West Sussex Safeguarding Adults Board
Making Safeguarding Personal

Safeguarding Adults Review

Safeguarding Adults Review in respect of Colin

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Author: Anna Berry
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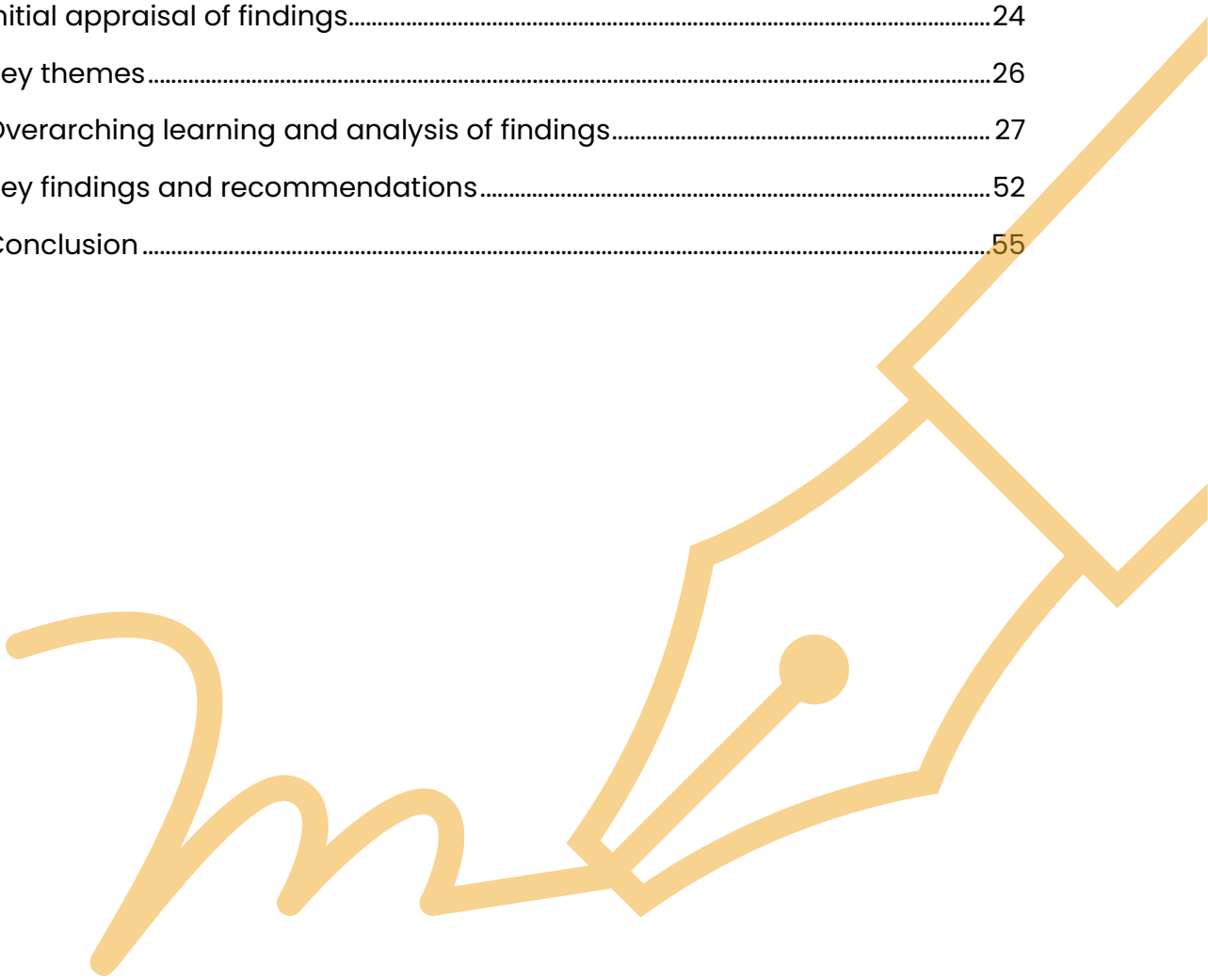


Foreword

The West Sussex Safeguarding Adults Board (the Board) has published this Safeguarding Adults Review (SAR) in relation to Colin. The Board and the Independent Reviewer express their sincere condolences to the family and friends of Colin. The family have contributed to this review and requested for Colin's name to be used, to ensure that his voice is heard.

Colin was a 77-year-old man, who was described by his wife as the solid foundation of the family, and previously as a physically and mentally strong person, who could turn his hand to anything. He lived in his own home, and was cared for by his wife Doreen, prior to being admitted to hospital where he sadly passed away 18 days later. Colin was physically disabled following a stroke and mobility was a significant factor in his care. He was also diabetic and had other medical conditions. The initial SAR referral highlighted safeguarding concerns around self-neglect and the deterioration of his physical health in relation to pressure ulcers.

The purpose of a SAR is to identify how lessons can be learned, and services improved for all those who use them, and for their families and carers. This review looked into the circumstances prior to Colin's death and considers the actions of involved agencies.

The review identified key learning in relation to; safeguarding and legal literacy, multi-agency approaches, professional curiosity, working with and supporting the family, and understanding the person (Making Safeguarding Personal). The review made overarching recommendations in these areas.

The Board is committed to taking forward and monitoring actions in response to all recommendations from this review in order to ensure service development and improvement in practice. The Board will also ensure that the learning from this review is widely shared and that the outcomes of the learning will lead to improved services in West Sussex.

Annie Callanan
West Sussex Safeguarding Adults Board Independent Chair

1. Introduction

1.1. A Safeguarding Adults Board has a statutory duty to arrange a Safeguarding Adults Review where:

- an adult with care and support needs has died and the Safeguarding Adults Board knows or suspects that the death resulted from abuse or neglect, or an adult is still alive, and the Safeguarding Adults Board knows or suspects that they have experienced serious abuse or neglect, and
- there is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

1.2. Board members must cooperate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons in the future. The purpose is not to apportion blame or responsibility, but to identify ways of improving how agencies work, singly and together, to help and protect adults with care and support needs who are at risk of abuse and neglect, including self-neglect, and are unable to protect themselves.

1.3. 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.

1.4. The aims of the Safeguarding Adults Review are to improve the way multi-agency systems work together to support adults with care and support needs and, if possible, to provide a legacy for family and friends.

1.5. 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.

1.6. The review process to meet these aims and objectives has followed a clear path. The methodology chosen for this review is a "Learning Together" approach. This included a panel to agree terms of reference and a focus on themes, patterns and factors together with family and practitioner discussions where possible. The Independent Reviewer has conducted research by analysing the information provided, culminating in an overview report for the West Sussex Safeguarding Adult Board.

1.7. The review will cover the period of June 2022 to the time of Colin's death in November 2022.

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

2.1. The Safeguarding Adults Review referral was received on 10 May 2023 and following this, the Safeguarding Adults Review subgroup panel found the case to meet the criteria for undertaking a review. The Independent Chair of the Board endorsed this decision and the Safeguarding Adults Review was commissioned. A Safeguarding Adults Review reviewer was appointed, and a panel established to conduct a review in order to make recommendations for future practice where this is necessary.

2.2. Participating agencies/panel members were:

- West Sussex County Council
- NHS Sussex Integrated Care Board
- Sussex Community NHS Foundation Trust
- Worthing Medical Group
- South East Coast Ambulance Service
- University Hospital Sussex NHS Foundation Trust

2.3. This review is about a 77-year-old man called Colin who died in November 2022. Colin lived in his own home and was cared for by his wife Doreen prior to being admitted to hospital in October 2022, 18 days prior to his death. Colin was physically disabled following a stroke a number of years prior, and mobility was a significant factor in his care. He was also diabetic and had other medical conditions, thus his risk of developing pressure ulcers was high. The initial Safeguarding Adults Review referral highlights safeguarding concerns which can be captured as “self-neglect”. Therefore, the primary issues were deterioration of physical health in relation to pressure ulcers in the context of self-neglect.

2.4. The Safeguarding Adults Review Panel acknowledged that there were areas of improvement identified for the planning and coordination of multi-agency care.

3. Key themes to be explored in this review

3.1. **Empowerment:** Making Safeguarding Personal: to what extent was Colin's voice and that of his family central to decision making?

3.2. **Prevention:** Were agencies proactive at an early enough stage to address physical deterioration in a coherent way? Were communication barriers understood well enough and taken into account?

3.3. **Proportionality:** Were legal frameworks and joint risk formulation used to best effect? In particular, the use of the Care Act and the Mental Capacity Act.

3.4. **Protection:** How robust were assessments of need and application of threshold? Was self-neglect considered and were local protocols applied?

3.5. **Partnership:** How effective was the coordination of required care and support across agencies? Did information sharing processes work well?

3.6. **Accountability:** Were safeguarding processes followed appropriately? Is there evidence of leadership, management oversight and supervision? Were issues or concerns escalated appropriately and were services always clear about who was accountable for care and support?

4. About Colin

4.1. This section of the report will provide a descriptive overview of the touch points with Colin, and the information that is known of him. Analysis against the identified themes will be carried out in due course.

4.2. Colin was a 77-year-old man who was known to different services in respect of his health issues. The primary reasons for agency involvement in the timescale of this review is management of diabetic foot ulcers/infection. The services that were predominantly in contact with Colin were the General Practitioner (GP), the podiatrist, the community nursing team, the occupational therapy service and the ambulance service.

4.3. In terms of medical history, Colin's notable issues were:

- Severe frailty
- Suspected chronic obstructive pulmonary disease (COPD)
- Glaucoma
- Hypertension (HTN)
- Stroke (in 2002)
- Dysphasia
- Type 2 diabetes (diagnosed in 2002)
- Bilateral cataracts
- Peripheral Vascular disease

4.4. Colin is repeatedly recorded by services to decline assessments, treatment, options for equipment and recommendations to attend hospital. The known reasons for this will be explored in due course. There was an ongoing assumption of capacity in terms of the decisions that Colin made, thus his presentation and resulting situation can be considered as self-neglect. This manifested in his carer's ability to look after him, agency's ability to fully assess him, the general environment, personal hygiene and overall deterioration of health; most significantly the development of pressure ulcers and sepsis that caused his death.

