was not eating or drinking enough. On suggesting to Ian’s son, that the home situation was unsustainable, he said that he wished his father to remain at home and for someone to check on him when he is alone. She responded that a referral could be made to ASCH and recorded that the situation should be discussed at a MAS Multi-Disciplinary Team (MDT) meeting, that his son will need support in coming to terms with the diagnosis of dementia, and that a referral to ASCH should be considered as the next step. Ian’s son was clearly seen as a protective factor. Two days later, the CPN emailed the GP, as Ian did not have prescribed medication.

* 1. Letters from MAS to the GP Practice on 12/09/22 and 14/09/22 confirmed the outcome of their assessment, that Ian was living with dementia, and the GP Practice intended to undertake a medical review on the basis of this information. It was stated correctly that a referral had been made to the SPFT Specialist Older Adults Mental Health Service (SOAMHS) and incorrectly that a referral had been made to ASCH. Following SOAMHS MDT meetings on 12/09/22 and 15/09/22, it was decided that a CPN would visit Ian on the following day to complete an Addenbrook Cognitive Examination (ACE), which is an assessment of memory decline, and to provide support pending ASCH involvement.
  2. A SOAMHS CPN visited Ian on 16/09/22 to complete the ACE assessment and a general review of his care needs; not a full needs assessment, as this was not within the remit of the team. She noted that the flat was untidy, was cluttered but not to a high level, and that the living space was unclean. Ian was in an unclean bed; was very unshaven, with long and unkempt hair; and he presented as thin and frail. He had water by his bed, which he sipped. During the assessment, Ian engaged and had good eye contact. However, he experienced difficulty in answering questions and his responses were delayed. He was disorientated in terms of time and the CPN was unable to complete the ACE assessment, as Ian lost concentration. She was concerned about his mental health and physical condition, as well as the absence of medication. Ian nodded when asked if he felt depressed and said that he did not know why he was not taking anti-depressant medication. The CPN engaged with Ian’s son about his perception of needs. He responded that his father stayed in bed, aside from using the bathroom; was not eating and was drinking very little; was not taking Sertraline for his depression; was not taking Donepezil for his dementia, which was prescribed on 13/09/22 by specialist services and not collected. He said that respite would help to relieve the home situation.
  3. The CPN contacted ASCH on 21/09/22 to check on the referral, to discover that it had not been sent. She therefore raised her concern about self-neglect and carer needs, requesting a social care assessment. In her referral, she noted that Ian was living with Alzheimer’s-type dementia; was not eating or drinking enough; that he required medication for depression, which his son could not oversee, and he had not had prescriptions collected for some time. It was noted that there were no mental capacity needs and the urgency of response was stated as within 5 days.
  4. On 18/09/22, Ian’s son dialled 999 for an emergency ambulance; stating that his father was in pain, lacking interest, not eating or drinking, sleeping excessively, had poor hygiene and was not compliant with medication. The attending Paramedics sent a Vulnerable Person Referral to ASCH on 18/09/23. They noted that there were no medical problems; there was no shortness of breath; he was not complaining of pain; he had stopped taking anti-depressant medication some years ago; he would become malnourished and systemically unwell; the property was in a poor state; and his son would be unable to cope with his increasing care needs. The primary concerns were recorded as self-neglect and increasing care needs, with no care package in place. Ian consented to the referral and was considered to have the capacity to give consent. The Paramedics gave worsening care advice and asked his son to contact the GP. Ian was not admitted to hospital on this occasion.
