Cumbria Safeguarding Adults Board

Safeguarding Adults Review

‘Matthew’

Overview Report

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Cumbria Safeguarding Adults Board

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Contents

1. Introduction

The Cumbria Safeguarding Adults Board (CSAB) commissioned this Safeguarding Adults Review (SAR) under Section 44 of the Care Act 2014[1] following the death of Matthew (pseudonym), a 55-year-old man who died in February 2024. The criteria for a statutory SAR were met because:

1. there was reasonable cause for concern about how agencies worked together to safeguard him in the months preceding his death; and
2. Matthew was an adult with care and support needs who appeared to have been at risk of, and to have experienced, neglect, self-neglect, possible undue influence, and significant deterioration in his physical health.

This review seeks to understand how local agencies recognised and responded to escalating risk in the context of Matthew’s chronic health conditions, persistent non-attendance for life-sustaining dialysis, lifelong communication and social-interaction differences, and his profound dependency on his twin brother. It is particularly concerned with the difficult interface between capacity, understanding, executive functioning and influence, and with the ways in which apparent “non-engagement” may signal something more complex than a refusal of help.

In Matthew’s case, practitioners across renal services, primary care, adult social care, policing, emergency services and hospital settings made sustained and thoughtful efforts to engage and support him. Staff at the Furness renal unit built trust over time, recognised subtle changes in his presentation, adjusted their approach to reduce distress, and repeatedly attempted to re-establish contact when he missed dialysis. GPs had known the family for decades and attempted multiple creative approaches to reach both brothers. Adult social care made several safeguarding enquiries and explored financial and environmental concerns. Police officers conducted welfare checks and shared information proactively. It is important to acknowledge the commitment, compassion and persistence demonstrated by these practitioners.

Despite these efforts, Matthew remained exceptionally vulnerable. He and his twin brother had lived for most of their lives in extreme social isolation, in a relationship described by professionals as highly unusual, deeply interdependent, and closed to outsiders. Matthew had a long-standing pattern of avoiding contact with services, difficulty tolerating unfamiliar environments, and intense reliance on his brother for daily routines. He experienced deteriorating physical health, lived in increasingly concerning home conditions, and struggled to sustain the treatment that kept him alive. These factors, combined with fear, dependency and communication barriers, made it difficult for services to see the cumulative nature of his risk.

A significant feature of this case is the hidden nature of Matthew’s world. The dynamics between the brothers were largely inaccessible to professionals, making it challenging to determine whether influence, fear or coercion were affecting his choices. His reluctance or inability to disclose concerns, the absence of social networks, and very limited external indicators meant that agencies operated with partial information throughout. Family members expressed frustration that opportunities for trust-building through face-to-face contact felt limited at times, and perceived that some services relied heavily on telephone contact where in-person engagement may have helped build confidence and understanding. What appeared outwardly as non-attendance or avoidance may, in context, have reflected reduced executive functioning, anxiety, longstanding patterns of withdrawal, or difficulty acting independently of his brother.

[1] Care Act 2014, s.44 (Safeguarding Adults Reviews). Statutory duty/criteria for SABs to commission SARs. Home: legislation.gov.uk. **Care Act 2014**

This review therefore approaches Matthew’s story with sensitivity to the possibility that autonomy and risk may have been more constrained than they appeared.

The review draws on the Early Analysis Report compiled in 2025, supplemented by multi-agency chronologies, information returns, and the reflections of practitioners who participated in the multi-agency learning event. Their contributions were candid, insightful and deeply reflective, and they are integrated throughout this report. Practitioners spoke openly about the relational work involved, the moral complexity of balancing autonomy and protection, and the challenges of managing life-threatening clinical risk in the context of non-engagement and uncertainty.

Finally, this report seeks to acknowledge Matthew as a person. He lived with significant challenges but also with moments of humour, familiarity and connection that practitioners recognised and valued. Staff who worked with him were affected by his death. This SAR aims to honour Matthew by supporting learning that strengthens the safety, dignity and wellbeing of adults with similarly complex lives, and by ensuring that the considerable efforts of practitioners contribute to meaningful and lasting system improvement.

2. About Matthew

Matthew was a 55-year-old man who had lived his entire life in Cumbria. He shared a close, lifelong relationship with his twin brother, with whom he lived and around whom his daily life was organised. From early childhood, the brothers developed a highly interdependent way of living, characterised by shared routines, distinctive communication patterns and a strong preference for one another’s company. While Matthew’s twin attended specialist educational provision during childhood and Matthew attended mainstream schooling, this difference did not materially alter their closeness. Over time, this relational bond became the central organising feature of Matthew’s life and shaped how he related to others, made decisions and engaged with services.