4.5. Colin was in receipt of services appropriate to his health conditions prior to the timeframe of this review, for example, his GP and the diabetes service. Colin was visited by the diabetes nurse because he had not responded to invites and calls to arrange his diabetes review which was due in June 2022. It was reported at the visit that Doreen was unable to remove Colin's shoes. This was escalated to the Advanced Nurse practitioner who attempted to visit several times. Doreen managed to remove Colin's shoes in August 2022 and sent a photo of his feet to the GP who visited the same day. This review considered the events and actions that took place from thereon.

4.6. Colin's cause of death is recorded as 1a) sepsis 1b) multiple infected pressure sores, and this is relevant to the exploration of the self-neglecting presentation in the last two months of his life.

4.7. Colin lived in his own home with his wife Doreen, his son and latterly Doreen's 91-year-old Mother. It is important to highlight that all four people living in the house during the timeframe of this review had care and support needs and thus the circumstances in the house were challenging and complex. This will be explored in due course.

4.8. Doreen reports that she has dyslexia and is diagnosed with attention deficit hyperactivity disorder (ADHD). Doreen and her sister describe her as "functionally illiterate", meaning that her reading and writing skills are not sufficient to manage daily living and complex tasks that require more advanced literacy skills. As a result of these issues Doreen states that she does not always fully comprehend or retain information, and prior to Colin becoming unwell had relied on him to coordinate most aspects of her life.

4.9. Colin and Doreen's son is diagnosed with ADHD and Autistic Spectrum Disorder (ASD). There is a long history of statutory service involvement during his childhood which forms the context of Colin's reluctance for service involvement.

4.10. Doreen's 91-year-old mother also lived in the house at the end of the timeframe of this review and required assistance with daily activities of living such as hygiene, mobility, nutrition, hydration and medication. This care was provided by Doreen.

4.11. Colin is described by his wife as the solid foundation of the family. Previously he was a very physically and mentally strong person who could turn his hand to anything. He had worked in the trucking/transport industry and was extremely practical and solution focused. Colin had many varied interests including joinery and cars, he built and raced his own stock car, and he kept parrots and parakeets.

4.12. Doreen describes how Colin supported her through her own challenges and taught her "everything she knows" and they had a long and happy relationship. After multiple miscarriages, their son was born and the relationship between father and son is described as very special because Colin had a good insight into his challenges and understood him. Doreen describes an extremely difficult period of time during their son's school years where statutory intervention of Children Services was required, and this was not a positive experience for the family.

4.13. Unfortunately, Colin suffered a stroke during his son's earlier childhood which compounded the pressure and challenges within the family and reversed the roles, with Doreen becoming Colin's carer, managing his needs for the next 16 year prior to his death. This was a difficult and complex period of time for the family as a whole, trying to navigate and understand multiple services.

4.14. There is clear recording from services about the risk of pressure ulcers in view of reduced mobility, inadequate furniture which consisted of an unsuitable chair and a normal bed, and the absence of any manual handling equipment which meant that observation and assessment of Colin's skin was not able to be carried out. Therefore, until Colin's admission to hospital on 22nd October 2022, neither professionals nor family were aware of the presence of the pressure ulcers. This is the reason why the tissue viability nurses (TVN) were not involved.

4.15. There is evidence of some good working practices with services visiting regularly and sometimes jointly to treat Colin's feet and to assess the environment that Colin was living in. There was absolute recognition that the circumstances as a whole were not ideal but within the two-month timeframe of this review, there was not an agreed solution identified which was often attributed to a lack of cooperation and "non-engagement". There is evidence of different ideas being put forward by professionals and family alike, but there was a disconnect in perceptions of what was suitable and possible, and no resolution reached. This will be carefully considered throughout this review in the context of statutory frameworks designed to aid such situations.

4.16. Colin's family outline that he had a suspicion of professionals which was exacerbated when he became ill. It took time for him to trust strangers in his home and therefore the family tried to care for him as best as they could. This was made worse when hospital admissions were suggested, adaptations mentioned, and respite care suggested. In particular, Colin was extremely fearful of dying in hospital and he did not want to leave his family. As such, this review will consider the value of professional curiosity and therapeutic relationships.

4.17. The review will focus on seven "opportunities" related to specific activities/groups of visits where capacity, decision making, self-neglect and carer related issues could have been considered differently by the agencies around Colin and his family. Colin was taken to hospital on 22 October 2022 after a fall, and the presence and extent of Colin's pressure ulcers was realised. Sadly, Colin did not recover from the sepsis caused by this and died a short time later in hospital.

4.18. Doreen described the family's experience of services prior to and during the timeframe of this review, and added context in terms of the family background, levels of functioning and overall complexity and challenges they have experienced. This resulted in different services being involved at different times, a mistrust of professionals and a degree of self-neglect that contributed to Colin's death. This caused concern to professionals and family alike and will be scrutinised and unpicked in the course of the following narrative.

5. Engagement with family

5.1. Engagement with family members and listening to their perspectives and experiences is essential to develop learning when undertaking a Safeguarding Adults Review. A focus on their understanding about how their family member was supported on a daily basis, their experience of services and whether they found these to be helpful, provides a more personal insight into how agencies managed events.

5.2. The statutory guidance requires early discussions with the individual (where possible), family and friends to agree how they wish to be involved. It further requires that families should be invited and understand how to be involved, with their expectations managed appropriately and sensitively[1].

5.3. Colin's wife Doreen, and sister-in-law Jane, contributed significantly to the review, providing multiple examples, anecdotes, and information. This provided a much wider context to the information that was available. Their contribution provided a rich and meaningful understanding of Colin's personality, life experiences and perspectives at different times.

5.4. The family were able to provide significant insight into Colin's life and his experiences which have helped to identify the learning for future practice.

5.5. The family believe that there is meaningful learning that can be gained from reviewing Colin's case. This learning includes recognition and response to self-neglect, person centred care, multidisciplinary coordination and delivery of care, family engagement and communication. They hope that agencies will use this learning to improve practice.

5.6. It is the wishes of the family that Colin and Doreen's real names are used throughout this review.

[1] Department of Health and Social Care (2020) Care and Support Statutory Guidance: Issued under the Care Act 2014. London: The Stationery Office (section 14.165)

6. Parallel processes

6.1. There are several notable processes that have taken place in addition to this Safeguarding Adults Review. They include:

- Coroner's inquest
- Adult Death Protocol multi-disciplinary team
- Section 42 enquiry
- Comprehensive investigation under the NHS serious incident framework (2015)
- Complaints procedures
- Investigation by professional bodies

6.2. For reference, background, and context it is helpful to consider the formal cause of death and other relevant statutory process and their conclusions. The formal medical cause of death is recorded as 1a) Sepsis 1b) multiple infected pressure sores. Colin's death was certified by a hospital doctor and a postmortem was not required to take place. In view of the safeguarding concerns which were being investigated in a Section 42 safeguarding enquiry, initially the Adult Death Protocol was followed and a multi-disciplinary team meeting held. In view of the safeguarding concerns, the matter was also referred to the coroner.

6.3. The coronial inquest into Colin's death took place on 19 December 2024. For reference, inquests are legal inquiries into the cause and circumstances of a death, and are limited, fact-finding inquiries[2].

6.4. The record of inquest states that Colin: "died on 8 November 2022 at Worthing Hospital, Lyndhurst Road, Worthing, West Sussex from sepsis as a result of multiple infected pressure sores which he developed whilst in the community. He was admitted to hospital on 22 October 2022 having become unwell and was treated for the infections but sadly could not recover from the same". The coroner recorded the death as "natural causes".

[2] Coroners | The Crown Prosecution Service (cps.gov.uk)

6.5. A comprehensive review of care was undertaken by Sussex Community NHS Foundation Trust, and their findings will be referred to later. This was also explored and recorded in the Section 42 enquiry. To note, this investigation was undertaken to establish whether there were lessons to be learned within the organisation. This is because Colin had been open to the Community Nursing Team at the time of his death. As a result, a subsequent action plan relating to the safeguarding response to self-neglect, and the identification of carers needs has been implemented within Sussex Community NHS Foundation Trust. This report was made available for the purpose of this review.

6.6. For reference, incidents that occur within the NHS were investigated at the time of this case in accordance with the NHS Serious Incident Framework (2015).[3] This has now been replaced by the new Patient Safety Incident Response Framework (PSIRF).

6.7. The family raised a complaint which captured several organisations, and the response was coordinated via NHS Sussex Integrated Care Board. The family have been supported by an advocate from Healthwatch throughout this process. The matters raised in this complaint have some similar themes to this Safeguarding Adults Review, but it is not the intention of this report to repeat the findings and conclusions unless relevant.

