

Thematic SAR relating to 7 adults who died in circumstances of self-neglect and/or hoarding

1. Who were the adults Purpose of the review

The City of York SAB commissioned this themed SAR after five adults were found between 2023–2024 living in conditions of extreme self-neglect, often combined with hoarding. 2 further adults were added later.

All seven adults died of natural causes, but the conditions in which they were found were unsafe, unsanitary, and in several cases uninhabitable.

The review aimed to understand:

- What professionals knew about their circumstances
- How concerns were interpreted and acted on
- What got in the way of earlier intervention
- What the system needs to change

2. Who were the adults

Across the 7 adults, there were many similarities. These shared characteristics help to identify risk indicators for self-neglect in the future:

- Aged 68–86; 6 adults lived alone; most were socially isolated.
- All had complex co-morbidities including frailty, disability, chronic pain, chronic fatigue syndrome, diabetes, or suspected dementia.
- A number had experienced bereavement, trauma, adverse life experiences or domestic abuse.
- Several had mistrust of professionals, resisted help, or concealed living conditions.
- Many lived in privately owned or social housing but were on the margins of poverty.
- All showed repeated refusal or avoidance of support, despite clear evidence of risk.

3. What was happening in the lives of the adults

All seven adults were living in environments that were unsafe for human habitation:

- Heavy hoarding restricting movement and blocking essential rooms.
- Accumulation of waste, rotten food, faeces, infestations.
- Lack of heating, electricity or running water.
- Sleeping in chairs, cars, or on floors.
- Clear episodes of medical self-neglect: untreated ulcers, infections, malnutrition, poor personal care.

“Despite multiple contacts with services, professionals often did not recognise what they were seeing as self-neglect or hoarding.”

Sarah Newsam, SAR Independent Author

4. Key Themes Identified

Professional Recognition of Self Neglect and Hoarding

- The language of “self-neglect” and “hoarding” was rarely used.
- Case notes typically described homes as “untidy” or adults as “private”, masking the scale of risk.
- Blue light services were more likely to raise safeguarding concerns than health or social care.
- The absence of clear recording meant patterns were invisible to others.

Barriers to Working with Complex Behaviour

- Professionals struggled to interpret behaviour shaped by trauma, bereavement, fear of services, or cognitive decline.
- There was **limited trauma-informed or psychologically informed practice**.
- Cases were frequently closed due to non-engagement or adults declining support—without further enquiry or follow-up.
- Staff had few places to discuss complex cases or share risk

Use of Legislation and Safeguarding

- There was **widespread misunderstanding** of the Care Act duties around self-neglect.
- Many believed that **a safeguarding referral could not be made without the adult's consent**—this is incorrect.
- Self-neglect was often viewed as a “lifestyle choice”, not as a safeguarding concern.
- Mental Capacity Act (MCA) practice was weak:
 - Capacity was often assumed when the adult refused support.
 - No exploration of executive functioning.
 - Little evidence of best-interests decision-making, even where cognition was in question.

Hospital Discharge Failures

Repeatedly, adults were discharged back to **unsafe homes**, despite:

- Clear evidence of self-neglect.
- Direct disclosures from adults.
- Safeguarding concerns raised by paramedics or Emergency Departments.

Contributing factors included rushed discharge, poor internal communication, and lack of a pathway for unsafe home environments.

5. Missed Opportunities

Across agencies, the review identified:

- **Missed chances to visit the home**, even after known concerns.
- **Inadequate recording** that masked the scale of the issues.
- **Failure to escalate**, seek safeguarding advice or initiate s42 enquiries.
- **No follow up** after non engagement.
- **Lack of oversight** linking concerns across agencies.

The cumulative impact was that deterioration went **unchallenged and unnoticed**, and interventions—when they happened—came too late.

6. Examples of Good Practice

Although limited, there were positive instances:

- Some Primary Care clinicians used **rapport-building** and proactive follow-up.
- Some GP practices adapted their approach (e.g., pre-booked leg ulcer clinics).
- Blue-light services often **recognised risk clearly** and raised safeguarding concerns.

These examples show what *is* possible when professionals are equipped and confident.

7. Recommendations

Improving Recognition and Professional Response

- Strengthen training, case studies, practice learning and “self-neglect champions”.
- Standardise responses to concerns about home conditions, including **mandatory home visits**.
- Improve recording and “red flagging” of self-neglect.
- Tighten ASC screening and decision making, with better follow up for adults who refuse support.

Supporting Trauma-Informed and Relational Practice

- Ensure supervision and training support work with complex behaviours.
- Provide guidance on **preserving trusted relationships** within safeguarding processes.

Using Legislation and Developing Multi-Agency Pathways

- Address myths around consent and safeguarding duties.
- Improve MCA legal literacy, with a focus on executive functioning and best interest decisions.

Develop a multi-agency risk management framework for adults who have capacity but remain at high risk.

- Build a city-wide pathway for responding to self-neglect and hoarding—including deep cleans step down options and psychologically informed support.

“Referrals were rare, late, or interpreted narrowly. Opportunities to intervene were repeatedly missed.”

Sarah Newsam, SAR Independent Author

8. Summary

This SAR highlights that extreme self-neglect is **predictable, identifiable and preventable** when organisations recognise risk earlier, act assertively, and work together. It shows the need for a **cultural shift**:

- from seeing decline as “choice” to understanding it as **distress**.
- from respecting autonomy **alone** to balancing autonomy with **safeguarding duties**.
- from individual practice to **co-ordinated, multi-agency responses**.

The learning is clear: **early recognition, assertive safeguarding, psychologically informed practice, and strong multi-agency systems save lives.**