Safeguarding Adults Review

‘Pauline and George’

Overview Report

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Date: April 2022

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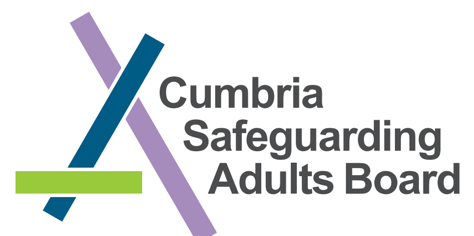

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1. Introduction

1.1. This Safeguarding Adult Review (SAR) concerns ‘Pauline’ and ‘George.’ Pauline was a white woman of British heritage who was in her late eighties when she died.

1.2. Pauline had been living with her husband George in their own home. George was also of white British heritage and was in his late sixties. Pauline had care and support needs due to mobility difficulties following a stroke in 2015. Though she could manage some tasks, she was very reliant on George as carer for many aspects of her day-to-day living. George had his own health needs due to diabetes and cancer of the prostate. The couple attended their GP Practice and outpatient clinics for their various health needs.

1.3. Pauline had experienced multiple falls over the years, and these were increasing in frequency. When on occasions, the couple called the ambulance to assist, although Pauline did not require a hospital admission, paramedics repeatedly raised concerns about the condition of the environment and levels of clutter. On some of those occasions, Pauline and George consented to referrals to Adult Social Care and North Cumbria Integrated Care (NCIC) as providers of community health services. Those agencies followed up the referrals by phone. Pauline and George consistently declined any assessment or support within their home environment.

1.4. When George missed an outpatient appointment, a GP made a home visit. Very sadly, Pauline and George were found to have died. Their deaths had occurred within eighteen days of being discovered. It is believed that George died before Pauline.

1.5. This SAR explores responses by agencies to Pauline and George to identify any learning for individual and multi-agency safeguarding practice.

2. Summary of the Learning Points from the Review

Learning Point 1: Building Relationships and Working with Resistance to Care

The review reinforced the importance of building relationships when working with self-neglect and resistance to care.

Agencies must ensure that the views and wishes of the cared for person, and the carer, are heard independently, recognising the potential for undue influence.

Building relationships needs to go hand-in-hand with using skills of professional curiosity and working respectfully with disguised engagement.

Practitioners need additional time to establish those relationships. Practitioners need space for reflective practice and supervision to explore ways to engage with people who are at risk but who are resistant to care. The Covid pandemic impacted on the ability of practitioners to do this.

Learning Point 2: Working with Risk

Making Safeguarding Personal means respecting an adult’s rights to self determine their affairs and keeping them at the centre of decisions that affect them. Making Safeguarding Personal also involves a duty of care. Non-engagement does not negate risk. Practitioners need to take additional steps, proportionate to the risk (and relevant legal framework), to reduce the potential harm to the adult’s wellbeing.

There was some good practice demonstrated by NWAS paramedics in working with risk. However, overall there was an episodic approach to concerns raised by NWAS that did not address key factors when working with risk.

Where an adult declines care and treatment, their views and wishes should form part of wider consideration to understand:

- The wider context of the adult’s circumstances, including historic information relevant to risks
- The implications of their decision including risk of harm to themselves or others
- Any impairment to decision making i.e. mental capacity to make the relevant decision; undue influence, impaired executive functioning
- Options for responses: mitigating actions/strengths to reduce risk, working within the relevant legal framework

Learning Point 3: Working Across Agencies and Communities

This review, like many other SARs,[1] has highlighted the importance of multi-agency working in safeguarding adults, including when working with self-neglect.

Multi-agency working is dependent upon effective systems to share information. There were significant gaps in sharing information between all agencies involved. The GP Practice was unaware of the muliple attendances by NWAS, the paramedics concerns about self-neglect, or the recurrent pattern of George and Pauline declining services.

There are opportunities to improve this connectivity across the system; capitalising on new ways of working developed during the pandemic, and using the new collaborative structures of the Integrated Care System.

There were missed opportunities to refer into multi-agency meetings. George and Pauline's self-neglectful circumstances were not recognised either through multi-agency complex case pathway, (using the Integrated Care Community meetings) or through using the CSAB safeguarding adult procedures and multi-agency self-neglect guidance.[2]

Multi-agency working develops a fuller picture of the individuals' circumstances and a shared view of risk. It uses the expertise of all partners to develop solutions, working creatively to find ways to engage with the adult(s) and negotiate change.

Working in partnership needs to be a default position for all practitioners.

Learning Point 4: Strategic Responses to Self Neglect

The review highlighted the importance of supporting practitioners through systems and processes, training and supervision.

The learning from this review mirrored some of the findings from a CSAB SAR in 2016 relating to self-neglect.

CSAB partners, need to demonstrate leadership in ensuring that practitioners have access to those key resources and that learning from SARs is disseminated and leading to improvements within their agencies.

The CSAB guidance for self-neglect would benefit from tools to aide assessment, including use of clutter rating scales. Learning from this review can also help in developing resources to support practitioners to work with disguised engagement.

There is significant interface between working with self-neglect/resistance to care, and multi-agency work with complex cases. Cumbria's Integrated Care Community multi-agency meetings, may provide an effective forum for earlier interventions in working with self-neglect. The terms of reference for that forum should reflect this preventative, safeguarding orientated practice and assure safeguarding is considered within case discussions.

Learning from this SAR should be used by the CSAB in their developmental and assurance work relating to self-neglect.

[1] Local Government Association: Analysis of Safeguarding Adult Review April 2017- March 2019; Executive Summary October 2020 https://www.local.gov.uk/analysis-safeguarding-adult-reviews-april-2017-march-2019 [Accessed January 2022]
[2] Cumbria Safeguarding Adult Board Safeguarding Adults Self Neglect Guidance October 2017

3. Context of Safeguarding Adults Reviews

3.1 The Care Act 2014 requires Safeguarding Adults Boards (SABs) to arrange a Safeguarding Adults Review (SAR) if an adult (for whom safeguarding duties apply) dies or experiences serious harm as a result of abuse or neglect and there is cause for concern about how agencies worked together.

3.2 The purpose of SARs is '[to] promote as to effective learning and improvement action to prevent future deaths or serious harm occurring again'.[3]

3.3 The SAR criteria were judged to be met because Pauline had care and support needs related to mobility difficulties, with George as her carer. There was concern about self-neglect in the circumstances surrounding the couple's deaths. CSAB identified potential learning in how agencies had worked together to support Pauline and George's needs.

3.4 Cumbria Safeguarding Adults Board (CSAB) commissioned an independent author, to carry out this review. Sylvia Manson is an experienced chair and author of reviews and is independent of CSAB and its partner agencies.

3.5 The Department of Health's six principles for adult safeguarding should be applied across all safeguarding activity[4]. The principles apply to the review as follows:

Empowerment:	Understanding Pauline and George's experience and how agencies maximised decision making, involvement and respected their views in line with Making Safeguarding Personnel.
Prevention:	Examining earlier opportunities to engage and reduce risk of future harm. The learning will be used to consider prevention of future harm to others.
Protection:	Considering how well risks were understood and the effectiveness of risk reduction measures.
Proportionality:	Weighing whether responses were reasonable and proportionate to the risks of harm and within legal parameters – least restrictive of rights and freedoms.
Partnership:	Reflecting on the quality of multi-agency interactions toward coordinated care planning and safeguarding responses. Using learning to improve partnership working.
Accountability:	Understanding accountable practice in line with statute and procedures. Promoting an open and transparent learning process.