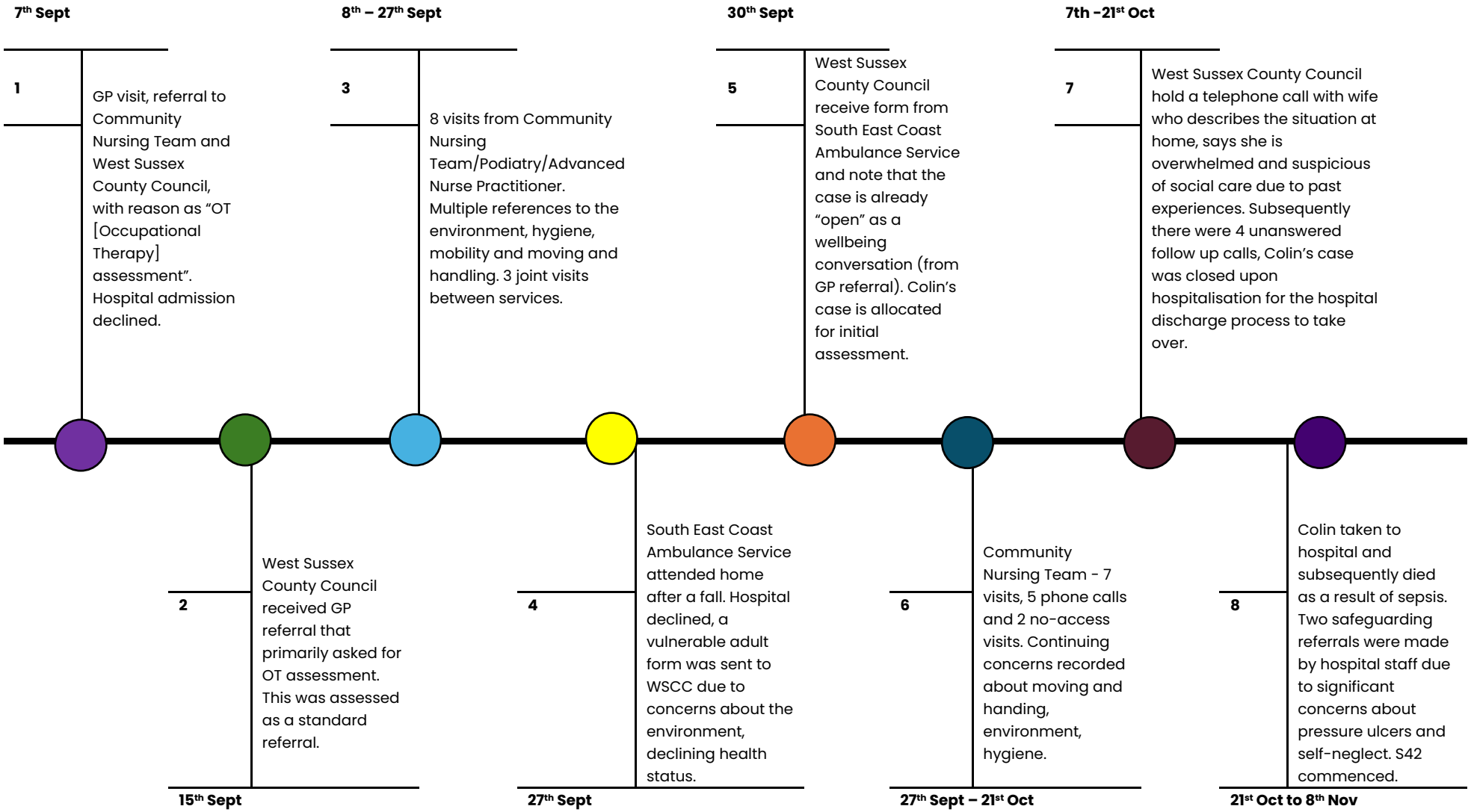
6.8. Lastly, there are some matters of conduct that were raised with relevant professional bodies during the course of the complaint process, namely with the Health Care Professionals Council (HCPC) and the Nursing and Midwifery Council (NMC) and both concluded that professional standards had been maintained and the processes were closed.

6.9. Where relevant, the report will cross reference parts of the above processes in order to capture learning.

[3] serious-incidnt-framwrk-upd.pdf (england.nhs.uk)

7. Timeline and key learning episodes

7.1. The below visual and table outlines very broadly the key episodes of care within the timeframe of the review. This does not contain each and every contact or conversation and is intended to act as a visual journey. Analysis will be made later in the report.


7th Sept
1
GP visit, referral to Community Nursing Team and West Sussex County Council, with reason as "OT [Occupational Therapy] assessment". Hospital admission declined.
15th Sept
2
West Sussex County Council received GP referral that primarily asked for OT assessment. This was assessed as a standard referral.
8th – 27th Sept
3
8 visits from Community Nursing Team/Podiatry/Advanced Nurse Practitioner. Multiple references to the environment, hygiene, mobility and moving and handling. 3 joint visits between services.
27th Sept
4
South East Coast Ambulance Service attended home after a fall. Hospital declined, a vulnerable adult form was sent to WSCC due to concerns about the environment, declining health status.
30th Sept
5
West Sussex County Council receive form from South East Coast Ambulance Service and note that the case is already "open" as a wellbeing conversation (from GP referral). Colin's case is allocated for initial assessment.
27th Sept – 21st Oct
6
Community Nursing Team - 7 visits, 5 phone calls and 2 no-access visits. Continuing concerns recorded about moving and handing, environment, hygiene.
7th -21st Oct
7
West Sussex County Council hold a telephone call with wife who describes the situation at home, says she is overwhelmed and suspicious of social care due to past experiences. Subsequently there were 4 unanswered follow up calls, Colin's case was closed upon hospitalisation for the hospital discharge process to take over.
21st Oct to 8th Nov
8
Colin taken to hospital and subsequently died as a result of sepsis. Two safeguarding referrals were made by hospital staff due to significant concerns about pressure ulcers and self-neglect. S42 commenced.

Episode	Descriptor	Points for analysis
1. 7 September 2022	The GP visited the home due to concerns about Colin's feet, this followed a home visit by the diabetic nurse and several contact attempts by the advanced nurse practitioner. Doreen sent photos of Colin's feet to the practice. Colin refused to attend hospital and was recorded by the GP to have capacity. This recording documents all stages of the capacity assessment. The GP was also worried about the overall situation at home, the environment, the equipment (chair/bed/moving and handling) and felt that Doreen and their son may need help. Referrals were made to West Sussex County Council (asking for an OT assessment), podiatry for a diabetic foot assessment and to the Community Nursing Team.	This was an opportunity to identify "self-neglect" and take safeguarding action.
2. 15 September 2022	West Sussex County Council received the referral from the GP and although the referral did include information about the environment in the house and the challenges with the equipment, it did not specifically request safeguarding action and West Sussex County Council did not know which other services were involved at this stage. There are a number of contact attempts articulated in episode 7 to capture West Sussex County Council activity. The GP referral was received and reviewed and placed on the allocation list for initial assessment.	The referral was not sent as a safeguarding referral and West Sussex County Council were not cited on the full situation and potential level of risk in terms of self-neglect.

3. 8 to 27 September 2022	During this period of time there were 8 separate visits to Colin at home as follows: 5 Community Nursing Team visits 1 Podiatry visit 1 joint visit (Community Nursing Team and Advanced Nurse Practitioner from the GP practice) 1 joint visit (Community Nursing Team and Occupational Therapy) Recorded throughout these visits were observations that Colin appearing to be unkempt, with long fingernails, faeces to parts of his body and on the floor, dirty clothing and sheets, unsafe handling (due to lack of appropriate equipment) which meant pressure areas could not be seen. Additionally, it was recorded several times that equipment that the family requested (a zimmer frame) could not be supplied as it was not safe for him. Other options were explored such as a hoist but overall, there were challenges with the space and the environment and therefore the professional assessments and advice did not align with the family's requests and opinions.	There were several opportunities throughout these episodes of care to have considered local self-neglect processes, considered a multi-agency meeting to share concerns and look at levels of risk. Capacity was recorded several times but based on "assumption of capacity". A multi-agency discussion may have prompted consideration of formal assessment and application of the self-neglect protocol. Professional curiosity and further consideration of carers assessment due to the background issues and needs of Colin's wife and son. Resolving any perceived dispute with Colin and family may have yielded further insight into their past experiences and facilitated a willingness to engage with other services.

4. 27 September 2022	South East Coast Ambulance Service attended the home after Colin had fallen whilst being moved out of bed. The crew noted that Colin had faeces to his body and the bed was also soiled and he was urinating in a bucket. It is recorded that his wife said Colin had been refusing medical help and needed support, she said that she hadn't been able to arrange carers because they are not allowed to lift Colin. The crew wanted to take Colin to hospital, and he refused, they record that he had capacity and that they spent time talking to Colin about consequences. A "vulnerable adult form" was submitted in line with South East Coast Ambulance Service policy. For reference, a South East Coast Ambulance Service vulnerable adult form is completed by staff and sent to the internal safeguarding team for review where subsequent action is decided - this may include a safeguarding referral to the West Sussex County Council safeguarding hub or a sharing of the form via email. In this instance, the form was shared as a request for assessment. When Adult Social Care received this report, it prompted a review of Colin's case, and due to this, his priority on the pending allocation list was increased and he was allocated shortly afterwards.	Was capacity recorded as an assumption? Was fluctuating capacity and/or executive capacity considered? What would have been an alternative action? Did the vulnerable adult form specifically identify the concern as "self-neglect"? Was there an opportunity to make a "safeguarding referral"? To what extent were the family views considered in this instance?

5. 30 September 2022	West Sussex County Council receive the South East Coast Ambulance Service vulnerable adult form which was requesting assessment. This included information as follows: • Environmental concerns (poor home environment) • Infected left foot (diabetic) • Mobility issues • Not wearing any clothes • Did not seem "well in himself" • Absence of support for family who are carers (notes son is autistic) • Refusal to go to hospital (states decision was at times supported by wife) It was noted that there was already an open case, and as a result of review of the vulnerable adult form, Colin's priority increased, and he was allocated for initial assessment shortly after.	The information provided thus far to Adult Social Care did not specifically report "self-neglect" or ask for a safeguarding response. Additionally, West Sussex County Council were not aware of the other services already involved with Colin's care. Was capacity explored further with the information sharer and/or other professionals involved in Colin's care? Was information triangulated? Were the needs of the carers explored and was carers assessment considered? Was professional curiosity applied in terms of the poor home environment, reluctance of Colin to accept treatment?