  5. The CPN and SECAmb referrals were received by ASCH on 21/09/22 and passed to the Mental Health and Substance Misuse Service. A duty officer attempted to ring Ian’s son on 27/09/22 and left a voicemail message. In a successful phone call on 29/09/22, his son agreed to ring duty after a planned GP visit. It was noted that an urgent home visit would be required if hospital admission was not arranged. The duty worker also left a voicemail message with SOAMHS on the same day, asking to discuss the concerns raised and for information on their involvement, and whether Ian’s presentation was due to low mood or a decline in functional ability.
  6. In May 2022, Ian’s brother developed an eye condition and contact from this point was limited to phone calls, which further increased Ian’s isolation.
  7. An SPFT Lead Practitioner was assigned on 23/09/22 and contacted Ian’s son on the same day to introduce herself. Ian’s son said that ‘we really need some help’ and a visit was confirmed for 30/09/22. The Lead Practitioner offered to relay this information to Ian, but his son said that he was in bed, and he would update his father. Contact was made by the Lead Practitioner with ASCH on 29/09/22 and a joint visit was agreed for 30/09/22.
  8. Ian’s brother and sister-in-law visited him on 29/09/22, when his son was also present, and were shocked to see his appearance and living conditions. They described him as lying in a foetal position and seemingly unable to get out of bed; that he was very thin; his fingernails were long; and he was unable to speak. They also observed significant hoarding; with three mattresses in the living room, no clear space, pans piled up, mould in cups and minimal food in the fridge. The family dialled 999 for an emergency ambulance and Ian was admitted to the Royal Sussex County Hospital in Brighton.
  9. On admission, Hospital records show that Ian presented as confused; frail and immobile; with nutritional deficiency; living with early onset Alzheimer’s-type dementia; not eating (one sandwich in three days) and seldom drinking; and not taking Sertraline medication in recent weeks or months. It was noted that there was no clear trigger for his deterioration in health and his son relayed that there had been increased confusion and weakness over the past week. Ian had no record of prescribed medication on admission, including no record of the previous prescriptions for Sertraline anti-depressants and of the more recent prescription for Donepezil.
  10. There was a scheduled joint assessment visit by ASCH and the SPFT Specialist Mental Health Service on 30/09/22, arising from the referral received by ASCH on 21/09/22 and the assignment of an SPFT Lead Practitioner on 23/09/22. There was no answer as Ian had been admitted to hospital. The Dementia Support Service had been due to visit on the same day to discuss support. On contacting Ian’s son and being made aware of the admission, the visit was postponed to a provisional date in October.
  11. Hospital records demonstrate that Ian received attentive care from a range of specialists. It was noted that there was a poor chance of recovery unless his severe depression and dietary intake were improved. His son, brother and niece visited four days before he died in hospital on 14/10/22, aged 67. A natural cause of death was recorded, referring to multiple organ failure, sepsis of unknown aetiology and Alzheimer’s-type dementia. It was also discovered that he had “probable metastatic cancer of unknown primary.”
  12. ASCH later reported Ian’s death to Sussex Police, under the Adult Death Protocol. An investigation found that there was no evidence of his son allowing the death or physical harm of a vulnerable adult. There was also no evidence of coercive control, and the home environment did not indicate severe neglect. t was also noted his son had possible care and support needs which led to an Adult Core Assessment completed in November 2022. A Safeguarding Adults Enquiry was undertaken from November 2022 to January 2023. This was in response to a Safeguarding Adults Concern raised by family on 8/11/22 and identified missed opportunities for earlier assessment and support to Ian and his son.