[3] HM Government Care and support statutory guidance Updated 21 April 2021 https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#safeguarding-1 {Accessed May 2021]
[4] Ibid

4. Terms of Reference and Methodology

4.1. Terms of Reference

4.1.1. The specifics areas of enquiry are as follows:

Terms of Reference: Areas of Enquiry
1. Referrals for assessment I. To what extent were agency responses timely, appropriate, and effective in providing earlier intervention to meet Pauline's needs and protecting Pauline when referrals were made? II. Did the frequency of referrals prompt any escalation or further action either within individual or to partner agencies? III. Was the rationale appropriate for the decision making in response to referrals and request for assessment? IV. Were there any triggers which should have prompted further action or exploration? V. How well did practitioners make objective and reasoned decisions, free from bias and assumptions?
2. Family Carer I. What consideration was given by agencies to George's own health needs and his ability to care for Pauline? II. Did agencies consider making referrals for a carer's assessment for George? Did practitioners consider the language used and the impact on the person either accepting or declining support/ assessment. III. How can agencies better intervene when professionals do not believe the informal carer has the ability to meet the persons' needs even if they feel they do? IV. Did agencies consider any possible undue influence over Pauline and her decision making? V. How did agencies ensure Pauline's voice was heard when referrals were made, in line with the Mental Capacity Act? VI. Was there any contingency planning for the future with George given his own care needs? VII. Were practitioners professionally curious to gain confidence and permission to challenge?
3. Risk assessment I. Were the potential risks identified and could this have been improved? II. Was the risk of the situation deteriorating further considered? (statutory prevention duties, Chapter 2 Care Act). III. Was there appropriate risk assessment in relation to equipment provision for Pauline and was this reviewed? IV. Was any risk assessment undertaken as a result of the cumulative nature of the referrals made in respect of Pauline's falls? V. Was there any consideration of Pauline and George's capacity to understand the risks that the property and neglect presented to Pauline's physical health?

Terms of Reference: Areas of Enquiry
4. Self-Neglect & Hoarding I. Was there any formal assessment of hoarding or use of clutter rating scales/tools used taking account of the confined living space and the impact on Pauline's mobility/falls? II. Did Pauline and George understand the risk the hoarding posed? III. What did practitioners do to support Pauline and George to understand the risks and the impact of self-neglect and hoarding and explore what support could be provided and/or signposting? IV. What consideration was given to CSAB self-neglect procedures and guidance and the legal options which might be available to protect the couple from neglect?
5. Lack of Engagement & Professional Curiosity I. How did practitioners attempt to engage with George & Pauline, particularly when declining support? II. Did practitioners engage with George & Pauline about their individual needs and explore co-dependencies? III. What were the barriers and challenges for the practitioners at the time? Does the system allow practitioners to develop relationships and trust (work pressures, pathways)? IV. To what extent did the practitioner's approach, language or the terminology used, influence the outcome and them declining support? V. To what extent did practitioners try to understand their motivation when declining support?
6. Communication & Information Sharing I. How effective was the multi-agency working and information sharing around the identification and management of risk, and what challenges did agencies face in achieving this? II. Were these communication methods and strategies used to engage with Pauline and George effective? III. Was consideration given to convening a multi-agency meeting to address the increasing risks in this situation?
7. Impact of COVID-19 I. To what extent did the lockdown impact on the provision of single and multi-agency support and safeguarding responses for Pauline?
II. What organisational or partnership systems factors aided or acted as a barrier to effective practice?
III. What good practice was identified?
IV. What have been the key points of learning for the agency and what relevant changes have been put in place subsequent to the review scope period

4.1.2. The scope period for this review is from February 2019, (the date the first concern was raised by Northwest Ambulance Service) to February 2021, the date of Pauline and George's deaths. However, agencies were asked to include any significant information before this time frame where relevant to the terms of reference.

4.2. Methodology

4.2.1 This Safeguarding Adults Review combined agency reports with a learning event for practitioners who had been directly involved with Pauline and George. This aimed to explore underlying factors including individual interactions and wider system factors that support or create barriers to good practice.

4.2.2. Understanding the experiences of those receiving support from agencies is central to learning. The CSAB is grateful to George's brother for his involvement and the time he generously gave. This provided greater insights into George and Pauline's lives. It is believed that Pauline did not have any other family.

4.2.3. Pseudonyms have been used to protect Pauline and George's privacy and dignity. George's brother chose the pseudonyms that we have adopted for him in this review. Dates and places have been deliberately generalised.

4.2.4. The role of the contributing agencies is outlined in the table below:

Participating Agencies and Context of Involvement	
Cumbria County Council	The Adult Social Care Single Point of Access (SPA) received five referrals from the ambulance services in the fourteen months before George and Pauline's deaths.
North Cumbria Integrated Care NHS Foundation Trust (NCIC)	NCIC provided Community Health services to Pauline and George. The NCIC received seven referrals from NWAS during the scope period.
North Cumbria Clinical Commissioning Group and The GP Practice	Provided information relating to involvement of Pauline and George's GP Practice and information about the wider strategic context for Health care systems.
Northwest Ambulance Service (NWAS) NHS Trust	NWAS responded to twelve emergency call outs to Pauline. NWAS made referrals to Adult Social Care SPA and the NCIC.

4.3 Review Timeline

Safeguarding Adults Reviews should be completed 'within 6 months of initiating it, unless there are good reasons for a longer period being required[5]'. This review was initiated during the Corona Virus Pandemic. The CSAB was mindful of the additional pressure agencies were under. Greater flexibility was required to enable agencies to provide good quality agency reports without compromising operational services. The SAR took nine months from point of the Chair ratifying the decision that criteria for a mandatory SAR were met, through until its conclusion.

4.4 Structure of Report

The report is structured as follows:

- Section 5 provides background and key events relating to agencies' involvement.
- Section 6 gives the context of self-neglect, followed by analysis and learning relating to George and Pauline.
- Section 7 provides a conclusion.
- Section 8 makes recommendations for the CSAB and its partner agencies.

[5] Department of Health (2017). Care and support statutory guidance.
[online] Available at: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

5. Background and Key Events Relevant to This Review

5.1. George and Pauline had been married for over 30 years and had lived in their own single storey home since that time. George had held a specialist role working in the police for many years. He had retired two or three years prior to his death. Pauline had worked in a clerical role within the same service but retired many years earlier.

5.2. The couple had friends in the local area and attended the local Church. George also had a brother that he maintained regular phone contact with. George and Pauline would visit George's brother two or three times a year.

5.3. George's brother described George and Pauline as having a very close but complex relationship. He believed Pauline took a very directive role in the relationship, with George acquiescing to her wishes.

5.4. Pauline had experienced falls for many years and had had investigations by neurology. Sadly, in 2015, she had a stroke. Agency records reference Pauline having care needs from that time. The frequency of her falls increased in the last two years of her life. George was committed to caring for Pauline. He had had type one diabetes for many years and was prescribed some medication to help with mild anxiety. In the last year of his life, George was diagnosed with cancer of the prostate. However, both his diabetes and cancer of the prostate were well controlled, and his death was not expected.

Summary of Events from 2019

5.5. In **February 2019** the NWAS was called to attend Pauline. Pauline had fallen late the previous night and was unable to mobilise. Pauline was admitted to hospital. NWAS made a referral to the Social Care, Single Point of Access (SPA), referencing their concerns that Pauline had been on the floor all night. The referral also referenced 'hoarding' and that there were 'grab rails' around the home.

5.6. The SPA contacted the hospital to confirm Pauline had been admitted. The referral information from NWAS was not transferred through to hospital ASC to inform discharge planning.