6. 27 September to 21 October 2022	During this period of time there were health related visits and contacts to Colin at home as follows: • 6 Community Nursing Team visits • 2 Community Nursing Team no access visits • 4 Community Nursing Team telephone calls • 2 Community Nursing Team deferred visits • 1 podiatry visit These visits were all related to Colin's foot dressings. Colin was discharged from the podiatry service as the Community Nursing Team were continuing with dressings and there was no further requirement for their service. The concerns about the environment continue to be recorded and it is documented that there was discussion with Colin and his wife about the possibility of respite care whilst adaptations were made to the environment to allow for equipment, however this was declined. It is recorded that Doreen explained that they had bad experiences with social services in the past and did not want them to be involved. The family suffered a significant bereavement in this period of time (Doreen's stepfather). On the last day of this period, Colin was taken to hospital and the Community Nursing Team were informed by the hospital that a safeguarding referral had been made due to "multiple life limiting pressure wounds".	As per number 3.

7. 7 October to 21 October 2022	Colin was open to WSCC at Carepoint 2 due to the GP referral on 7 September, and the subsequent vulnerable adult form from South East Coast Ambulance Service received on 30 September. West Sussex County Council held a telephone call with Doreen on 7 October 2022 as Colin was asleep. Doreen described Colin's physical and health related difficulties and explained that Colin didn't want to go to hospital as he had a fear of dying there. Doreen described the significant issues she was having caring for Colin due to the environment, mobility, equipment, and incontinence as Colin refused to wear any pads. Doreen had been trying to look at solutions such as carers and adapting a wet room for Colin but explained that neither seemed to be a possibility. Doreen again identified the family suspicion of social services due to poor experiences in the past. There was a plan for further contact and carers needs were recorded. Following this initial call, there were 4 more attempted calls with a plan to gain more information and insight and for further assessment with the most appropriate community team. However Colin was admitted to hospital, and the case was closed to Carepoint 2, with a request for hospital discharge pathway to be followed when Colin was medically fit for discharge. A letter was sent to Colin's address to advise him of this.	At this stage, West Sussex County Council were not aware of other services being involved and did not know that there were concerns about self-neglect. To what extent was professional curiosity applied - previous history with social care was mentioned as a significant barrier to the family accepting help, how could this have been explored and resolution achieved?

8. 22 October to 8 November 2022	On 22 October, South East Coast Ambulance Service attended Colin's home after a fall and Colin was taken to Worthing Hospital. A safeguarding referral was made by hospital staff due to significant concerns about multiple pressure ulcers, some ungradable. The hospital were concerned that professionals had been visiting Colin for some time and there were conflicting accounts from family and professionals about the home circumstances. The hospital also articulated concern about capacity and a Deprivation of Liberty Safeguards (DoLS) application was made. Due to clinical need, Colin was transferred to the Royal Sussex County Hospital (RSCH) in Brighton and subsequently back to Worthing Hospital. A second hospital safeguarding referral was made by RSCH for the same reason as the first. Colin died on 8 November and a Section 42 enquiry commenced.	

8. Initial appraisal of findings

8.1. The way that different teams worked together in the context of a multi-agency plan for Colin was not as evident as it should have been. This could have been improved through systems such as supervision or escalation.

8.2. There was limited evidence of the time taken to explore Colin's experiences and wishes and to collectively understand the reasons he did not wish for assessments, treatment, adaptations, or periods of hospitalisation to occur in his best interest.

8.3. In the last 3 months of his life, Colin lived in circumstances that professionals consistently identified as inadequate for his needs, and which contributed to his deterioration. This did not prompt wider attention to self-neglect responses and the steps that could and should be taken (including local protocol). Therefore, there was insufficient attention given to self-neglect and the associated risk.

8.4. A formal capacity assessment was conducted and recorded by the GP from the visit on 7th September 2022. Following this, Colin was consistently recorded by health professionals to have capacity (prior to his period of hospitalisation), but it was not always clear how this had been ascertained throughout the two months. Consequently, there was a specific issue with "unwise decision making" when services and support were refused but there was an absence of multi-agency meetings to consider self-neglect, or wider discussion to consider the presenting issues and risks.

8.5. Person centred care planning was not as evident as it could have been. There was limited evidence of the time taken to explore Colin's experiences and wishes and to understand the reasons he did not wish for assessments, treatment, adaptations, or periods of hospitalisation to occur in his best interests. There is evidence that these reasons had started to be explored as the Adult Social Care initial assessment commenced however this was shortly prior to his hospitalisation.

8.6. There was a barrier to communication because Colin had speech difficulties; this was compounded by the fact that both of his carers are neurodiverse and there is little evidence that this was known/considered in terms of the way agencies sought to communicate with them and seek resolution.

8.7. It is acknowledged that there was a persistence of health professionals prior to and during this timeframe, in visiting Colin and seeking to understand the circumstances, but this did not translate in a multi-agency response or resolution.

9. Key themes

- **Multi-agency communication and working**
- **Person-centred care planning and compassionate practice**
- **Legal literacy – application of statutory frameworks**
- **Professional curiosity**
- **Self-neglect – recognition and response**
- **Family support and carers assessments**
- **Professional supervision and escalation**
- **Wider issues – previous experiences with services**

10. Overarching learning and analysis of findings

10.1. The review has identified learning following consideration of the following areas of practice that were identified during review process:

- Safeguarding and legal literacy
- Multi-agency approaches and professional curiosity
- Working with and supporting the family
- Understanding the person

Safeguarding and legal literacy

10.2. It is a helpful starting point to summarise the safeguarding concerns that agencies had about Colin, namely significant self-neglect as a result of his presenting physical health state, his environment, his hygiene and declining important assessments and treatment. These concerns were noted by the GP, the health staff who were visiting Colin and by South East Coast Ambulance Service who shared a vulnerable adult form with West Sussex County Council with a request for assessment. Subsequently when Colin was admitted to hospital and the extent of his pressure ulcers was known, two safeguarding referrals were made to West Sussex County Council and a section 42 enquiry commenced.

10.3. The Care Act 2014 recognises self-neglect as a category of abuse and neglect. It is helpful to consider what we mean by self-neglect and how this relates to Colin's circumstances. Colin had a stroke many years prior to his death which left him with significant mobility and communication problems. He was diabetic and had several other health related conditions. His wife and son who are both neurodiverse and have their own care and support needs were his carers. Colin and his family have had negative experiences of statutory services and were reluctant to accept help from social care, thus declined referrals for assessment under The Care Act.

10.4. Colin's health significantly deteriorated, and he was relatively immobile with inadequate pressure relieving or manual handling equipment, and thus there was a high risk of pressure ulcers. Whilst being treated for diabetic foot ulcers he declined hospital admission, home adaptations and equipment thus meaning that he could not be fully assessed from head to toe. He was also recorded on more than one occasion to have faeces on his body, soiled sheets and clothes and unclean fingernails. Colin had significant and infected pressure ulcers which was not known until he was admitted to hospital. Throughout this period of time there was an assumption of capacity recorded by health professionals.

10.5. The Care Act 2014 clarified the position of self-neglect and safeguarding in its definition; "self-neglect - this covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding". Under the Act, self-neglect now falls under the definition of causes to make safeguarding enquiries. To note, Care and Support Statutory Guidance (2016) clarified that self-neglect may not necessarily prompt an enquiry under section 42 of the Care Act (often referred to as a 'Section 42 enquiry').

10.6. An assessment should be made on a case-by-case basis, and 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. However, there may come a point when they are no longer able to do this without external support. Section 42 of the Care Act states:

> **'Enquiry by local authority**
>
> (1) This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there) – (a) has needs for care and support (whether or not the authority is meeting any of those needs), (b) is experiencing, or is at risk of, abuse or neglect, and (c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.
>
> (2) The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case (whether under this Part or otherwise) and, if so, what and by whom.'

10.7. The most common type of abuse identified in the National Safeguarding Adults Review analysis was self-neglect[4].

10.8. Regarding the above points it is timely to consider the degree of self-neglect in the context of the legal frameworks and safeguarding responses. Many of these aspects and indicators were present in Colin's case and required a degree of unpicking, underpinned by good professional curiosity and joint approaches.

10.9. *"Safeguarding duties will apply where the adult has care and support needs, and they are at risk of self-neglect, and they are unable to protect themselves because of their care and support needs. In most cases, the intervention should seek to minimise the risk while respecting the individual's choices. It is rare that a total transformation will take place and positive change should be seen as a long-term, incremental process."*[5]

10.10. The review notes the constant presence of Doreen who was his main carer, and his son who also significantly contributed to his dad's care. This will be considered in more detail later and the family have provided insight into their experiences and views. It is acknowledged by the family that they did not understand who was leading the coordination and oversight of Colin's care. It should be acknowledged that the health and social care system is not easy to understand and thus the expectations of relatives to know how to navigate through the system was possibly unrealistic and unfair, particularly taking into account the fact that both of his carers are neurodiverse and have care and support needs themselves.

10.11. Ambulance staff raised a vulnerable adult form in September 2022 when Colin refused to attend hospital; this was shared at Carepoint 2 which is where Colin's case was being assessed following the GP referral. This was not a safeguarding referral but included indications of self-neglect and can be seen as an opportunity to fully and more widely explore the background information. We will explore multi-agency working further in due course, but we know that agencies individually did hold insight into the family circumstances, but this did not translate into a coherent multi-agency response.

[4] National analysis of safeguarding adult reviews

[5] Self-neglect: At a glance | SCIE

10.12. Thus, it is to be acknowledged that the full range of safeguarding issues were only fully explored in retrospect and not at the time, which indicates a lack of understanding of the local process for self-neglect, insufficient action relating to professional curiosity and an absence of multi-agency working. There was an opportunity for the GP to have made a safeguarding referral early in the timeframe, however, to maintain relationships with the family, the referral asked for an Occupational Therapy assessment. There was a further opportunity for South East Coast Ambulance Service to raise a safeguarding referral rather than a vulnerable adult form. There was also opportunity for health professionals to have made a safeguarding referral throughout the time frame. Altogether application of local protocols would have prompted all of the agencies collectively applying their knowledge of the circumstances.