## Analysis & findings

**Examples of positive practice:**

* 1. Letters from the MAS to the GP Practice on 12/09/22 and 14/09/22 confirmed the outcome of their assessment, that Ian was living with dementia, and the GP Practice intended to undertake a medical review on the basis of this information. It was stated correctly that a referral had been made to the SPFT Specialist Older Adults Mental Health Service (SOAMHS) and incorrectly that a referral had been made to ASCH. Following SOAMHS MDT meetings on 12/09/22 and 15/09/22, it was decided that a CPN would visit Ian on the following day to complete an Addenbrook Cognitive Examination[[3]](#footnote-3) (ACE), which is an assessment of memory decline, and to provide support pending ASCH involvement.
  2. A significant characteristic of this review is the limited agency involvement, particularly with Gwen, and the reliance of both Gwen and Ian on family carers who were experiencing difficulty in managing. There is evidence that professionals and agencies endeavoured to meet their needs in a personalised and efficient manner and there were notable examples of good practice.
  3. The GP and Community Nurses were attentive in attempting to engage with Gwen and her daughter in April and May 2018. SECAmb Paramedics provided timely and attentive support to Gwen in October 2021, involving her daughter sensitively in decision-making and in escalating the Safeguarding Adults Concern.
  4. Ian’s non-attendance for medical appointments were followed up by a GP home visit in April 2022 and a referral for a dementia assessment.
  5. A Community Psychiatric Nurse (CPN) in September 2022 was proactive in addressing a referral that had not been processed. Practitioners also had respectful and skilled discussions with his son.
  6. The planned joint ASCH and SPFT visit at the end of September 2022, had Ian not been admitted to the Royal Sussex County Hospital, would probably have led to a coordinated and comprehensive assessment of needs, care planning and intervention. He also received very attentive and personalised palliative care on admission to hospital.

* 1. However, lead professionals and practitioners across all agencies in the review have recognised that there were significant missed opportunities to respond to self-neglect and carers needs, including the difficulty in engaging, through multi-agency needs assessment and risk management. These missed opportunities are considered in this section. They lead directly to recommendations to improve service provision and to enhance the safety and wellbeing of adults at risk.

**How effective was multi-agency needs and risk assessment?**

**Engagement by agencies:**

* 1. **Gwen**: There were missed opportunities to escalate concerns about the difficulty experienced by agencies in engaging with Gwen and her daughter. By July 2018, it was clear that efforts by the GP and Community Nurses to visit and follow a treatment plan in the previous two months had not been successful. Also, Gwen’s regular prescriptions had not been collected from the dispensary after January 2021. These were opportunities for further efforts at engagement, annual medical reviews, escalating concerns to Adult Social Care & Health (ASCH), and triggering a multi-agency risk management meeting, involving cross-border communication.
  2. **Ian:** Whilst Ian’s prescriptions for Sertraline anti-depressant medication were irregular and in response to episodes of depression, he appears to have been depressed from the start of 2022 or before and had not requested or collected this medication since July 2021. There is no formal follow-up arrangement in these circumstances at the GP Practice and Dispensary, as it is assumed in these circumstances that the medicine is no longer needed. There is an arrangement for medical reviews to be undertaken on patient’s birthdays and, if the patient is experiencing memory issues (as Ian had been), there is an expected automatic medical review arrangement.

His prescription in September 2022 for Donepezil medication to manage his dementia, arranged by secondary care Specialist Services rather than the GP Practice, was never collected.

* 1. Vulnerable adult list and risk management flag system: There is an opportunity to develop a flexible system across primary care teams, locally and nationally, to (i) list clinically vulnerable patients (such as patients experiencing dementia, significant mental health concerns, confinement to home, significant carer needs or current safeguarding concerns) and (ii) flag when high risk factors arise (such as non-engagement in a treatment plan, missed appointments, declining home visits and not collecting regular prescriptions). This could trigger welfare contacts, welfare visits and potentially escalation to other agencies. Primary care teams have different types and levels of resources at their disposal, such as clinical meetings and community coordinators. Therefore, it is important to adopt a collaborative, flexible and adaptable approach, with autonomy for primary care teams to consider the best fit in terms of local systems and resources. It is noted by the Reviewer that vulnerability lists are active in many primary care teams and were not utilised during the Covid pandemic.