5.7. Pauline was seen by her GP in **March 2019** for follow up blood tests. George also contacted the surgery for some minor treatments for himself. He had declined Occupational Therapy on Pauline's behalf. He also asked Community Nurses not to visit them at home as he would bring Pauline to the GP Practice. He was described as being very abrupt when a Community Nurse then made a home visit.

5.8. During **2019**, Pauline had face-to face check-ups at the GP Practice. George was also seen for his health needs including diabetic review and tests for prostate cancer. The GP Practice also had phone consultations with Pauline and with George for their medication reviews.

5.9. During **February 2020**, George had a series of tests. Unfortunately, in **March 2020**, George was diagnosed with prostate cancer. He was seen by Oncology in **April 2020**. Pauline was due to attend an outpatient's appointment, but George cancelled this due to worries about the Corona virus.

5.10. In **May 2020**, NWAS responded to a 999 call. Pauline had fallen and George was unable to lift her. NWAS talked to the couple about referrals to Social Care and NCIC as provider of community health services, but Pauline and George refused. NWAS recorded there were no concerns about Pauline's mental capacity. Pauline was assisted by NWAS but did not require hospital admission.

5.11. **June 2020** NWAS was called to attend Pauline following a further fall. Paramedics noted no care package in place. They spoke with the couple about the clutter and trip hazards, offering a referral to Social Care and the GP. The records note George appeared to become quite defensive – saying he could still manage and would contact the GP himself. Paramedics noted both had mental capacity. She did not require hospital admission.

5.12. In **July 2020**, Pauline and George were seen at the GP Practice for their individual health needs. They made no reference to Pauline's falls.

5.13. **August 2020** NWAS were called out on two further occasions following falls and supported Pauline at home. Pauline continued to decline a referral to Social Care but did consent to information being sent to her GP and a referral made to the NCIC. (There is no record of these communications being made.)

5.14. In **September and October 2020**, Pauline had some contact with her GP Practice. She cancelled one appointment due to concerns about exposure to the Corona virus but did attend surgery for her Covid vaccine. George also attended his GP Practice for a diabetic review.

5.15. In **October 2020**, NWAS attended Pauline again following a fall. On this occasion, Pauline told staff that she no longer wanted George to care of her personal needs due to her bladder weakness. Pauline agreed to NWAS making a referral to Social Care. The NWAS referral to the Social Care SPA noted concerns about the cluttered environment and the potential fire risk. Pauline remained at home.

5.16. The SPA officer phoned and spoke with Pauline and George. They did not want any help and declined to take the number for Adult Social Care.

5.17. NCIC received a referral reporting that Pauline had had three falls in five weeks. NCIC triage duty worker phoned and spoke with Pauline. Pauline minimised the concerns saying she had had 'Two falls at the most, momentary blip,' and was not forthcoming with details. NCIC offered a discussion on falls and what help could be provided. Pauline stated she was happy, did not need this and declined information being sent by post.

5.18. Pauline was due to attend her GP for urinary problems but cancelled as she did not feel safe attending (presumed to be due to Covid pandemic).

5.19. In **November 2020**, NWAS was called out again following a further fall. NWAS gave advice but follow up referrals were declined and Pauline remained at home.

5.20. In **December 2020**, George called the ambulance as Pauline had fallen getting out of bed and banged her head. Pauline was adamant that she would not go into hospital and was assessed as having capacity for the decision. NWAS liaised with the Out of Hours GP service about the call out and Pauline's refusal of admission. This was recorded within her GP records.

5.21. NWAS also made a referral to Social Care SPA. This referral referenced hoarding, that the home appeared dirty, and that Pauline and George would benefit from care and support and a full assessment of needs. The SPA contacted Pauline and George. The couple talked about the grab rails around the home and that they felt they were managing. They declined any support.

5.22. NWAS had also made a referral to NCIC. The referral referenced the level of clutter as being 4 out of 10 on clutter scale.[6] The NCIC triage duty worker phoned and initially spoke with George and then Pauline. Pauline declined offers of a home visit and was recorded as having capacity to make this decision. The NCIC duty worker discussed falls prevention and advice. Pauline accepted the offer of follow up information being posted to her but did not want a therapy visit.

5.23. When the NCIC duty worker spoke with George, he acknowledged 'some clutter' in the house. He said he had plans to hire a skip and have a clean out in the New Year. He confirmed there were clear walkway to bedroom, lounge and toilet and said their property also had grab rails in place and lights were left on at night. George added that a commode was available, but Pauline did not wish to use it. The practitioner talked through mobility exercises.

[6] Clutter Scales use 9 images of levels of clutter with 1 being standard/no clutter to 9 being extreme clutter.

5.24. In **January 2021**, the ambulance service was attending Pauline again following another fall. George talked to the paramedics about his health needs and that he was struggling with Pauline's care needs. The paramedic's records described Pauline's appearance as unkempt. George and Pauline agreed to NWAS contacting Social Care. The NWAS referral to the SPA highlighted George's determination to care for Pauline but that he believed he would not be able to continue for much longer due to his own health needs. The referral also noted that their home was extremely cluttered.

5.25. A SPA officer contacted George and Pauline, to offer a Care and Support assessment. They also offered George a Carer's assessment, but he declined. George spoke of being determined to continue to manage on his own. He talked about driving to their local garage for groceries and having information about telecare and the Wellbeing Team. The SPA officer provided contact details should he change his mind.

5.26. The NCIC triage duty worker also followed up on an electronic referral following the fall. They phoned and spoke with George with Pauline in the background. Pauline declined a referral to the Community Response Service.

5.27. A few days later, Pauline received her second Covid vaccination. The following day NWAS were called out again due to Pauline having a further fall. She did not need to be conveyed to hospital but NWAS made a further referral to Social Care SPA and to NCIC. The SPA contacted and spoke with George. He declined offers of support.

5.28. NCIC triage duty worker phoned and spoke with George as Pauline was sleeping. George thought her fall was due to exhaustion and that she had got out of bed too quickly. He did not think the Community Response Team was required.

5.29. In early **February 2021** George was admitted to oncology ward but discharged home the same day. The next day George called NWAS out as Pauline had an upset stomach and was unable to get to the toilet. NWAS attended and supported Pauline at home. Pauline was more receptive to receiving support. NWAS referred again to Social Care and to NCIC. The referral included information about clutter in the home. The Social Care duty worker phoned the couple. George spoke of his own health needs but declined any support stating everything is fine but accepted a contact number for Social Care.

5.30. One week later, Pauline had a further fall. NWAS attended and discussed again referrals to Social Care and NCIC – Pauline agreed to the falls referral but declined a Social Care referral. NWAS used the clutter scales scoring the property 4/9. The NCIC triage duty worker phoned George who described the aids they had in place. He requested a Mangor ELK lifting device.[7] NCIC were unable to provide this but gave George Social Care's number for self-referral.

5.31. NWAS had informed the GP Out of Hours service of their attendance but that she had not been conveyed to hospital. The records noted the view from the paramedic that 'Pauline has had another fall today, has had a few falls in the past six months but appears to have an ambulance to her at least once a month for falls and other things. Clinical support suggest that she had a review due to her deterioration. She has no injuries from today's incident.'

5.32. This information was transferred into Pauline's GP records. The GP Practice noted the paramedics comments and referred this to their GP Practice care coordinator. The care coordinator referred to Social Prescribing[8] asking that the service referred to Adult Social Care Reablement services. There is no record of that referral.

[7] A Mangor ELK is an air cushion that is inflated in stages, raising a patient up slowly off the floor. It should not be used by one person alone as a 2nd person is required to steady the patient. This is a lifting tool that has been used by NWAS staff on numerous occasions to assist Mrs A off the floor.