Family members described Matthew as more socially engaged during his early adolescence. He attended school, had friends and appeared less withdrawn until around the age of 14 or 15, when a noticeable change occurred. From this point, Matthew became quieter, increasingly retreated from wider social contact, and turned more exclusively towards his brother for companionship and reassurance. This period coincided with both brothers attending a comprehensive school, where family members recalled experiences of bullying and verbal abuse by peers, which appeared to reinforce Matthew’s withdrawal and reliance on his brother.

Practitioners with longstanding involvement described the brothers’ world as unusually insular. They relied on familiar routines, were anxious about external involvement, and rarely opened their home to visitors. Their daily lives were structured around predictability, mutual reassurance and the comfort of being together. For Matthew, this provided emotional safety and continuity, but it also meant that engagement with professionals was difficult and inconsistent, particularly when he was asked to navigate unfamiliar environments or engage independently of his brother.

Matthew lived with multiple chronic health conditions, including end-stage renal disease requiring regular dialysis. He had a complex relationship with health services: he formed trusting relationships with familiar renal staff and was described as gentle, polite and appreciative when at ease, yet he struggled with changes to routine, new faces or anything that disrupted the predictability he relied upon. His attendance fluctuated considerably, influenced less by cognitive understanding than by emotional factors such as anxiety about leaving his brother, fear of unfamiliar settings, or distress associated with transitions.

Despite his limited world, Matthew did have personal interests. He enjoyed fishing and, at times, travelled independently by bus to pursue this. When dialysis commenced, practitioners noted that Matthew was initially travelling more independently and spending more time outside the home, which appeared to widen his world and increase his confidence.

At home, Matthew lived in conditions that were a longstanding concern for both family members and professionals. The household environment reflected the brothers’ difficulties with maintaining routines of daily living and their avoidance of external help. Despite sporadic efforts from relatives and services, the home remained cluttered, poorly maintained and at times hazardous. Nevertheless, it was familiar and deeply connected to the brothers’ shared identity, and attempts to intervene could be experienced as intrusive or destabilising.

Matthew had a very limited social network beyond his twin. There was no meaningful contact with extended family during the review period, although records indicate that relatives had, at points in the past, attempted to provide support. His emotional world was therefore narrow, with his brother providing companionship, structure and continuity, but also unintentionally shaping and constraining the choices available to him.

Professionals who worked with Matthew over many years consistently noted the small but meaningful signs of trust he showed to those who invested time in building relationships with him. Family members reflected that when Matthew began to engage more independently, this could create tension within the brothers’ relationship, with his growing independence experienced as unsettling and familiar routines re-asserted. This dynamic was not described as coercive, but as part of a longstanding, complex interdependence.

Matthew’s story is one of a man who lived with significant vulnerability alongside deep attachment and loyalty. His life was shaped by patterns of routine, communication and relational dependency that offered comfort and stability but also contributed to risk. This review seeks to honour Matthew by recognising the person he was, the context in which he lived, and the complexity of the challenges faced by those who sought to support him.

3. Methodology

3.1 Purpose and Approach

This Safeguarding Adults Review (SAR) has been undertaken under Section 44 of the Care Act 2014 to identify learning that can strengthen the safeguarding system in Cumbria. The purpose of a SAR is not to reinvestigate events, nor to attribute blame to individual practitioners, but to understand how professional decisions were shaped by organisational conditions, statutory frameworks, resource constraints, and the inherent complexity of human behaviour. Practitioner reflections from the multi-agency learning event have been integrated throughout this methodology, helping to illuminate how decisions made sense at the time and how practitioners understood their roles within organisational constraints.

The aim of this SAR is to explore how organisational context, practice frameworks, professional assumptions and structural limitations influenced the response to Matthew’s circumstances. This review is therefore grounded in a systems methodology[2], recognising that frontline practitioners made decisions under conditions of uncertainty, high demand, limited and sometimes conflicting information, and considerable relational complexity. This approach is consistent with the SCIE SAR Quality Markers (2022) and the national focus on understanding cases through the interaction of structural, procedural and cultural factors.

A systems approach acknowledges that practitioners act on the information available to them at the time, shaped by workload, risk signals, policy clarity, organisational expectations and the adult’s presentation. The review is therefore concerned with why practice occurred as it did, not simply what happened.