**Needs and carers assessments.**

* 1. Gwen - Referral to Adult Social Care & Health (ASCH) in September 2020: There was a missed opportunity in September 2020 for Adult Social Care & Health (ASCH) and the GP Practice to have responded to the referral by a neighbour. This was sufficiently detailed to have raised a significant concern about how Gwen and her daughter were managing, and, with initial exploration, it would have been evident that Gwen had not been seen by anyone outside the household for more than two years. The referral was not passed to an ASCH care management team to consider a Care Act Section 9 needs assessment, a Section 10 carers assessment, and potentially a self-neglect risk management response (within or outside safeguarding). It was passed after a few days to the GP Practice, for consideration without a specific request for action, and this did not lead to a welfare contact, visit, or joint communication to clarify the information and decide on a proportionate response. The information received was added to the ASCH record for Gwen’s daughter and a record was not created for Gwen.
  2. The ASCH, Health & Social Care Connect (HSCC) duty team is the access point for most referrals, including safeguarding adult’s concerns. Whilst the neighbour relayed holistic concerns, there was an apparent agency focus on the mental health needs of Gwen’s daughter. The care needs of Gwen and the needs of her daughter as a carer did not seem to be actively considered. The ASCH SAR panel representative confirms that, had the referral been forwarded to an ASCH care management team, this would have led to consideration of self-neglect risk management, a social care assessment and safeguarding action. Care management teams continued to conduct home visits during the Covid pandemic however, this was only in exceptional circumstances, and based on risk assessment approach. There was no indication that the referral was considered to be a lower priority because it was generated by a member of the public.
  3. Ian – Intended GP Practice referral to ASCH in April 2022: There was a missed opportunity in April 2022 for the GP Practice to trigger a Care Act Section 9 needs assessment, a Section 10 carers assessment, and potentially a self-neglect risk management response (within or outside safeguarding). A GP referral to the SPFT Memory Assessment Service (MAS) ensured the engagement of mental health services and a dementia assessment. However, due to an administrative error, an intended referral to ASCH for a needs and carers assessment was not sent or followed-up. The GP Practice has introduced an improved administration system to mitigate against this risk; including a note of multiple actions when referral tasks are forwarded by Clinicians to Administrators.
  4. The referral, if progressed, would typically have been transferred to the ASCH Mental Health and Substance Misuse Team, in view of the pending dementia assessment. This would have enabled a social work visit and communication with the GP and other agencies. It is evident that Ian had eligible needs for care and support and that his son had eligible needs as a carer. There was every indication that his son would have accepted ASCH support, including respite.
  5. It would also have been appropriate to have referred the self-neglect concern to Local Authority Housing, leading to consideration of joint working on property concerns. A Tenancy Sustainment Officer has a remit to support tenants directly with hoarding and Tenancy Managers routinely visit in these circumstances to assess against the clutter rating and to provide support.
  6. Ian - SPFT Memory Assessment Service (MAS) Screening in May 2022: The two-to-three-month timescale for the SPFT Memory Assessment Service (MAS) to triage and screen the referral for Ian was not unusual and there would not have been clinician involvement before triage. The MAS referral form states that the service covers routine memory assessments and urgent risk circumstances should be referred directly to the SPFT Specialist Older Adults Mental Health Service (SOAMHS).
  7. Ian – SPFT Memory Assessment Service (MAS) visits in August and September 2022: A MAS Community Psychiatric Nurse (CPN) visited Ian in August 2022, by which time it is likely that his physical health had significantly deteriorated and discussed a referral to ASCH with his son. A decision to refer to ASCH was forwarded for consideration at a MAS Multi-Disciplinary Team (MDT) meeting, which was delayed, rather than directly referring to ASCH after the visit or requesting a priority review at the next weekly MDT meeting**,** both of which were available options.A MAS MDT meeting in September 2022 confirmed a diagnosis of early onset moderate Alzheimer’s Disease and the GP Practice was notified of this in a letter, after which MAS closed involvement and referred to SOAMHS. A SOAMHS MDT meeting in September 2022 noted incorrectly that a referral had been made to ASCH. As a service improvement, a reminder has been sent to all Clinicians within MAS on the option to directly refer to ASCH via a MAS Administrator, with Lead Administrator monitoring. A further review of the system is planned for September 2023. Also, an SPFT Initial Management Review (IMR) in April 2023 led to an action that Clinical and Administrative staff would be advised to ensure that all appropriate referrals are completed before an episode is closed. The error was recognised by a visiting SOAMHS CPN on 16/09/22, who directly referred to ASCH on 21/09/22.