[8] Social Prescribing is a way for local agencies to refer people to a link worker. Link workers give people time, focusing on 'what matters to me' and taking a holistic approach to people's health and wellbeing. They connect people to community groups and statutory services for practical and emotional support.

5.33. Very sadly, George and Pauline were found dead in their home two and a half weeks later. George had missed an oncology out-patient appointment. The Oncology department had been trying to get in touch with George to arrange a further appointment but could not contact him. A Locum GP had made a home visit and discovered the couple had died.

5.34. Police described the home address as in a cluttered, dirty and dishevelled state to the point it was difficult to walk through. There was evidence of mobility aids in the chalet. There was plentiful food and insulin in the fridge and the heating was turned up full. The post-mortem revealed atheroma (fatty deposits) within George's coronary artery, reducing the flow of blood to his heart. George's death had not been expected but the Coroner's verdict was that he had died from natural causes.

5.35. It is believed that George died before Pauline. Pauline's cause of death was given as from natural causes and the coronial investigation did not progress to an Inquest.

6. Analysis and Learning

6.1. Context of Self Neglect

6.1.1. The CSAB self-neglect guidance[9] references that self-neglect may include lack of self-care in areas such as personal hygiene, dietary needs and health needs. Self-neglect may also relate to lack of care to one's environment –for example unkempt, unsafe or unhygienic home conditions; clutter arising from hoarding resulting in risks to health and safety and fire risks. Self-neglect may be shown in refusal of assessments and interventions by services that may alleviate the issues.

6.1.2. The Care Act 2014 recognises self-neglect as a category of abuse. It places a duty of co-operation on all agencies to work together to establish systems and processes for working with adults (for whom safeguarding duties apply) who are self-neglecting. However, defining self-neglect can be very open to interpretation with subjective judgements about personal standards. The CSAB guidance references the need for professional judgements about 'acceptable levels of risk' and what constitutes wellbeing for the individual.

6.1.3. The Care and Support Statutory Guidance[10] states that 'self-neglect may not prompt a Section 42 enquiry[11]. An assessment should be made on a case-by-case basis. 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. There may come a point when they are no longer able to do this, without external support'

6.1.4. Safeguarding Adults should be founded on Making Safeguarding Personal, keeping the adult at the centre of decisions about how they manage risks and safeguarding responses. However, the respect for self-determination needs to be balanced with duty of care, taking reasonable steps proportionate to risk.[12]

[9] Cumbria Safeguarding Adult Board Safeguarding Adults Self Neglect Guidance October 2021 https://www.cumbria.gov.uk/eLibrary/Content/Internet/327/949/43214103754.pdf [Accessed December 2021]
[10] Care and Support Statutory Guidance (2017) Ch14.7, Available from: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance [Accessed: 22/01/18]
[11] Duties under the Care Act to carry out a safeguarding adult enquiry
[12] LGA and ADASS Myths and realities about Making Safeguarding Personal 2019 https://www.local.gov.uk/sites/default/files/documents/25.144%20MSP%20Myths_04%20WEB.pdf [Accessed January 2022]

6.1.5. All these factors create a complex context for multi-agency working. Research has highlighted the significant challenges that individual practitioners, agencies, and safeguarding partnerships have in responding to self-neglect, particularly where the adult has the mental capacity to make decisions and is declining support[13]. In a national review of Safeguarding Adult Reviews, self-neglect was the most common category of abuse of all cases that had resulted in a SAR, (45%)[14].

6.1.6. Cumbria has had its own challenges in working with self-neglect. Section 6.3 will cross reference to learning from a CSAB SAR in 2016 that centred around the death of a couple in circumstances of self-neglect.

6.1.7. The Care Act emphasises the importance of early intervention and preventative actions to minimise risk and harm. Research[15] has outlined factors that support best practice in working with self-neglect. These were grouped under:

1. Practice Factors
2. Strategic Factors

6.1.8. The analysis and learning from this review are structured around those best practice factors.

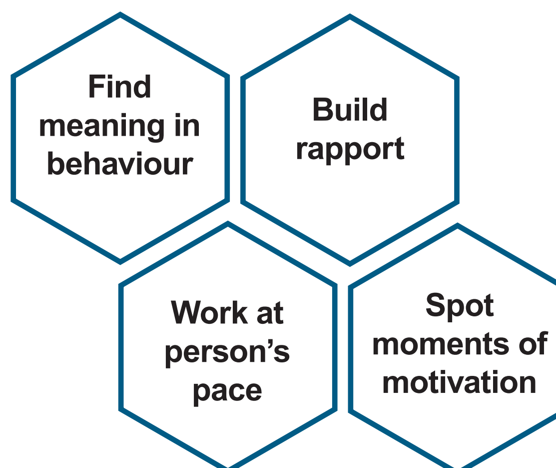
6.2. Practice Responses to Self-Neglect

6.2.1. The table below summarises the factors highlighted in the SCIE research that led to more successful practice responses to self-neglect.

Practice Factors Most Successful in Self Neglect	
Engaging	1. Time to build rapport and a relationship of trust, through persistence, patience, and continuity of involvement
	2. Trying to 'find' the whole person and to understand the meaning of their self-neglect in the context of their life history
	3. Working at the individual's pace, but spotting moments of motivation that could facilitate change, even if the steps towards it were small
Working with Risk	4. Understanding the nature of the individual's mental capacity in respect of self-care decisions
	5. Having an in-depth understanding of legal mandates providing options for intervention
	6. Being honest, open and transparent about risks and options
Working Across Agencies and Communities	7. Creative and flexible interventions, including family members and community resources where appropriate
	8. Effective multi-agency working to ensure inter-disciplinary and specialist perspectives, and coordination of work towards shared goals.

[13] Social Care Institute for Excellence, Braye., S, Orr, D., and Preston-Shoot, M., (2015), Self-neglect Policy and Practice: Research Messages for Managers, Available from: https://www.scie.org.uk [Accessed January 2022]
[14] Local Government Association: Analysis of Safeguarding Adult Review April 2017- March 2019; Executive Summary October 2020 https://www.local.gov.uk/analysis-safeguarding-adult-reviews-april-2017-march-2019 [Accessed January 2022]
[15] Social Care Institute for Excellence, Braye., S, Orr, D., and Preston-Shoot, M., (2015), Self-neglect Policy and Practice: Research Messages for Managers, Available from: https://www.scie.org.uk [Accessed January 2022]

Engaging with Adults



6.2.2. Agencies knew very little about Pauline and George.

6.2.3. George's brother gave some insights into the barriers agencies faced in engaging Pauline and George. He described that in the past, George had been a fastidious person who took great care of his appearance and environment. It was a deep shock to George's brother to see the conditions the couple had been living in. He described their living conditions as 'beyond squalor.'

6.2.4. George's brother had had regular contact with him over the years, their last contact being just before his death was discovered. However, their contact was either by phone or when George and Pauline visited his home two-three times a year. George's brother had not been to their home for many years. Although George appeared to be outgoing and sociable, his brother believed that he had become very adept at masking parts of his life including his poor living conditions.

6.2.5. The couple were not reclusive. They frequently went out and George did some shopping most days. George and Pauline had both regularly accessed health care at the GP Practice and at outpatient clinics. The review scope period covered the peak of the Covid pandemic. The occassions when Pauline or George cancelled appointments were neither uncommon nor unreasonable during that time with many people avoiding unnecessary contact and not wishing to add pressure to a stretched NHS.

6.2.6. Pauline and George's resistance appeared to centre around people accessing their property. This had pre-dated the Covid pandemic. It came as no surprise to George's brother that the couple had not wished to receive care and support services into their home. This mirrored his own experience. The couple appeared to want to keep people at arms length from where they lived, whether this be professionals, family or friends.