The review has been conducted in line with the principles of Making Safeguarding Personal (MSP), recognising the importance of autonomy, dignity and an understanding of lived experience. Ethical considerations included avoiding hindsight bias, ensuring that practitioner accounts were treated respectfully, and focusing on system learning rather than individual attribution of fault. These principles informed the design of the methodology and the interpretation of evidence.

3.2 Evidence base

This SAR draws on a wide range of evidence sources, including:

- The Early Analysis Report (EAR) prepared by the reviewer in 2025, which collated initial chronologies, multi-agency submissions and emerging hypotheses.
- Detailed information returns from:
    - Lancashire Teaching Hospitals and Furness Renal Unit (dialysis attendance, clinical records, safeguarding contacts, Multi-Disciplinary Team (MDT) notes)
    - University Hospitals of Morecambe Bay (Emergency Department (ED)/Acute Medical Unit (AMU) attendances, safeguarding referrals, admission records)
    - Westmorland and Furness Adult Social Care (safeguarding enquiries, triage decisions, strategy/planning meeting notes)

[2] SCIE (2026) Learning Together (systems approach and analytic tools for case reviews). **Learning Together to safeguard adults and children: a multi-agency systems approach - SCIE**

- The multi-agency Practitioner Learning Event, held in late 2025, attended by renal services, ASC, hospital safeguarding teams, the GP, police, and other involved practitioners.
  The practitioner learning event provided rich insight into the frontline realities of working with Matthew, including the high volume of effort invested across agencies, the barriers to gaining consistent access, and the challenges in applying safeguarding pathways where engagement was limited. These reflections were used to contextualise the documentary evidence and to understand not only what happened, but why certain decisions were made.
- Relevant national SARs relating to self-neglect, fluctuating capacity, non-engagement in life-sustaining treatment, influence/undue pressure within family systems, and adults with communication differences.
- Pertinent academic and practice literature, including work on executive functioning, coercion-affected decision-making, treatment non-adherence, and safeguarding adults with chronic medical conditions.

Where possible, evidence was triangulated across agencies; where discrepancies arose, these were explored through the lens of context rather than as factual inconsistencies.

3.3 Scope of the review

The review period spans **February 2023 to February 2024**, covering the months during which concerns escalated regarding missed dialysis sessions, deterioration in Matthew’s health, financial worries, home conditions, and possible undue influence within the household. Earlier history is included selectively where it supports understanding of cumulative vulnerability, particularly:

- Long-standing patterns of non-engagement with statutory services
- Communication and social-interaction differences
- Previous safeguarding attempts
- Capacity assessments and the best-interests decision to commence dialysis in 2020
- Multi-decade GP knowledge of the family.

Family involvement in Matthew’s care during the review period was shaped by the complexity and intensity of the brothers’ circumstances. Contact details were held for a family member, and the Safeguarding Adults Board will continue to offer opportunities for family involvement in the SAR process, in keeping with Making Safeguarding Personal (MSP). During the review, a family member was consulted and was able to offer their perspective on Matthew’s life, relationships and experiences of services. Family members described sustained efforts to support the brothers over time, alongside periods where they needed to step back when the situation became particularly challenging.

3.4 Analytical lens

Understanding Matthew’s circumstances requires a multi-layered analytical lens that brings together the dynamics of twinship, communication differences, executive functioning, long-term self-neglect, and systemic pressures. Practitioners consistently described a pattern of engagement shaped by Matthew’s relationship with his twin brother and by longstanding communication and interaction differences known since childhood.

Twinship, relational dependency and enmeshment

Matthew and his brother grew up as twins with a long history of relying primarily on one another for communication, emotional support and daily functioning. Over time, this developed into a highly interdependent relational system. Staff with long-term involvement noted that the brothers tended to operate as a single unit, preferred each other’s company, and had very limited engagement with others. This is consistent with established research showing that twins frequently form highly exclusive, mutually dependent social systems that reduce engagement with wider networks and influence the development of autonomous decision-making[3][4][5].

Professionals also reflected that the relational dynamic between the brothers could be difficult to interpret. Their behaviour often appeared synchronous and strongly patterned. Academic literature on twins and closely bonded sibling dyads notes that such relationships may become enmeshed over time, with blurred boundaries between individual preferences and shared routines[6][7]. In such contexts, assessing a person’s independent wishes is inherently more complex.