10.13. Whilst we know that the pressure ulcers were only detected when Colin went to hospital in October 2022, it is acknowledged that the risk of pressure ulcers was frequently documented. Let us consider the correlation between pressure ulcers and safeguarding. They may occur as a result of neglect and in some instances, this is highly likely to result in significant preventable skin damage. In Colin's case, he did not recover due to the extent and infection to his pressure ulcers.

10.14. Where unintentional neglect may be due to self-neglect, or an unpaid carer struggling to provide care or not knowing the signs of developing pressure ulcers or why the person they care for is at risk, an appropriate response would be to revise the package of care and ensure that the carer has the support and equipment to care safely. In these circumstances it can be highly distressing to talk to carers about abuse and neglect, particularly where they have been dedicated in providing care but have not been given advice and support to prevent pressure ulcers. In Colin's case, we know that he did not want to consent to an assessment for a package of care, or steps that could be taken to provide equipment. This review will consider capacity, communication, comprehension and professional curiosity as we progress.

10.15. It is helpful to define what pressure ulcers are and consider the responses and risk indicators in Colin's case. Skin damage has a number of causes. Pressure ulcers are caused by sustained pressure, including pressure associated with shear, where the person's individual tissue tolerance and susceptibility to pressure has been overcome. External shear forces occur due to movement of the skin and deeper tissue relative to a supporting surface, such as when an individual slides down the bed when in a semi-recumbent sitting position. This results in distortion of the soft tissue layers, including the blood vessels. Shear commonly occurs at the sacrum and heels. Internal shear forces can occur within the soft tissue layers due to both compression and external shear forces[6]. The Department for Health and Social Care (2024) also provide the following information:

> Some causes of skin damage relate to the individual person, including factors such as the person's:
>
> - medical condition
> - immobility
> - lack of sensation
> - poor blood supply
> - poor nutrition and hydration
>
> External factors may contribute to this, including:
>
> - poor care
> - poor communication between carers and nurses
> - ineffective multi-disciplinary team working
> - lack of access to appropriate resources such as equipment and staffing
>
> In line with shared decision making, when advising an individual who has capacity about self-care and prevention of pressure ulcers, it is important to establish that the person:
>
> - has understood the advice
> - can put the advice into practice and chooses to do so
> - has any necessary equipment and knows how to use it
> - understands the implications of not following the advice

[6] DFHSC (2024) Pressure Ulcers: How to safeguard adults.

10.16. Considering the information above, we can agree that Colin had high risk factors due to medical conditions and immobility, external factors which we will explore in further detail such as compromised communication skills, insufficient multi-agency working and lack of access to appropriate equipment. We have discovered that Colin declined multiple aspects of care and support and was recorded to have capacity on several occasions, but we don't know whether he understood the advice given, and the implications of not following it each and every time in the two-month period. We will explore capacity and executive capacity presently but overall; this leads us to identify self-neglect amongst other factors and the next question is whether that was clearly identified and appropriate action taken.

10.17. "Where an individual, for reasons that seem sensible to them, chooses not to agree to follow advice, compromise and alternatives must be discussed and agreed upon if possible. Where an individual chooses not to follow any or some of the advice, an agreement to revisit the conversation must be made. Where it appears that the individual is neglectful in caring for themselves or the environment, staff should seek further advice from someone with the relevant knowledge and skills. It is recognised that not all pressure ulcers can be prevented and the risk factors for each person should be looked at on an individual basis and an appropriate care plan put in place that is regularly and frequently reviewed"[7].

10.18. Since the implementation of the Care Act in 2014, self-neglect has been defined as a form of abuse and neglect which comes under the remit of safeguarding adult practice. Safeguarding Adult Boards have a statutory duty to help and protect adults with care and support needs who are experiencing, or at risk of abuse and neglect. Practitioners within health care also have a statutory duty to work with and support those patients who self-neglect[8].

10.19. In summary so far, we know that:

- The primary reason for concern were indicators of self-neglect relating to Colin's overall deterioration of health, environment, hygiene, skin integrity and because he declined assessments, equipment, support and treatment.

[7] DFHSC (2024) Pressure Ulcers: How to safeguard adults.
[8] Social Care Institute for Excellence [SCIE], 2018

- Colin was recorded by the GP and the Community Nursing Team to have capacity.
- There is one occasion where a vulnerable adult form was shared by South East Coast Ambulance Service but this did not translate into a safeguarding referral thus there is an absence of self-neglect being clearly identified and action taken. Therefore, there was a lack of understanding of the full safeguarding concerns.
- Application of professional curiosity could have been improved.
- The family understanding and comprehension of Colin's presentation was not fully explored and may have yielded a richer insight into his life and experiences.

10.20. The summary of issues has facilitated consideration of how different frameworks could be used. We have found that there was a lack of evidence that the safeguarding concern was clearly defined as self-neglect or that it had been acted upon or communicated effectively between multi-agency teams. A safeguarding referral was not made to WSCC throughout the timeframe of this review, other than at the latter stages of Colin's life, once he had been admitted to hospital. We also know that primarily the assumption of capacity was made but this did not lead to a multi-agency exploration of self-neglect. We can put this into the context of the legal powers available when there are safeguarding concerns outlined in Section 42 of the Care Act:

- needs for care and support (whether or not the authority is meeting any of those needs)
- is experiencing, or is at risk of, abuse or neglect
- as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

10.21. The review carefully considered the discussions of the panel with recognition that certain legal frameworks such as how the Care Act (2014) and the Mental Capacity Act (2005) could be used to help people. There was a general consensus that the Care Act could have been better considered and used at different points. The consensus of all contributing agencies was that Colin was recorded to have capacity and each agency investigation has yielded no evidence that there should have been doubt on this point.

10.22. Let us take each framework in turn and explore how Colin's circumstances apply to each:

- The Care Act (with the inclusion of self-neglect as a form of neglect)
- The Mental Capacity Act (MCA)

10.23. It is acknowledged by the GP practice and by West Sussex County Council in their own agency reviews that identification of self-neglect and associated action should be improved and there are actions plans related to their findings.

10.24. Let us now consider the Mental Capacity Act (2005). It is designed to protect and restore power to vulnerable people who lack capacity. The MCA states:

- assume a person has the capacity to make a decision themselves, unless it's proved otherwise.
- wherever possible, help people to make their own decisions.
- do not treat a person as lacking the capacity to make a decision just because they make an unwise decision.
- if you make a decision for someone who does not have capacity, it must be in their best interests.
- treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms.

10.25. There is often a perception that a person cannot be vulnerable or self-neglect if they have capacity, for example, they can choose their lifestyle and thus make a conscious choice to self-neglect. Under the Care Act 2014 and the Social Services and Well-being (Wales) Act 2014, you do not need to lack mental capacity to be vulnerable or self-neglecting. Even if someone appears to be making 'free' choices that lead to self-neglect, it is still self-neglect and action is required.

10.26. This means that assessing that someone has capacity does not automatically mean there is no longer a case for taking action to safeguard them; a duty of care still exists on professionals to explore why the adult is making an unwise choice and what can be done to support them in caring for themselves. This is the relationship and application of the legal tools and provisions of the Mental Capacity Act and the Care Act.

10.27. The first principle of the MCA is to assume the adult has capacity unless proven otherwise. The correct application of the presumption of capacity in s.1(2) MCA[9] is a difficult question and often misunderstood by those involved in care. It is sometimes used to support non-intervention, lack of engagement or non-concordance with treatment but this can leave people with care and support needs exposed to risk of harm. This was the case in Colin's circumstances.

10.28. It is identified in the West Sussex meta-analysis of Safeguarding Adult Reviews featuring self-neglect (2024) that there can be a challenge in terms of when to question mental capacity, particularly when someone is able to show decisional capacity (they are able to comprehend questions and formulate and express answers with sufficient verbal skill) but do not show the executive capacity to put expressed decisions into action. As a result of that learning, the Sussex Safeguarding Adults Policy and Procedures now make clear reference to the need to distinguish between 'decisional and executive capacity' described as 'the difference between capacity to make a decision (decisional capacity) and capacity to actually carry out the decision (executive capacity)'. Whilst the procedural amendment was made after Colin's death, it is still a relevant point as this could have been considered with respect to Colin's decision making.

10.29. The procedure now states that "*Where decisional capacity is not accompanied by the ability to carry out the decision, overall capacity is impaired and interventions by professionals to reduce risk and safeguard wellbeing may be legitimate'. The meta-analysis points out that this work is complex and the current procedures "do not provide any specific guidance as to how practitioners should undertake the assessments required to distinguish between decisional and executive capacity*".

[9] MCA (2005)

10.30. Colin is recorded on quite a few occasions to have capacity, by the GP, South East Coast Ambulance Service and the Community Nursing Team. Also recorded are lengthy conversations with him about the risks related to pressure damage, manual handling and lack of equipment. The only occasion when Colin was assessed and recorded to lack capacity is when he was taken to hospital on 21st October 2022 and a DoLs application was made. For reference, the DoLS, is an amendment to the Mental Capacity Act 2005 and ensures people who cannot consent to their care arrangements in a care home or hospital are protected if those arrangements deprive them of their liberty. In Colin's case, this arrangement was put into place because he was significantly unwell and required hospitalisation.

10.31. It is not within the gift of this review to conclude on whether Colin did or did not have capacity in the two months prior to his hospitalisation, but it is important to highlight that capacity is decision and time specific. It may have changed over the two months as Colin became more unwell, and an absence of formal assessment after the GP recording on 7th September 2022, meant that fluctuating, decisional and executive capacity were not fully assessed. This is a point for reflection.

10.32. With reference to principle 3 of the MCA, the Code of Practice[10] highlights "the difference between unwise decisions, which a person has the right to make, and decisions based on a lack of understanding of risks or inability to weigh up information about a decision, particularly if someone makes decisions that put them at risk or result in harm to them or someone else".