6.2.7. It is not clear what the reasons were for the couple's poor and cluttered environment. George would talk to his brother about the various DIY projects he had planned. He had spent substantial sums on DIY materials. However, the condition of the home on their deaths did not indicate George had carried out any work.

6.2.8. George's brother believes the state of the property had simply got beyond George's control and that he was embarrased to ask for help or for anyone to see the conditions of their home. The fact that it was only under emergency situations when NWAS were given access, perhaps supports this view.

6.2.9. The terms of reference for the review questioned how well the individual views of Pauline and George were heard and their needs understood. The importance of understanding the distinct needs of carers and the cared for person, is reinforced in policy and under the Care Act 2014. Learning from SARs also highlighted themes regarding working with carers and the cared for person when Safeguarding Adults[16].This included:

i) The need to distinguish between assessment of the carer's support needs and assessment of the capability of the carer to meet the needs of the cared for person and any risks arising, and

ii) The need to understand the potential for coercive and controlling behaviours within carer/cared for relationships when working with people who are resistant to care.

6.2.10. The dynamics within carer/cared for relationships can be complex. The potential for undue influence can be motivated by laudable reasons such as compassion; protection and self-sacrifice, as well as the adverse factors of control and coercion that can be seen in circumstances of domestic abuse. In all circumstances, it is important to hear individual voices, free from influence.

6.2.11. The records do in general specify that when contacted, professionals tried to confirm the views and wishes of both Pauline and George. One phone contact by a duty Community Nurse demonstrated good practice of ensuring that both were spoken to – on this occasion, the nurse tried to open up conversation with George about the levels of clutter that NWAS had referenced in their referral. George acknowledged the place was a bit cluttered and spoke of his plans to get in a skip. The nurse had no reason to question his intent.

6.2.12. Although NWAS, NCIC and SPA did make some attempts to speak to George and Pauline individually, the couple's close physical proximity meant that the other partner, was always in the background. This was not always apparent to NCIC and SPA, as their contacts were by phone.

6.2.13. It is George's brother's view that Pauline was the driving force in making any decisions about their lifestyle. This impacted on the standards of cleanliness and clutter within their environment, and not wishing to accept any interference in their lives. It was his view that as Pauline became more dependent upon George, this dynamic with their relationship became more entrenched. Pauline became more directive and as George wanted to support her, he would not go against her wishes. However, George's brother also believed that had George been given space on his own to talk, he may well have acknowledged the difficulties they were having and the need for support from services. Whether this would have been sufficient to sway Pauline to accepting care is debatable.

6.2.14. George's brother acknowledges that it may have been difficult for services to speak with George or Pauline on their own, free from any influence. The GP Practice was developing use of Advanced Care Plans (ACP). ACPs are good practice; a means of setting out future wishes for a point when the person may not have the capacity to make their wishes known. The Practice was developing ACP's especially for patients with specific needs such as long term conditions and/or end of life care planning. Carers' circumstances are also important to consider in prioritising ACPs, particularly where there is high dependency on a carer who may themselves be vulnerable.

6.2.15. Developing an ACP may have offered an opportunity to understand the couple's circumstances better. Pauline may have been within the target group for developing an ACP. However, as George was 20 years younger than Pauline, and his own health conditions were well controlled, the care relationship was not seen as precarious. The GP Practice knew of no concerns about her care and Pauline may not have fallen into the priority group for an ACP.

[16] East Midlands Safeguarding Adult Network Report from a thematic review of Safeguarding Adult Reviews within the East Midlands 2017 https://nsab.nottinghamshire.gov.uk/media/tlqcjdmh/emsanthematicreviewsars.pdf [Accessed January 2022]

6.2.16. There may also have been an opportunitiy for GP Practice staff to speak with George or Pauline on their own during their visits to the GP Practice. However, the GP Practice staff were not aware that there were any concerns about the couple's living conditions or that there was a pattern of resistance to care. This meant that there were missed those opportuities to try and engage, and explore their views free from the influence of the other. The lack of sharing information between agencies is discussed further in the section below, 'Working Across Agencies and Communities.'

6.2.17. It does appear that NWAS took all reasonable steps to try and encourage George and Pauline to accept care and support. The paramedics used those opportunities that a crisis can bring, when the couple may have been more open to accepting help.

6.2.18. There were some specific windows of opportunity – the occasion when Pauline acknowledged she didn't feel comfortable in George providing all her personal care; an occasion in January 2021 when George spoke of struggling to cope. Good practice was demonstrated by NWAS paramedics, capitalising on those occassions, taking time to talk to Pauline and George and following through with referrals. It was also good practice by the SPA and by the NCIC that those referrals had a quick response time – this maximised using those moments of motivation. Sadly, the apparent engagement was short lived.

6.2.19. Contributors to the review discussed the concept of disguised engagement i.e. behaviours where the adult or the adult's carer may be appearing to accept help but this being a false reassurance. This is a concept commonly referred to in Safeguarding Childen as 'disguised compliance.'

6.2.20. We know that identifying and working with disguised engagement can be challenging for practitioners, recognising an adult's rights to self-determine their affairs. Guidance references the need for practitioners to hone skills in professional curiousity, using a strengths based approach but avoiding over optimism, critically evaluating the whole picture, not just what is being said. This might lead to having some difficult conversations and a need to respectfully challenge the adults views about their own, or the cared for person's circumstances.

6.2.21. Guidance also talks about encouraging reflective practice – asking staff to consider how their approach may be invoking disguised engagment.[17] Professionals at the learning review discussed the need to consider language and attitudes. The person may feel an invasion on their privacy. Staff need to be respectful of their wish to be self-reliant, reframing the concept of passively accepting support, to using language focused on retaining independence. One example given was using the clutter rating scale as a tool to have a non-judgemental conversation about how they saw their living situation.

6.2.22. In relation to George and Pauline, practitioners were constrained in carrying out this best practice by:

i) The lack of time required for this reflective practice

ii) The lack of a consistent practitioner to build a relationship.

6.2.23. The impact of the Covid pandemic should not be under-estimated. Contributors to the review reflected on the highly pressured working environment in the early stages of the pandemic. Staff were actively encouraged to avoid close contact with people wherever possible. The working conditions meant they had very limited space to step back, reflect, be professionally curious or test out if there was disguised engagement.

[17] David Wilkins, University of Bedfordshire We need to rethink our approach to disguised compliance 2017 https://www.communitycare.co.uk/2017/03/16/need-rethink-approach-disguised-compliance/ [Accessed January 2022]

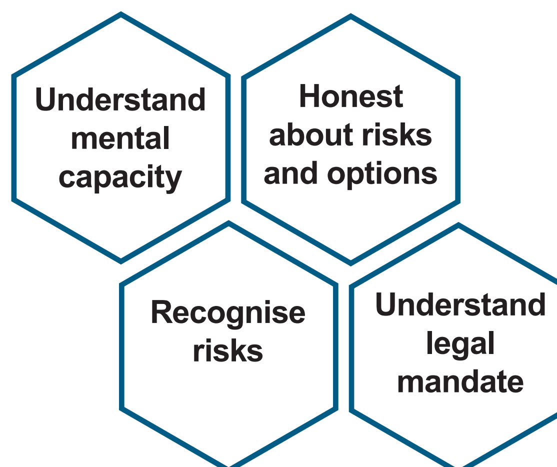
6.2.24. Even without the additional pressures of Covid, the ability for any practitioner to build a relationship can be constrained by resources and the structure of services. The Named GP for Safeguarding, commented that Pauline and George's GP Practice, like many across the UK, was struggling to recruit GP's and was reliant on locums. This made it more challenging to provide continuity of care. The Practice did have a lead GP for Safeguarding as is good practice. Had the concerns been known, that GP could have endeavoured to provide greater oversight and continuity of care. The fact that a locum GP had taken the time to do a home visit when George missed his oncology appointment was noted by all as unusual, but very good practice. George's brother also commended that GP's sensitivity in their responses to discovering the couple's deaths.