Although slightly delayed, this demonstrated positive practice in terms of professional curiosity and a proactive approach.

* 1. Ian – South East Coast Ambulance Service (SECAmb) visits in September 2022: The Ambulance Service attended to Ian on 18 and 29 September 2022. On the initial visit, the Paramedics decided that support at home was appropriate, and Ian’s son was asked to contact the GP Practice in the morning for follow-up. The SECAmb representative considers that it was appropriate and consistent with Ambulance Service practice to have avoided hospital admission at this stage and to have enlisted the support of Ian’s son, who was clearly concerned about his father. Whilst the Reviewer respects this specialist judgement and acknowledges the pressures on the Service, it may have been appropriate for Paramedics to have followed up by contacting the GP Practice directly in the morning, given the risk circumstances. A Safeguarding Adults Concern was raised with ASCH, received on 21 September 2022.
  2. SECAmb conveyed Ian to hospital on the second visit. The SECAmb representative confirms that the clinical observations seemed to have worsened in the eleven days that had elapsed since the previous visit. A Safeguarding Adults Concern was not raised on this occasion.
  3. Ian – Referrals to Adult Social Care & Health (ASCH) in September 2022: ASCH received the CPN and SECAmb referrals on 21 September 2022. The CPN referral contained information that Ian had a recent diagnosis of dementia, was spending all day in bed and required a needs assessment. Self-neglect was written against 'known risk to self' on the referral and the urgency of response was noted as within 5 days, the lowest priority available. The SECAmb referral contained information that there were no medical problems and that clinical observations were good, there was no pain on arrival, the property was in a poor state, he would become malnourished and systemically unwell, and his son was trying his best with no support. These referrals could have more clearly emphasised the urgency of the risk circumstances, although this was also the role of duty screening.
  4. The referrals were passed to the Mental Health and Substance Misuse Team on 22 September. The CPN was contacted on the following day to confirm receipt. Ian’s son was contacted on 29 September (following a no reply two days earlier), to arrange a joint visit with SPFT on 30 September if Ian was not admitted to hospital. A planned joint visit was good practice, and it was likely that this would have enabled the arrangement of a comprehensive support package, including respite care, and potentially a self-neglect multi-agency risk management meeting (within or outside safeguarding). Also, the planned visit was within three working days of the referrals, which were not clear about the urgent circumstances. However, the Reviewer considers that a timelier clarification of the urgent circumstances and timelier joint visit were warranted.
  5. It is unclear whether Ian’s dementia, combined with his depression, had impacted on his self-care, including his diet, and whether earlier ASCH, SPFT and GP Practice support could have prevented the severity of self-neglect that contributed to Ian’s death. It is also possible that Ian’s son may have been regarded primarily as a protective factor, when he was a young carer and clearly needed support to manage.

**Practitioner-level risk management:**

* 1. There is a robust pan-Sussex self-neglect risk management procedure in place; the Sussex Multi-Agency Procedure to Support Adults who Self-Neglect [[4]](#footnote-4)(embedded within the Sussex Safeguarding Policy & Procedures). This was established in 2019 and is currently under review.
  2. It seems that the procedure may not be sufficiently embedded in practice across all agencies. There is a clear direction that agencies should report Safeguarding Adults Concerns to ASCH, for lead-coordination of the multi-agency response, if it is suspected that the safeguarding statutory requirements are met. However, it does not seem to be sufficiently clear that any agency can convene a multi-agency self-neglect risk management meeting at any time. The procedure suggests that, even if the safeguarding duty does not apply, there should be a referral to ASCH before determining the lead agency to convene a meeting. It is important, however, that ASCH is invited to and engaged in self-neglect risk management meetings, to contribute to discussion and planning and as an assurance that the safeguarding duty has not been missed. There also seems to be uncertainty about when the safeguarding conditions are met; based on the level of risk or whether non-safeguarding risk management efforts have been exhausted.
  3. For both Gwen and Ian, there were no multi-agency risk management meetings. This represented a significant missed opportunity (or opportunities) to have developed a coordinated risk management plan to address rapidly increasing self-neglect and carer concerns.
  4. Multi-Agency Risk Management (MARM) Meetings: A MARM[[5]](#footnote-5) is established in East Sussex however, it is designed to provide guidance for practitioners on working with adults with multiple complex needs and managing cases in which there is a high level of risk. The MARM is being reviewed in 2023 and this should incorporate an assurance that all relevant agencies are familiar with the role of the forum and fully engaged in regular meetings. The needs and risks presented by both Gwen and Ian would not have met the current criteria for MARM consideration.