10.33. We know that the risk associated with Colin's self-neglect was high and to a certain extent un-assessed as it was not possible for professionals to fully assess Colin from head to toe because of the restrictions with manual handling. There may have been points where a "risk" conversation should have taken place within the Community Nursing Team, Occupational Therapy service, Podiatry service or GP practice. This may have been through supervision, or via a full self-neglect professionals meeting to discuss a) capacity b) self-neglect and consider next steps in terms of a safeguarding plan.

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

10.34. We have considered 7 opportunities that may have prompted different action:

- 7 September 2022 - GP visit, referral for Occupational Therapy, podiatry and Community Nursing Team.
- 15 September – West Sussex County Council receipt of GP referral for Occupational Therapy.
- 8 to 27 September 2022 – 8 visits (some joint) by Community Nursing Team, Advanced Nurse Practitioner, Podiatrist and Occupational Therapy.
- 27 September 2022 - South East Coast Ambulance Service attended the house, vulnerable adult form sent to West Sussex County Council requesting assessment.
- 30 September 2022 - West Sussex County Council received vulnerable adult form received which prompted the case to be allocated, however West Sussex County Council were unaware of other agency involvement or safeguarding concern.
- 27 September to 21 October - 6 Community Nursing Team home visits, 4 Community Nursing Team telephone calls and 1 Podiatry visit.
- 7 October to 21 October 2022 - West Sussex County Council hold telephone call with Doreen, followed by 4 unanswered calls, case was closed due to Colin being hospitalised as the hospital team would coordinate discharge arrangements and plans.

10.35. Throughout this two-month time period, we can see that Colin continued to be treated for his diabetic foot ulcers which seemed to be improving, however he was becoming more unwell. There was not a lack of action by, and between these services, there were regular visits and continued dialogue with Colin and family, but it was not effective, and it did not change the circumstances. Although one vulnerable adult form was shared in the timeframe prior to Colin's admission to hospital, there was not a clearly defined understanding across agencies of the required response.

10.36. The reviewer explored this with panel and family members, and cross referenced these discussions with chronologies, notes and reports to consider how the statutory provisions could have been applied differently to prevent the risks related to Colin's self-neglecting presentation. One consideration is the issue and methodology of multi-agency working to aid decision making which will be explored shortly. What we know is:

- Colin had a deep mistrust of professionals, and this needed to be understood more robustly and collectively by all professionals in order to reach a resolution.
- There were specific and complex challenges related to his carers ability to care for Colin, to fully comprehend what services wanted to do and what support could be accessed to make it easier.
- Colin's carers were struggling, and both have neurodiverse conditions that impacted on their level of understanding and retention of information.
- The environment in the home and the degree of self-neglect that was occurring was significant and should have prompted multi-agency discussion about a) capacity b) self-neglect.

10.37. Identified above are indicators relating to identification of self-neglect, a high degree of "unknowns" and the application of the Care Act and the Mental Capacity Act. Running through all these issues was insufficient multi-agency working therefore consideration of how the legal powers were understood and applied is very relevant.

10.38. In summary, due to the complex and interlinked issues of self-neglect, and the challenges of informal carers who are family members who may not fully understand the issues, risks or possible solutions, the provisions of these two Acts could have been considered and applied more effectively and coherently. This will be considered in terms of methods of multi-agency working. These findings are not new to West Sussex and have been highlighted in previous Safeguarding Adults Reviews and most recently in the West Sussex meta-analysis of Self Neglect (2024).

Key finding 1

10.39. It is noted that self-neglect can be a difficult area for intervention as issues of capacity and lifestyle choice are often involved, which includes individual judgments about what is an acceptable way of living and degree of risks to self. Even in cases where it appears the risk to the individual may be significant, there may be no clear legal grounds to intervene. The issues of self-neglect, degree of risk and persistent difficulties working with Colin, could have been more strongly investigated under the provisions of the MCA and the Care Act in the context of capacity and self-neglect.

Multi-agency approaches and professional curiosity

10.40. We have explored the self-neglect concerns that health professionals had and considered how the different frameworks may have been utilised differently in Colin's case. Specifically recognised is the fact that the MCA and the Care Act made provision for Colin's situation. In terms of self-neglect this is translated into the local Self Neglect procedures and in terms of complex safeguarding the Sussex Multi-Agency Risk Management (MARM) Protocol. Colin was receiving services from his GP and associated Advanced Nurse Practitioner, the Community Nursing Team, the Occupational Therapist, the Podiatry team and on one occasion prior to becoming hospitalised, the ambulance service. He was also an open case to West Sussex County Council due to the earlier GP referral and the later vulnerable adult form made by South East Coast Ambulance Service. This prompts exploration of how these services interfaced with each other.

10.41. In terms of safeguarding action and multi-agency working, it is demonstrated that the safeguarding actions and the way that services worked together did not improve or change the situation experienced by Colin, and it is certainly indicated that a more risk aware response and additional professional curiosity may have yielded a richer insight into the reasons for Colin's situation and better coordination of his care.

10.42. We have already discussed application of the MCA and Care Act which could have facilitated a multi-agency exploration of several things, possibly including legal options for intervention, discussion around advance care planning, a plan for emergency care and treatment, do not attempt cardiopulmonary resuscitation, advance decisions to refuse treatment, and lasting power of attorney. It is documented several times that Colin was informed that he might die if he refused treatment and therefore these would have all been proportionate considerations in that case.

10.43. In Colin's case, it can be seen that there were some joint visits by health professionals, however, there is no evidence that all agencies ever came together to discuss Colin and family and to consider the risks and options. That meant that the GP, the Community Nursing Team, Podiatrist and Occupational Therapist never had a joint conversation to share their insights and concerns, to apply self-neglect procedures or MARM, raise a safeguarding referral or to share their collective information with West Sussex County Council who were undertaking an initial assessment. The Sussex Safeguarding Adults Policy and Procedures provide a clear pathway to assist professionals from any organisation to use a multi-agency approach when working with adults who are displaying self-neglecting behaviours. Therefore, the review finds that there was a problem applying this to practice.

10.44. Whilst there were a few joint visits, Colin was not considered in a multi-agency way despite the complexity and difficulties each service had. West Sussex has the correct tools in the box, but they were not applied to Colin. The self-neglect procedure was the correct initial process to follow and may have been followed by an "escalation" to the MARM protocol:

- **Self-neglect procedures** - 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.
- **MARM** - The role of the MARM subgroup is to discuss and consider all available options for increasing the safety of the adult at risk and to advise and agree on co-ordinated actions to reduce or remove risk.

10.45. Although individually, services had concerns and tried to work with the family, it appears to be a narrow lens on the full situation and there is no evidence of a clearly identified lead professional/agency, or recognition of the need for a multi-agency meeting. Therefore, the picture seems to be that single agencies were continuing their own sphere of work and trying hard to find solutions, but this was not escalated to multi-agency work. In summary, the procedures are there but were not applied to practice. This is a repeated finding in West Sussex.

10.46. A multi-agency approach would have facilitated information sharing, and joint risk formulation with a better coalition of services around the table. There is also no evidence that Colin's case was escalated in terms of risk as part of supervision or managerial oversight. This can be seen in in the absence of professionals seeking specialist safeguarding advice and supervision within their own agencies. This has already been acknowledged by West Sussex County Council, Sussex Community NHS Foundation Trust and the GP in their own reviews.

10.47. Multi-agency safeguarding discussion and working, and joint risk formulation was absent in this case until the occasion when Colin was taken to hospital and the extent of his pressure ulcers and sepsis meant that it became a matter of crisis, which Colin did not survive.

10.48. This brings us back to the issue of professional curiosity. The national analysis of Safeguarding Adults Reviews (April 2017 – March 2019) highlights the need for practitioners to 'exercise sufficient professional curiosity' and 'authoritative doubt'.

10.49. Professional curiosity could be described as a combination of looking, listening, asking direct questions, checking out and reflecting on information received. It means not taking a single source of information and accepting it at face value. It involves testing your assumptions and triangulating information from different sources. In Colin's case we can observe services working in silo and demonstrating limited insight into the family functioning. Therefore, the collective coming together of agencies to explore what was happening for Colin and to establish a shared understanding of risk is not as evident as it could be. There was no one time in the timeframe of the review when all agencies and services came together despite there being opportunity to do so.

10.50. Therefore, a consistent, timely and coherent way of all agencies and services to come together and consider all their information may have assisted with the following aspects:

- A coming together of agencies and professionals to consider risk.
- The identification of a clear lead agency or professional.
- Timely information sharing, shared decision making and responsibility for managing risk.
- Improved involvement and engagement.
- A clear understanding of roles, responsibilities and actions.

- Better opportunity to align the perspective of Colin, family and professionals.

10.51. Multi-agency best practice to establish risk means working collaboratively with other agencies around the adult to gain a full picture, assess risk and plan any strategy to address it. Defensible decisions should be clearly recorded, and are especially important where situations are complex, high risk or controversial. Decisions should make reference to relevant legislation and be regularly reviewed.[11] The way services worked together in this case was fragmented, did not take full account of the risk indicators and therefore did not work effectively.

Key finding 2

10.52. Following on from key finding 1 (legal literacy), agencies did not clearly respond to self-neglect and follow the local procedures which provide a framework for managing self-neglect cases and cases where risk is escalating. Consequently, there was an absence of multi-agency communication and action, risk formulation and escalation.

Key finding 3

10.53. Professional curiosity is a core responsibility of all practitioners. Being more curious as professionals and 'digging deeper' into areas where there is little, or no information will help to inform assessments and empower professionals to influence key moments of decision making to reduce risks. This review has found that whilst some professionals may have sought to understand the family and look for solutions, they did not apply that curiosity collectively.

Working with and supporting the family

10.54. During the course of the review, it was apparent that Doreen was Colin's main source of support and care; she was aided by their son. Doreen also took responsibility to care for her elderly mother who was by this time living with them. All four adults in the house had their own care and support needs. There is limited evidence in the agency information that this was taken into account or that arrangements were facilitated to assess this. However, during the telephone call with Doreen, West Sussex County Council did start to explore the situation at home and planned to follow this up during their initial assessment.