6.2.25. The structure of services within the SPA and NCIC meant that there were different staff screening, or triaging referrals. The follow up was by phone calls by different duty staff. This standard service response, may be acceptable in most circumstances. However, this transactional, task focused approach is not conducive to forming relationships with people who may be at risk of harm due to their resistant to care. That needed an enhanced response. The following section considers how well risks were recognised, that should have triggered an enhanced response.

6.2.26. Section 6.3 references work the CSAB is carrying out in relation to professional curiousity. This provides a good opportunity to use the learning from this review.

Recommendation 1

6.2.27. **Working with Risk**



6.2.28 George's brother expressed some frustration about what he saw as the constraints imposed upon those professionals who were trying to provide care. He believed that more should have been done to enforce the couple to accept help rather than accepting their rights to self-determination. It is perhaps understandable that family express such frustrations where a loved ones actions, places themselves or others at risk. Nonetheless, there would have to be a lawful basis for any interventions that compelled George and Pauline to accept support without their consent – there was none.

6.2.29. Where an adult declines care and treatment, their views and wishes should form part of wider consideration to understand:

- The wider context of the adult's circumstances
- The implications of their decision including risk of harm to themselves or others
- Any impairment to decision making i.e. mental capacity to make the relevant decision; undue influence, impaired executive functioning[18]
- Options for responses: mitigating actions/strengths to reduce risk; understanding and applying the legal framework.

[17] David Wilkins, University of Bedfordshire We need to rethink our approach to disguised compliance 2017 https://www.communitycare.co.uk/2017/03/16/need-rethink-approach-disguised-compliance/ [Accessed January 2022]

[18] Executive functioning refers to the ability to think abstractly, integrate inputs such as situation and memory, to put a decision into action

6.2.30. There was variable evidence of how well agencies explored all these factors and used in the responses that followed.

6.2.31. There was evidence of NWAS working well with risk. They listened to George and Pauline's views but evaluated this alongside the evidence of what they saw – the conditions of their environment, the evidence of falls, the risks of further falls and potential fire hazard if no support was given.

6.2.32. The paramedics took time to explore those risks with Pauline and George, and to support their decision making. Where care and treatment was declined, they recorded that there was no reason to doubt capacity. There were no legal grounds to act without consent but staff took reasonable additional steps. They were persuasive in seeking consent to make referrals to NCIC and the Adult Social Care SPA. One example was their attendance in December 2020, when Pauline had a head injury from a fall. All of this was good practice by NWAS paramedics.

6.2.33. The NWAS author reflected that the referrals may have benefitted from more detailed description. There was some description of the nature of self-neglect and the associated risks, for example, falls, fire risks, unkempt and dirty conditions. Some of the referrals attached a clutter scale but this was not consistent – some were sent to NCIC but none accompanied the referrals to the Adult Social Care SPA.

6.2.34. Practitioners at the learning event discussed the value of using clutter scales. The clutter scale helps to quantify the nature and degree of the concern. It can provide a common language across multi-agency disciplines. It can provide some level of objectivity and a baseline to measure improvement or deterioration. Clutter scales were not part of the CSAB guidance and were not routinely in use. Not all practitioners were familiar with them, or with the CSAB self-neglect guidance. (section 6.3 explores further the guidance that was in place and the systems supporting practice.)

Recommendation 2

6.2.35. Although the referrals from NWAS would have benefitted from more detail, the concerns of self-neglect were referenced. The responses to those referrals did not adequately address those concerns.

6.2.36. Agencies reflected that there had been an episodic response to each interaction with George and Pauline. Assessing historical factors, is a fundamental component of any risk assessment. The history would have shown the recurrent concerns by the NWAS and the pattern of non-acceptance of any help. This understanding was key to assessing risks and recognising the need to find different ways to try and reduce risks. Neither NWAS, SPA or NCIC drew together or analysed this chronology and so there was simply a repeat of unsuccessful attempts to engage with George and Pauline.

6.2.37. The NWAS paramedics were not able to access records about Pauline's history of falls, nor of their previous referrals to NCIC and Adult Social Care. Their referrals could not therefore reference the cumulative risks: the sustained poor conditions in the home; the increasing frequency of falls and the emerging picture of disguised engagement. It was fortuitous that one of their paramedics had attended Pauline on three occassions. It was reliance on their memory, rather than any record system, that led to them calling the Out of Hours GP in January 2021, to raise concerns about the numbers of falls Pauline had had.

6.2.38. NWAS agreed there needed to be a more resilient system in place. NWAS did have a system to identify and work with people who are high intensity users but the numbers of calls by Pauline and George would not have met this threshold. NWAS has recently improved their use of technology. NWAS paramedics can now access computer records when out on calls. Paramedics can also upload referrals electronically, including photos (with consent). This is an improved system but paramedics can only view information about the last attendance, rather than a chronology of call outs.

The NWAS author also highlighted that as frontline staff will be sending through referrals direct, they would need further safeguarding training to ensure the referrals provide the necessary information.

Recommendation 3

6.2.39. NCIC do have an IT system (ERRIS) for referrals from NWAS that would have recorded the chronology of previous referrals. NCIC had been sent seven referrals by NWAS in the scope period, five of these were in the last 3 months of Pauline and George's lives. Three of those referrals had clutter scales attached, indicating level 4 (mid-range on the scale 1 -9) and all referrals referenced concerns. The NCIC community staff that triaged the NWAS referrals, did not access this chronology. This was an ommission. It meant that when staff contacted Pauline and George, they were not aware of the full picture. Pauline and George minimised the concerns and refuted information in the referrals. NCIC duty staff did not carry out any further risk assessment or, as outlined above, demonstrate professional curiosity that may have revealed a pattern of disguised engagement. This meant there were no strategies put in place to overcome resistance. Nor did staff escalate the concerns to NCIC's safeguarding team for advice and support in managing self-neglect.

6.2.40. There was some evidence that NCIC staff considered mental capacity in their responses. The NCIC author noted that one of their contact records specified Pauline was assumed to have capacity to decline the referral. However, there was no information about how this decision was reached or whether the potential for undue influence/coercion had been considered.

6.2.41. The NCIC author felt that the reactive response by their triage staff, may be explained by Covid work pressures at that time. This is acknowledged. Nonetheless, the NCIC author highlighted learning about the basic measures that should be in place where people decline care. Effective systems and processes become more important to support staff in times of pressure.

6.2.42. The Adult Social Care author raised similar concerns about how their service had responded to the referrals. They also recognised an episodic response to the five referrals that had been made.

However, the author highlighted that even on the basis of the individual referrals, the SPA officers should have been more responsive to the concerns raised.

6.2.43. The SPA provides a gateway into Adult Social Care. Where a referral has been made by an external agency, and the adult declines a service, this should have been escalated to a qualified Social Worker within the Screening and Assessment Team. The fact that this did not happen was an error in practice. Adult Social Care has already taken steps to put this escalation process in place.