**How effective was decision-making in response to safeguarding concerns?**

**Escalation of safeguarding concerns:**

* 1. There were opportunities to escalate self-neglect Safeguarding Adults Concerns for both Gwen and Ian, as well as Safeguarding Adults Concerns that were escalated and did not lead to safeguarding or other effective action. It would have been appropriate to have triggered needs and carers assessments, alongside self-neglect multi-agency risk management meetings, for both Gwen and Ian; regardless of whether the safeguarding conditions were met.
  2. **Gwen:** There was an opportunity by July 2018 to have escalated concerns about engagement, leading to needs and carers assessments. The referral by a neighbour in September 2020 was an opportunity to undertake these assessments, aligned to a self-neglect risk management response, whether the safeguarding conditions were met or not. Initially triaged by ASCH as a safeguarding concern, the referral was not progressed to a duty visit or other action, aside from informing the GP Practice.
  3. SECAmb raised a Safeguarding Adults Concern in October 2021, regarding long-term neglect, after Gwen had died in hospital. A concern was also submitted in relation to Gwen’s daughter, which was good practice in terms of a holistic, whole family approach. The resulting enquiry found that there had been missed opportunities to support Gwen and her daughter more effectively.
  4. There has been an Adult Death Protocol in Sussex since November 2020, it outlines the process that should be followed in responding to situations in which an unexpected adult death takes place and there is a suspicion, or it is known, that abuse or neglect by a third party directly contributed to the death. The protocol is triggered when agencies believe that a third party may have been involved in a person’s death. The suspected abuse and neglect do not have to be the direct cause. This would have been appropriate in respect of Gwen however, Gwen was admitted to a hospital in Kent and died in Kent and not Sussex, and there is no cross-border mutual agreement. In these circumstances, it seems that an approach commensurate with that of safeguarding children was warranted.
  5. **Ian:** Had the GP Practice referral been forwarded to ASCH in April 2022, as intended, this would have been an opportunity to have undertaken needs and carers assessments, aligned to a self-neglect multi-agency risk management response, whether the safeguarding statutory criteria were met or not.
  6. By September 2022, the visiting SPFT CPN recognised rapidly increasing risk circumstances and that the intended referral to ASCH was not sent, which had been a missed opportunity and was also good practice on the part of the CPN in addressing the error. The CPN and SECAmb referrals in September 2021 led to a planned joint visit by ASCH and SPFT, but the Independent Reviewer considers that the planned intervention was not sufficiently timely as a crisis intervention response seems to have been warranted. Ian was admitted to hospital on the day of the planned visit. It is likely that this visit would have led to a coordinated and comprehensive intervention.
  7. SECAmb acknowledged that a Safeguarding Adults Concern should have been raised after the visit in late September 2022, in which Ian was conveyed to hospital. The responsible Paramedic has subsequently undertaken mandatory safeguarding adults training.
  8. A Safeguarding Adults Concern regarding neglect was raised by Ian’s family after his admission to hospital. The resulting Safeguarding Adults Enquiry found that there were missed opportunities to meet the needs and address the risks experienced by Ian and his son more effectively.
  9. Sussex Police were contacted within the terms of the Adult Death Protocol, as appropriate.