[11] https://hgs.uhb.nhs.uk/wp-content/uploads/Risk-Enablement.pdf

10.55. It is helpful to consider what a carers assessment is. The Care Act 2014 (section 9 and 10)[12] uses the term 'assessment' to refer to either a Care Act assessment of an individual's needs for care and support (Colin) and/or a carer's needs for support and determination of eligibility (in this case Doreen and their son). In consideration of Colin, Doreen and their son, notwithstanding the need to overcome the issue of consent and willingness to work with services, it may have been good practice to carry out a Care Act assessment and a carers assessment simultaneously. As noted above, early conversations did start to take place during the West Sussex County Council initial assessment. This theme will be captured as a key finding.

10.56. In terms of the 'carers assessment', when a carer is found to have support needs following assessment under section 10 of the Care Act 2014, the local authority must determine whether those needs are at a level sufficient to meet the "eligibility criteria" under section 13 of the Act. It is noted that Doreen had asked for help, and this is recorded in several places including the West Sussex County Council telephone call that took place on 7 October with Doreen. Doreen admittedly did not and still does not know what "support" could have looked like and expresses that as a family, they are very fearful of social care involvement due to their past experiences when their son was growing up.

10.57. From discussion with Doreen there is a sense that she was very preoccupied with "holding everything together", respecting Colin's wishes and balancing that with doing the right things, and she didn't always comprehend what that was. Doreen says that she was confused a lot of the time about the information she was being given, and she possibly underestimated the impact that the situation was having on her, or didn't fully recognise that she needed support in her own right. It is difficult to conclude without hindsight bias whether she would have been assessed to have eligible needs, however, on balance the review concludes that she was more likely than not to have been.

[12] The Care Act (2014) sections 9 & 10

10.58. Mentioned earlier is the specific issue of neurodiversity for Doreen and their son. Doreen has spent time explaining how this manifests itself and how it impacted on her during this incredibly stressful time. Doreen states that she cannot always understand complex health related information and did not, at the time, understand the risk of pressure ulcers and the importance of the preventative measures related to it. Her own recollection is that she was trying to come up with solutions in the house and although she acknowledges that there may be very good professional reasons why certain things (such as a zimmer frame) might not be ideal, she didn't at the time because she was living in a "nightmare". She is also very clear that she does not retain information either and her perception was that professionals visiting the home were sometimes impatient and annoyed with her and that they "blamed and judged" her for the situation in the house.

10.59. The review has found that a carers assessment had not been formally requested or facilitated but we can see that support for Doreen is mentioned several times. We can also see that she told West Sussex County Council on 7 October via telephone call that she needed support and as a result of that, the intention was to explore this further, however Colin was subsequently admitted to hospital where he sadly died.

10.60. There was opportunity to approach the situation from a whole family perspective due to the level of unassessed need in the home and the degree of self-neglect, which affected not only Colin but the family as a whole. A Care Act assessment and carers assessment may have facilitated a deeper understanding from all angles with a more coordinated approach and joint risk formulation.

10.61. Doreen has described an extremely difficult 16 years since Colin had the stroke, her own struggles with life and although outside the terms of reference for this review, a challenging experience of statutory intervention for their son. This was related to his own diagnoses and safeguarding issues related to non-school attendance. Doreen feels that her family was judged, and they were treated punitively and therefore Colin, and Doreen to a certain extent were extremely reluctant to cooperate with services, particularly social care. She did, however, recognise that she was struggling and desperately worried about Colin because she knew something was very wrong. It undoubtably does increase awareness of some of the complexities within a family which may cause stress or impact on the ability to function, or times where a person may have struggled to cope.

10.62. Different conversations with Doreen may have provided insight into the wider family background, the inter-caring relationships and the reasons for the decisions that Colin made. These issues were certainly acknowledged at different times by professionals but did not necessarily change the approaches taken. Strengths based and relationship focused approaches can certainly help support better engagement with people who self-neglect and their families.

10.63. It can sometimes be difficult for families to understand the importance and significance of care, and the consequences of not engaging with required treatment. The reviewer can see on one hand that health professionals who visited the home regularly tried to explore possible solutions. On the other hand, Doreen's perception was that her own suggestions and solutions were not listened to. This indicated a disconnect that needed resolution.

10.64. Both of Colin's carers are neurodiverse, this means that they both process information in different ways to someone who is not neurodiverse. The use of language when articulating complex medical terminology is extremely important. Word choices and negative and blaming terminology was upsetting and frustrating for Doreen and left her feeling confused and unclear about what had been discussed. Negative or blaming language and behaviours are often cited within health care as being a factor when people decline to work with services. "*Language is important; it is a vehicle for sharing knowledge and understanding, and a means by which we can express and communicate our values to others. In a medical context, language does more than transfer information between patients and healthcare providers—it has the potential to shape therapeutic relationships*"[13]

[13] BMJ (2022) Presenting complaint: use of language that disempowers patients

10.65. To recap, considering the responsibility that Doreen had in caring for Colin, it would have been pertinent to consider a carers assessment at an earlier stage. During the initial telephone call with West Sussex County Council, we know that Doreen had voiced anxiety about the home situation and recognised that she needed more help but may not have known how to articulate that, or what support she needed. It was noted during this call that Doreen had in fact had a carers assessment previously and had Colin not been admitted to hospital, West Sussex County Council planned to continue with this assessment in the community. There was also earlier opportunity within the timeframe for services within health to have come together and captured the very important issue of carers support, and this could have been facilitated in a compassionate and structured way.

10.66. Making safeguarding personal and professional curiosity should be central to practice supporting safeguarding both carers and the person they care for. Timely and careful assessments should be provided for both the carer and the person they are caring for, including understanding the competing needs of each and having separate focus on each[14].

10.67. The full extent to which agencies understood the challenges that Doreen and her son were experiencing is not clear and different conversations could have been had with her to explore the overall situation. There are examples of interactions that have been cited by the family that have left Doreen feeling like a failure in her husband's care. This may not have been the intention, but it was how certainly how Doreen processed the interactions. Indeed, the extent to which professionals understood the full set of issues could have been strengthened, for example more inquisitive conversations about past experiences and relationships. The review has already found that there could and should have been better application of multi-agency coordination and joint risk formulation to understand and address these issues.

Key finding 4

10.68. Professionals need to have confident and courageous conversations in relation to any safeguarding concerns between the cared for person and the carer, and between generations within a family unit. This should take into account any barriers to understanding, such as neurodiversity, and the approach to carers assessment should reflect this.

[14] https://www.local.gov.uk/parliament/briefings-and-responses/carers-and-safeguarding-briefing-people-who-work-carers

Understanding the person

10.69. It is very difficult to capture a sense of Colin's voice from the agencies who had contact with him, for all the reasons we have explored; he had communication difficulties, his fear of services meant that he was constantly recorded as being uncooperative, non-engaging and refusing of services. We know that professional curiosity could have been strengthened, safeguarding concerns were not articulated or responded to in the main, and the use of statutory frameworks could have been strengthened.

10.70. In order to understand his daily experiences and get a sense of his perspective, the review has drawn on exploration of panel and family views and records, chronology and some of the significant background factors that may have strongly contributed to how Colin responded to services.

10.71. Self-neglect can arise due to a range of factors rather than simply being someone's own choice. These factors include mental and physical health, as well as social and environmental factors. It could be a longstanding pattern, a recent change, be linked to loss, past trauma, as well as low self-esteem. Evidence of good practice recommends taking time to build rapport and a relationship of trust through persistence, patience, and continuity of involvement. Equally as important in Colin's case, seeking to 'find' the whole person and to understand the meaning of their self-neglect in the context of their life history.

10.72. It is recommended that direct practice with the adult is characterised by a person-centred approach that comprises proactive rather than reactive engagement, and a detailed exploration of the person's wishes, feelings, views, experiences, needs and desired outcomes; work to build motivation with a focus on a person's fluctuating and conflicting hopes, fears and beliefs, and the barriers to change[15].

[15] Preston-Shoot, M. (2019) 'Self-neglect and safeguarding adult reviews: towards a model of understanding facilitators and barriers to best practice.' Journal of Adult Protection, 21 (4), 219-234

10.73. To support this, a combination of concerned and authoritative curiosity appears helpful, characterised by gentle persistence, skilled questioning, conveyed empathy and relationship-building skills; early and sustained intervention includes supporting people to engage with services, assertive outreach and maximising the opportunities that encounter brings[16].

10.74. In Colin's case, there was a constant issue of "non-engagement and refusal" which ultimately created a serious self-neglecting situation over two months. When faced with service refusal, there should be a full exploration of this "choice" or "decision", with detailed discussion of what might lie behind a person's refusal to engage; failing to explore "choices" prevents deeper analysis; contact should be maintained rather than the case closed so that trust can be built up. It is also helpful to build up a picture of the person's history, and to address this "backstory"[17], which may include recognition of and work to address issues of loss and trauma in a person's life experience that can underlie refusals to engage or manifest themselves in repetitive patterns. There are distinct parallels between Colin's case and this observation.

10.75. The reviewer considered Doreen's description of how she felt "judged" and "blamed", which reinforced previous experiences of services who she felt did not try to understand her family. She also explained that this fear of intervention ran deep within Colin, and specifically he was frightened to die in hospital, and he was fearful of leaving his family. Therefore, the occasions when he refused to go to hospital or cooperate with solutions such as respite care may well have been overcome with a compassionate and understanding multi-agency approach. It is notable that within the agency's own investigations of care, whilst there is recognition of learning themes around awareness of self-neglect and carers assessment, there are no specific acknowledgements or actions about relationship based or trauma informed approaches. This is very important in this case.