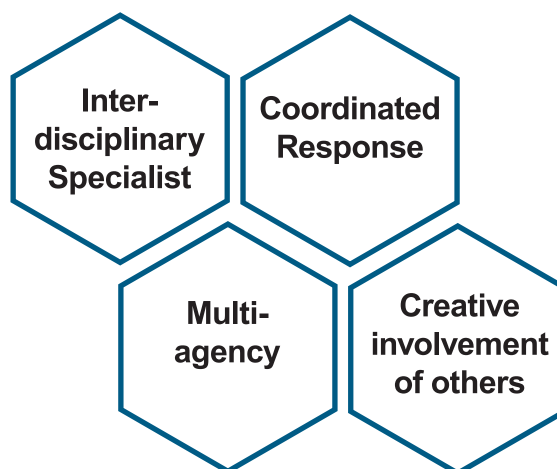
6.2.44. The SPA response was focused on reablement support due to the number of falls Pauline had had[19]. However, this was too narrow a view. There was very limited evidence of assessing the factors outlined in 6.2.28 above. There was an absence of safeguarding minded practice that took account of the references in the NWAS referrals to hoarding, clutter and self-neglect. There was also no apparent response to the concerns in the referral about fire risk. We know from learning from other SARs,[20] the increased fire risks relating to combined factors of limited mobility; confined space and hoarding. Fire and Rescue Service are able to provide services to help reduce risks of fire but are reliant on a partnership approach to identify and refer those people who are in the most vulnerable circumstances. There is a need for all professions to be knowledgeable and vigilant to fire safety concerns, integrate this into care planning for people in higher risk groups and understand referral routes for fire safety checks.

Recommendation 4

[19] Reablement is person centred goal focused and time limited intervention to support people to regain functioning and life skills. SCIE Role and principles of reablement 2020 https://www.scie.org.uk/reablement/what-is/principles-of-reablement [Accessed January 2022]2]
[20] Example: Lincolnshire Safeguarding Adult Board Safeguarding Adult Review 'RJ' https://www.lincolnshire.gov.uk/downloads/file/5070/sar-rj-overview-report [Accessed December 2021]

6.2.45. Had the SPA escalated the concerns, it should have led to a home visit by an appropriate practitioner. This would have enabled a much clearer assessment of the home conditions and of the couple's circumstances. It may also have increased the chances of George and Pauline accepting help. Even had they continued to decline, this could then have triggered a multi-agency response, either through case management or potentially as a Safeguarding Adult enquiry, as guided by the self-neglect guidance. In this instance, self-neglect guidance was not followed by the SPA or the SAT.

6.2.46. **Working Across Agencies and Communities**



6.2.47. The review highlighted that the agencies were all working in isolation from one another. Attendees at the review learning event commented that agencies were not all on the same agenda –in fact, they didn't know what that agenda should be. It appeared that George and Pauline's circumstances were not recognised either through multi-agency complex case pathway, or through using the CSAB multi-agency self-neglect guidance.

6.2.48. As with many Safeguarding Adult Reviews[21] there were pockets of information held by some agencies. This information was not brought together to give a full picture of George and Pauline's needs and risks and to coordinate a way forward.

6.2.49. Cumbria has Integrated Care Communities (ICC). The ICCs bring together Health and Social Care to work in partnership with a remit to support people's care outside of hospital. The ICC for George and Pauline's area has the facility to hold multi-agency meetings for people with more complex needs. The meeting should be solution focused, using the skills of all the different professional disciplines to coordinate a support plan. It has the potential to be flexible and creative – all the factors that are known to be more successful in working with self-neglect. Any agency can refer into this ICC meeting – none did.

6.2.50. Attendees at the learning event agreed that the ICC multi-agency meeting would have been an appropriate route to explore concerns about Pauline and George. This would have enabled a fuller and shared assessment of the degree of self-neglect, as one contributor commented, 'a stop point to bring together a richer discussion.' It may also have led to a coordinated plan, for example, capitalising on the positive relationship the couple had with their GP Practice, to hear their individual perspectives and to encourage support from services. It should also have identified when a Safeguarding Adult referral was appropriate i.e. where risks could not be mitigated.

6.2.51. Contributors considered the reasons why referral to ICC multi-agency meeting was missed. In addition to the lack of effective risk assessments by single agencies (noted above), contributors also recognised that in the early stages of the Covid Pandemic, there were not effective systems to support multi-agency working. The ICC representative to the review, felt confident that systems had evolved dramatically during the pandemic. One positive development has been more robust systems for virtual meetings and a workforce more confident in using this medium.

[21] Local Government Association: Analysis of Safeguarding Adult Review April 2017- March 2019; Executive Summary October 2020 https://www.local.gov.uk/analysis-safeguarding-adult-reviews-april-2017-march-2019 [Accessed Jan 2021]

Recommendation 5

6.2.52. Information sharing was a barrier, particularly for the GP Practice. NWAS, in common with other ambulance Trusts, do not routinely notify GPs of attendances where the person is not conveyed to hospital. The GP Practice remained unaware of the number of occasions NWAS had attended Pauline, and the concerns NWAS had about self-neglect. The GP Practice had received some information that George and Pauline had declined support from NCIC. However, these notifications had not been filtered out by their administrative processes so were not drawn to the attention of a clinician. The GP Practice was not aware of NWAS referrals to Adult Social Care and Adult Social Care had not communicated with the GP that the couple had declined care, or the concerns of self-neglect.

6.2.53. The only notifications from NWAS that the GP Practice received were via the Out of Hours GP Service when NWAS contacted them about Pauline's recurrent falls in February 2021. The Out of Hours service made an entry in the GP's patient record. This triggered the GP Practice to refer for Social Prescribing – sadly this was too late.

6.2.54. We don't know whether this referral to Social Prescribing may have culminated in an ICC multi-agency meeting. We also do not know whether an ICC meeting could have made the substantive difference to George and Pauline accepting some help.

6.2.55. However, learning has highlighted gaps in the system of care that may make a difference to others. Ambulance Trusts are expanding their role in preventing admissions to hospital. They will hold key information following their attendances, that will be very relevant to other parts of the Health and Social Care system. The current lack of communication across the system means that this information held by ambulance Trusts is being lost.

6.2.56. Contributors to the review agreed that NWAS could make a valuable contribution to ICC multi-agency meetings and resolved to extend the invite list. Whilst that is a positive development, it does not resolve the gap in the earlier part of the pathway – identifying emerging concerns that would trigger a referral to the ICC.

6.2.57. North Cumbria, as in all regions, has a new Integrated Care System[22]. This is a strategic partnership across health and social care that develops services for their local population. The ICS aims to develop new ways of working, using technology to innovate. North Cumbria Clinical Commissioning Group, working on behalf of the Northeast and North Cumbria Integrated Care Board, should lead work to improve the communication systems between those partners within the ICS, specifically, exploring the feasibility/benefits of GPs being notified of all attendances by NWAS.

Recommendation 3

[22] Integrated care systems (ICSs) https://www.england.nhs.uk/integratedcare/what-is-integrated-care/

6.3. Strategic Responses to Self-Neglect

Organisational Factors to Support Practice in Self Neglect	
Systems and Structures	1. A clear location for strategic responsibility for self-neglect
	2. Data collection on self-referrals, interventions and outcomes
	3. Clear referral routes
	4. Systems in place to ensure coordination and shared risk management between agencies
Supporting Workforce	5. Time allocations within workflow patterns that allow for longer-term supportive relationship-based involvement
	6. Training and practice development around the ethical challenges, legal options and skills involved in working with adults who self-neglect
	7. Supervision systems that both challenge and support practitioners

6.3.1. The review considered the systems and process that were in place to support practitioners in working with self-neglect.