**How effective was the consideration of mental health, mental capacity and personalisation?**

**Mental health**

* 1. **Gwen**: There is no indication that Gwen was experiencing mental health concerns, although there was a considerable period in which she was not seen by anyone outside the household and her state of mind was not known during this time. Her daughter’s ability to care and acceptance of support were impeded by her own mental health concerns. A carers assessment and an effort to develop a trusting relationship may potentially have opened a door to support.
  2. **Ian:** Having experienced a history of depressive episodes, Ian did not request a repeat prescription of Sertraline anti-depressant medication after July 2021, and this did not trigger a medication review. There were a series of potentially traumatic events that may have contributed to his depression and physical health decline in 2022. Ian confirmed to the CPN in September 2022 that he felt depressed and was unaware why he was no longer taking anti-depressant medication. The GP referral to the Memory Assessment Service in April 2022 led to a diagnosis of dementia by September 2022 and his family feel that this diagnosis may also have been traumatic to Ian. He did not begin taking the Donepezil medication for dementia, prescribed in September 2022, and his cognitive impairment and memory loss may also have been impacting on his self-care and wellbeing.

**Mental capacity**

* 1. **General:** It does not appear that Mental Capacity Assessments were missed or carried out inappropriately. There are clear examples of agencies risk assessing whether there were grounds to consider mental capacity in relation to treatment and care decisions, although this seems to have been variable.
  2. **Gwen:** There is no indication that there were grounds to have considered a Mental Capacity Assessment during the period that Gwen was not seen, although this cannot be verified. The GP Practice records make no reference to mental health or mental capacity, with all records focussed on her physical health, and ASCH records of later involvement do not mention mental capacity. In October 2021, SECAmb assessed that Gwen did not have capacity to make a decision regarding medical treatment when she was in a state of semi-consciousness and was conveyed to hospital.
  3. **Ian**: Mental capacity is not mentioned in GP Practice, ASCH, SPFT and Housing records. SECAmb recorded in September 2022, when referring to ASCH, that Ian consented to the referral and had capacity to give consent. The CPN also recorded in September 2022 that there were no Mental Capacity Assessment needs. When in hospital in September 2022, there is no record of mental capacity consideration.

**Personalisation**

* 1. It is clear that practitioners were sensitive and skilled in communicating with Gwen, Ian, and their family carers. This is particularly evident in the GP and Community Nursing interactions with Gwen and her daughter in April and May 2018 and in the sensitivity and tact shown by the Ambulance crew to her daughter in October 2021. It is also evident in the GP follow-up with Ian in March and April 2022 and in the CPN interactions with his son in August and September 2022.
  2. However, there was limited agency involvement, particularly with Gwen, and this will have impacted on the ability of practitioners to develop close, trusting professional relationships. Also, telephone contact was inevitably with their family carers, restricting their voice and adding to their isolation.
  3. Ian experienced a series of traumatic events, which undoubtedly contributed to the rapid decline in his mental health and ultimately his physical health at a relatively young age. There was not a sense of professionals spending time to explore and fully understand the impact of these events, through trauma-informed practice, professional curiosity, active listening, adopting a strengths-based approach and establishing what he felt would be a good life. In contrast, it is notable that the Hospital Consultant was very sensitive to his views and feelings about end-of-life care. Ian’s son may have been unprepared for the cognitive decline of his father and his request for support, particularly respite, was not actively followed up. There is a need to embed a consideration of lived experience in the intervention of all practitioners with service users.
  4. The pan-Sussex Multi-Agency Self-Neglect Procedures and accompanying briefings stress the importance of a person-centred and compassionate approach, to building a rapport and trust over time, and to reaching an understanding of the complex causes of self-neglect.