[16] Alcohol Change UK (2019) Learning from Tragedies: An Analysis of Alcohol-Related Safeguarding Adult Reviews Published in 2017. London: Alcohol Change UK. Public Health England (2018) Evidence Review: Adults with Complex Needs (with a particular focus on street begging and street sleeping). London: PHE. Ward, M. and Holmes, M. (2014) Working with Change Resistant Drinkers. The Project Manual. London: Alcohol Concern.

[17] Alcohol Change UK (2019) Learning from Tragedies: An Analysis of Alcohol-Related Safeguarding Adult Reviews Published in 2017. London: Alcohol Change UK. NICE (2018) People's Experience in Adult Social Care Services: Improving the Experience of Care and Support for People Using Adult Social Care Services. London: National Institute for Health and Clinical Excellence.

10.76. In terms of safeguarding, perhaps the focus on Making Safeguarding Personal was distracted by the complexities of this case. It is likely that services were focused on trying to work out a solution and Colin's voice got lost in that. There would have been opportunity to explore this throughout his West Sussex County Council assessment; unfortunately he was admitted to hospital before this progressed any further. Doreen recalls a very different person prior to this episode of care, a strong and supportive man who was now reduced to the situation he was in. We have a limited understanding of how Colin must have felt during these two months but given the extent of his pressure ulcers, we can only imagine the fear and pain he must have experienced and possibly was not able or did not want to admit to professionals. There was a high number of visits from professionals and an opportunity for all of the services to have worked collectively to build a trusting and therapeutic relationship during this time.

10.77. Trauma is defined as "an event, series of events, or set of circumstances that is experienced by an individual as harmful or life threatening. While unique to the individual, generally the experience of trauma can cause lasting adverse effects, limiting the ability to function and achieve mental, physical, social, emotional, or spiritual well-being"[18]. The process of this review has provided the family with an opportunity to describe some of their significant challenges and barriers and to explain that past experiences and interventions with services made them deeply mistrustful of professionals, resulting in a very insular situation that each one of them found to be lonely and frightening.

10.78. A therapeutic relationship is a close and consistent association between a healthcare professional and a person in therapy. The purpose of this relationship is to assist the individual in therapy to change their life for the better. It is essential as it is often the first setting in which the person receiving treatment shares intimate thoughts, beliefs and emotions regarding the issue(s) in question. Trust, respect, and congruence are major components of a good therapeutic relationship. Therapists are encouraged to show empathy and genuineness. We know that in this case there were no "therapists", but the same principles can be applied to any relationship between professionals and person/family.

[18] Working definition of trauma-informed practice - GOV.UK (www.gov.uk)

10.79. It is helpful to try to view the scenario through Colin's own eyes, how uncomfortable he must have been in terms of the environment and the hygiene issues and how unwell he must have felt. Yet, the approaches taken and some of the language used in agency chronologies and described by the family felt negative and often blaming. This prompts one to think about how different conversations, better professional curiosity and a strengthened multi-agency response may have made a difference.

Key finding 5

10.80. The safeguarding process has been developed to ensure that the principles of making safeguarding personal are central. It is important that all agencies are clear on the reason for and the status of any safeguarding action, the application of any multi-agency models and a shared understanding of risk aware responses.

Local developments and improvements

10.81. Articulated in section 7 are a range of parallel processes which include complaint responses and single agency investigations into Colin's care. Resulting from those, there are specific service improvements already in progress related to Colin's case.

10.82. Additionally, there are Board actions and improvements in progress following the West Sussex meta-analysis of self-neglect, which draw parallels to the findings and recommendations of this review.

10.83. Some of the improvements are as follows:

- GP Practice - self neglect awareness training for practice staff
- GP Practice - strengthening and implementation of a consistent approach to standardise the process of recording capacity assessments
- Safeguarding Adults Board - MARM protocol (initially released in December 2020 and reviewed in August 2023 and April 2024)
- Safeguarding Adults Board - Development of a complex needs toolkit (published November 2024)
- Safeguarding Adults Board - A self-neglect action plan (resulting from the self-neglect meta-analysis published in June 2024 - in progress)

- Sussex Community NHS Foundation Trust - additional awareness raising on self-neglect and Safeguarding Adults Review learning via intranet page (commencing early 2025).
- Sussex Community NHS Foundation Trust - Awareness raising about carers need
- Sussex Adults Safeguarding Policies & Procedures – updates to self-neglect chapter (published and repromoted January 2025)
- Self-neglect practice guidance (published October 2024)
- Mental Capacity Act learning resources (published July 2023)

11. Key findings and recommendations

11.1. The findings and recommendations made in this review should be applied as learning for the system where deeper and continual assurance is required and an action plan developed against them.

11.2. Arising from the analysis in this review the following findings and recommendations are made to the West Sussex Safeguarding Adult Board:

Key finding	Key points	Recommendations
Legal literacy (key finding 1)	Self-neglect can be a difficult area for intervention as issues of capacity and lifestyle choice are often involved, which includes individual judgments about what is an acceptable way of living and degree of risks to self. Even in cases where it appears the risk to the individual may be significant, there may be no clear legal grounds to intervene. The issues of self-neglect, degree of risk and persistent difficulties working with Colin, could have been more strongly investigated under the provisions of the MCA and the Care Act in the context of capacity and self-neglect.	The Board is asked to review its procedures and resources related to the application and coordination of statutory frameworks, especially in recognition of self-neglect, and to seek assurance that procedures are embedded into practice. Practice development sessions and shared practice aids may be a suggested method. With reference to capacity**,** specific practice guidance should be developed on how practitioners can continually review capacity and undertake mental capacity assessments to distinguish between decisional and executive capacity.

Multi-agency coordination (key finding 2)	Following on from key finding 1 (legal literacy), agencies did not clearly identify self-neglect and follow the local procedures which provide a framework for managing self-neglect cases and cases where risk is escalating. The review found that there were missed opportunities for agencies to come together to explore their full understanding of what was happening and to establish a shared understanding of risk. Multi-agency best practice to establish risk means working collaboratively with other agencies around the adult to gain a full picture, assess risk and plan any strategy to address it.	It is noted that the meta-analysis of self-neglect recommends that a specific self-neglect and hoarding procedure is developed - this review supports that recommendation. Overall, the Board are asked to consider its approaches to multi-agency working to include shared practice guidance for the workforce and to consider: • Assurance of its effectiveness • Escalation processes both single agency and multi-agency • Managerial and professional supervision • Coordination and decision making • Alignment with risk management processes and protocols (MARM) • Alignment with local self-neglect processes
Professional curiosity and Making Safeguarding Personal (key finding 3 and 5)	Professional curiosity is a core responsibility of all practitioners. Being more curious as professionals and 'digging deeper' into areas where there is little, or no information will help to inform assessments and empower professionals to influence key moments of decision making to reduce risks. Escalating concerns that could cause drift, delay and a shift in focus from the adults' best interests should be embraced and seen as effective care and support. This review has found that although professionals did seek to understand Colin and his family, the collective response led to a narrow lens on the family and insufficient action.	The Board is asked to seek reassurance that Making Safeguarding Personal is accurately understood, and that understanding is embedded in practice across partner agencies. Additionally, as part of Making Safeguarding Personal and multi-agency coordination the SAB should continue to promote professional curiosity in practice and: • Consider its effectiveness and seek assurance that professionals are routinely applying professional curiosity in their practice and that this is proactively informing decision making and escalation of conversations into a multi-agency setting. • Ensure that professionals are trained on responding to self-neglect. • Strengthen single and multi-agency supervision models and reflective practice opportunities. • Promote exploration of life experiences that are contributory to family dynamics and functioning.

Family involvement (key finding 4)	This is somewhat related to key finding 3 (professional curiosity). Professionals need to have confident and courageous conversations in relation to any safeguarding concerns between the cared for person and the carer, and between generations within a family unit. This should take into account any barriers to understanding such as neurodiversity and the approach to carers assessment should reflect this. Social and health care professionals should proactively explore methods of working with families in situations such as Colin's. This may facilitate methodology to communicate with family members, understand their perspective and act in the best interest of the person. Reflecting on Colin's case, this review suggests that trauma-informed approaches need to be further developed.	The Board should strengthen communication and seek assurance that agencies are aware of the process for carers assessments; how to identify need and how to refer. This may require a specific communication campaign across member agencies. It is noted that one of the systems change priorities for the Sussex Changing Futures programme is to build a Trauma Informed workforce across Sussex and therefore there is no specific recommendation to this.

12. Conclusion

12.1. This Safeguarding Adults Review overview report is the West Sussex Safeguarding Adult Board response to the death of Colin, to share learning that will improve the way agencies work individually and together.

12.2. Colin was a 77-year-old man who died in hospital as a result of sepsis associated with multiple pressure ulcers. He spent the last two months of his life in a difficult environment that was not set up to respond to his needs and he declined assessments, interventions, equipment and options that may have changed that. This review shines a light on the different ways that the system as a whole could have responded to self-neglect and worked with him and his family in a different way.

12.3. It is likely that Colin would have experienced an improved quality of life and a better opportunity for pressure ulcers to be detected and treated earlier, if his overall care and support had been responded to in a more connected and multi-agency way using the range of legal powers available. The areas that could be strengthened in summary are:

- Considering the voice and daily lived experience of the person.
- Different family conversations to ensure common understanding by family and professionals leading to more coordinated support.
- A strong multi-disciplinary approach with the person at the centre.
- Better application of professional curiosity.
- Strengthened consideration of the carers needs.

12.4. And from all of the above:

- A strengthened application of legal frameworks and actions arising from that.

12.5. With reference to person centred care planning, good safeguarding practice must incorporate Making Safeguarding Personal as well as professional curiosity, to ensure that there is confidence to have challenging conversations with individuals and their family whilst focusing on wider wellbeing. Robust safeguarding practice also requires applied knowledge of the interface and alignment between legislative frameworks covering mental capacity and safeguarding.

12.6. To learn the lessons from this review and many other similar Safeguarding Adults Reviews, all agencies must have a commitment to improving practice through regular communication, case discussion and reflection, shared risk assessment and risk management and shared decision making.