6.3.2. In 2016, CSAB published a SAR relating to the deaths of Mr and Mrs Z in circumstances of self-neglect.[23] It is concerning that the key areas of learning identified within that review, were also evident in the responses to Pauline and George. The findings from the 2016 SAR included:

6.3.3. • Each agency involved focused on their own areas of responsibility, resulting in a less than rounded picture of the full situation

- Adult social care was very focused on eligibility for service, and there was no evidence of a joint approach to assessment and trying to find a solution
- The benefits of a multi- agency approach to assess the risk of harm in cases of self-neglect, determining roles and responsibilities of all agencies were not realised.
- The lack of interagency communication when interventions were closed was a cause for concern, together with unresolved issues of when information can be shared whilst respecting the confidentiality of the person
- Adult social care response was not of the standard to be expected in making an initial assessment of needs, gathering further information and determining a course of action
- Application of the requirements of the Mental Capacity Act…… and weighing up the potential broad range of legal frameworks available to promote the six fundamental principles of safeguarding
- Hesitancy on the part of the professionals involved to consider opportunities to intervene, for example where they did not attend appointments or manage medication appropriately

[23] Cumbria Safeguarding Adult Board, Safeguarding Adults Review Mr and Mrs Z Overview Report 02 September 2016

6.3.4. The CSAB did have guidance for self-neglect in place during the scope period. The guidance was issued in 2017,[24] post-dating the publication of Mr and Mrs Z SAR. However, this review highlighted that some practitioners were not aware of the self-neglect guidance. Others were aware of it but it was not at the forefront of their thinking.

6.3.5. This raises questions about how well each constituent agency of the CSAB, supports staff in working with self-neglect:

- Disseminating learning from SARs
- Raising awareness of CSAB procedures and guidance
- Providing training in self-neglect
- Providing leadership and supervision for staff in working with self-neglect

Recommendation 4

6.3.6. The CSAB 2017 self neglect guidance was relatively limited in content. It was revised in October 2021, providing greater detail describing different levels of self-neglect and potential responses. Contributors to this review felt that the use of assessment tools, such as clutter rating scales/responses, would[25] be a useful addition to the new guidance.

Recommendation 2

6.3.7. The levels of response to self-neglect also need to be cross referenced to other relevant policy and procedures. There is significant inter-face between working with self-neglect and multi-agency working with complex care needs. As noted, the ICC multi-agency meeting may have been an appropriate forum to respond to the initial concerns of self-neglect, escalating through Safeguarding Adult procedures as a section 42 enquiry where those efforts were unsuccessful or where risk remained/increased. Terms of reference for that ICC multi-agency meeting need to reflect this safeguarding orientated preventative practice, and agendas for case discussions, need to include safeguarding considerations.

Recommendation 5

6.3.8. Where practitioners are working with self-neglect, managers need to build in additional capacity weighting for staff working with people who are resistant to care and self-neglecting. A clear message from contributors to this review was the need for additional time to build relationships, reflect and be supported by supervision.

6.3.9. There has been some effective work carried out by CSAB and the CSAB partners in relation to self-neglect. Contributors referenced good work being developed jointly by Adult Social Care and Fire and Rescue Service in relation to fire safety. As noted, in the case of George and Pauline, the fire safety concerns raised by NWAS, were not adequately addressed. The CSAB should consider whether further quality assurance/awareness raising work is needed in relation to fire safety in the context of self-neglect.

Recommendation 4

6.3.10. At time of the review, representatives from the CSAB were developing resources in relation to professional curiousity. The learning from this review relating to professional curiousity and working with disguised engagement will be useful to feed into this work.

[24] Cumbria Safeguarding Adult Board Safeguarding Adults Self Neglect Guidance October 2017

[25] Example of process for clutter rating tool

http://www.safeguardingdurhamadults.info/media/31539/Clutter-Rating-Tool/pdf/ClutterRatingTool.pdf?m=637332579098030000

7. Conclusions

7.1. This review has considered the sad circumstances surrounding the deaths of Pauline and George.

7.2. The review recognises the considerable challenges that practitioners face when working with people who are self-neglecting and resistant to accepting help. This work requires time and skill to engage with people and hear their individual views free from influence of others. It requires well-structured risk assessments that evaluates the whole picture and the legal mandates available. It requires sharing information between partners and using the expertise of different agencies to be creative and solution focused, working together to minimise risks and improve wellbeing.

7.3.The review identified pockets of good practice. However, there was also significant learning for agencies about how well they responded to concerns of self-neglect. Undoubtably, the Covid pandemic added to challenges, but there were also omissions in practice and gaps in the systems and process that support practice.

7.4. Pauline and George were very clear about their wish to remain independent of care. We do not know whether improved practice responses may have led them to accept care and support. Had they accepted services, we don’t know whether this would have averted the sad circumstances of their deaths.

7.5. George’s brother recognised the challenges that agencies faced and was supportive of the efforts that practitioners made. He hoped that the learning from the review would help the CSAB partnership to strengthen how they respond to others in circumstances of self-neglect. The following recommendations support this aim, taking account of improvements already underway within agencies.

8. Recommendations

Recommendation 1: Staff Support:

Developing resources in working with disguised engagement: The CSAB should use learning from this SAR to assist in their developmental work relating to professional curiosity, i.e. training and tools to assist practitioners.

Recommendation 2: Procedural Development

CSAB Self Neglect Guidance: The CSAB should use the learning from this review to augment the CSAB Self Neglect Guidance 2021. This may include:

i) Tools such as the clutter rating scales, to support practitioners in the assessment and referral process

ii) Guidance on fire hazard risk assessments/actions, related to hoarding and cluttered environments

iii) Information about referral routes to multi-agency forums such as the Integrated Care Communities, for early intervention and lower-level concerns,

iv) The need for managers to recognise the additional resources required for engaging and working with people who are self-neglecting e.g. additional time for practitioners is weighted within case load management systems

Recommendation 3: Systems Development

NWAS Information sharing: North Cumbria Clinical Commissioning Group, should work with NWAS to improve the flow of information across the system: specifically, carrying out a feasibility/benefits analysis of GP Practices being notified of the circumstances of all attendances by NWAS.

Recommendation 4: Monitoring and Review:

Embedding Learning: The CSAB should assure how constituent partners have disseminated learning from this SAR and how the learning has been used to improve outcomes when working with people in circumstances of self-neglect. Agencies should report back on progress within 6 months of the SARs conclusion.

Recommendation 5: Procedural Development

Safeguarding minded practice within the Integrated Care Communities: The leaders of North Cumbria Integrated Care Communities should

i) Review the terms of reference for the ICC multi-agency case discussion to assure safeguarding responsibilities (including self-neglect) are highlighted

ii) Review any documentation used for case discussion, so that the case discussion agendas, prompt safeguarding minded practice.

Sylvia Manson

Sylman Consulting

Date: April 2022

Glossary

ACP Advanced Care Plan

ASC Adult Social Care

CSAB Cumbria Safeguarding Adult Board

ICC Integrated Care Community

ICS Integrated Care System

ICB Integrated Care Board

NCIC North Cumbria Integrated Care

NWAS North-West Ambulance Service NHS Trust

SAR Safeguarding Adult Review

SPA Single Point of Access

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About the Reviewer

The review report was written by Sylvia Manson, of Sylman Consulting. Sylvia is a mental health social worker by background and has many years' experience in Health and Social Care senior management and commissioning. Sylvia has held regional and national roles in implementing legislation and developing safeguarding policy, including as Department of Health, lead for NHS, developing the Safeguarding Adult Principles, now incorporated into the Care Act statutory guidance.

Sylvia now works for the Mental Health Tribunal along with independent consultancy focused on partnership development, service improvement and statutory learning reviews.

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