**How did resources and environmental factors impact on care?**

* 1. It is probable that the Covid pandemic will have had some effect on home visits, although the extent to which this was a factor for Gwen and Ian is unclear. Both GP Practices visited in response to non-attendance at medical appointments and other agencies visited them at home. However, it is notable that the standard operating practice changed significantly during the Covid pandemic from March 2020 and most of the next two years. This included the suspension of most routine follow-ups for stable chronic conditions. Most practices also discontinued their monthly MDT meetings with Adult Social Care and Community Nursing during this period. As Gwen and Ian lived in remote locations, it may be that this made them less visible to the outside world.
  2. It is recognised that austerity has had a significant impact on available resources across health and social care, with the added concern that practitioners are managing increased workloads. However, resource provision has not been identified as directly responsible for any of the concerns relating to the support provided to Gwen and Ian.

**How compliant were agencies with legislation, policies, procedures, and practice guidance?**

* 1. The Care Act 2014 responsibilities of ASCH to undertake needs assessments, risk assessments, carers assessments and potentially safeguarding enquiries were not fully met in regard to Gwen. It is noted that ASCH were not informed of the concerns relating to Ian until a very late stage. The responsibilities of other agencies in referring for these actions to be undertaken were also not fully met.
  2. The pan-Sussex self-neglect procedures were not triggered by agencies when there was a need for multi-agency risk management in relation to both Gwen and Ian.

**What were the cross-border implications for practice?**

* 1. There were no identifiable complications due to cross-border communication. However, the learning in this review can benefit practice across Sussex and Kent, with actions to address engagement by primary health care having potential national implications.

**What is the learning from other Safeguarding Adults Reviews concerning self-neglect?**

* 1. **Thematic Safeguarding Adults Review** (Kent & Medway, 2021): This review involved relatable circumstances and useful learning. Four adults died at home in 2018 and their circumstances included poor health, isolation, disengagement from services (not attending GP appointments, not responding to contact, and not collecting prescriptions), and a safeguarding referral regarding self-neglect that was not progressed. The recommendations included GP Practices maintaining an up-to-date vulnerable adults list, evidencing arrangements to cover vulnerable adults who do not attend, all agencies raising staff awareness of the self-neglect and hoarding policy, and the SAB developing a multi-agency risk management framework.
  2. **SAR Adult E** [[6]](#footnote-6)(West Sussex, 2018): In this review, it was recommended that “effective and proportionate multi-agency processes should be in place for monitoring the provision of repeat prescriptions and the flagging of failures to either request or collect or have made up repeat prescriptions, particularly for those living alone or known to be at risk.”

## 

## Recommendations

**10.1 Engagement by agencies**

**Recommendation 1**

* East Sussex SAB and NHS Sussex ICB to develop a specific learning briefing for primary care on best practice recommendations, self-neglect referrals and carers assessment.

**10.2 Risk management & Safeguarding Adults Concerns**

**Recommendation 2**

* East Sussex SAB, in collaboration with West Sussex SAB and Brighton & Hove SAB, to oversee a review of the pan-Sussex Multi-Agency Self-Neglect Procedures; with a focus on the responsibility of all agencies to trigger practitioner-level risk management meetings when the safeguarding statutory criteria is not met; and with involvement of ASCH to ensure that a safeguarding duty is not missed. As part of this, ASCH to consider an audit of front door referral information, screening and recording of self-neglect referrals, including the needs of any identified carers.

**Recommendation 3**

* East Sussex SAB to be given assurance that the provision of appropriate risk management training across relevant agencies, is aligned to the pan-Sussex Multi-Agency Self-Neglect Procedures, with a focus on professional curiosity and active listening.

**10.3 Needs and carers assessments**

**Recommendation 4**

* East Sussex SAB to obtain assurance that the relevant GP Practice and SPFT Memory Assessment Service improved referral arrangements, including follow-up, are embedded, and working.

**10.4 Personalisation**

**Recommendation 5**

* East Sussex SAB partners to review the provision of information leaflets they publish for members of the public, to ensure that service users, families and the public have clear information on who to contact in the event of concerns about care, as well as what will happen when concerns are raised.

**Recommendation 6**

* East Susses SAB to promote trauma-informed approaches, professional curiosity & active listening in service user interviews, incorporating this principle within risk management training; including a mapping exercise to identify and learn from good practice across health and social care agencies in Sussex.

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