Communication differences and private interaction styles

Practitioners described persistent challenges engaging the brothers in conventional dialogue and interpreting responses. From childhood, both twins were known to have communication and interaction differences. Their adulthood presentation; limited verbal engagement with others, idiosyncratic ways of communicating with each other, and reliance on familiar routines, is consistent with private systems of communication between the brothers, which can unintentionally reinforce social isolation and limit opportunities for external support[8].

Personality disorder, psychotic symptoms and their effect on engagement

Renal clinicians confirmed that Matthew had a history of schizoid personality disorder and schizoaffective disorder, both of which shaped his relational world and capacity to participate in assessment. Schizoid personality disorder is characterised by emotional detachment, restricted affect, a preference for solitary or highly familiar relationships and limited expression of needs[9]. Schizoaffective disorder may involve episodic disturbances in mood and reality-testing, disorganised thought processes and internal preoccupation[10].

[3] Segal, N. L. (2017). Twin Mythconceptions: False Beliefs, Fables, and Facts About Twins. Academic Press.

[4] Neyer, F. J. (2002). Twin relationships in old age: A closer look at monozygotic and dizygotic twins. Journal of Social and Personal Relationships, 19(2), 155–177.

[5] Neyer, F. J., & Lang, F. R. (2003). Blood is thicker than water: Twin relationships across the lifespan. Human Development, 46, 273–290.

[6] Schave, B., & Ciriello, J. (1983). Identity and Intimacy in Twinship. Praeger.

[7] Bakker, P. (1994). Autonomous languages of twins. Acta Geneticae Medicae et Gemellologiae: Twin Research, 43(1), 35–62.

[8] Thorpe, K. (2006). Twin children’s language development. In M. E. Lamb (Ed.), Handbook of Child Psychology (Vol. 2).

[9] Millon, T., Grossman, S., Millon, C., Meagher, S., & Ramnath, R. (2018). Personality Disorders in Modern Life (3rd ed.). Wiley

[10] Oldham, J. M., & Skodol, A. E. (2000). The Personality Disorders. Cambridge University Press.

These diagnostic features help explain several longstanding patterns described by practitioners:

- Minimal interaction with others
- Withdrawal when approached
- Unusual or idiosyncratic communication
- Difficulty sustaining engagement
- Possible internal conversations or preoccupation
- Dependence on predictable routines

Such presentations significantly complicate safeguarding, as they limit opportunities for direct dialogue, reduce help-seeking, and impair professionals’ ability to interpret decision-making, risk perception and executive functioning.

Capacity, consent, executive functioning and influence

Professionals attempted to assess Matthew’s understanding of the risks associated with missing dialysis. Although he could articulate these risks, his attendance patterns suggested that relational, emotional or cognitive factors may have influenced his ability to act on that understanding. Research on twins demonstrates that decision-making can be shaped by relational loyalty, emotional interdependence, or distress associated with separation, rather than cognitive comprehension alone[11]. This makes executive capacity a critical consideration: whether an individual can translate intellectual understanding into autonomous action when embedded in a highly dependent relational system.

Self-neglect, chronic health deterioration and barriers to engagement

Matthew’s pattern of non-attendance, deteriorating physical health and difficulties maintaining a safe home environment were intertwined with this relational context. Practitioners encountered consistent barriers: difficulty accessing the home, challenges separating the brothers for assessment, and limited success in sustaining practical interventions. These features align with broader research on entrenched self-neglect, in which emotional safety, familiar routines and resistance to outside involvement can outweigh serious risks to health and wellbeing[12].

Systemic constraints affecting practice

Across agencies, practitioners encountered structural and procedural challenges, including limited opportunities to engage Matthew independently, uncertainty about action where consent could not be obtained, and gaps in historical records that reduced organisational memory. These systemic constraints shaped professional reasoning and illustrate the interaction between individual, relational and organisational factors in safeguarding.

Practitioners’ accounts consistently highlighted how these relational, communicative and systemic factors shaped both risk perception and intervention. Their insight has been essential in understanding the dynamics of engagement, the perceived limitations of available options, and the emotional impact associated with managing declining health and mounting uncertainty.

[11] Segal, N. L. (2012). Born Together—Reared Apart: The Landmark Minnesota Twin Study. Harvard University Press.

[12] Braye, S., Orr, D., & Preston-Shoot, M. (2015). Self-neglect policy and practice: Building an evidence base for adult safeguarding. Social Care Institute for Excellence (SCIE).

4. Key Practice Episodes (KPEs)

The following Key Practice Episodes (KPEs) set out the most significant points in the timeline of multi-agency involvement with Matthew during the review period. They reflect the moments at which practitioners recognised changes in risk, attempted intervention, or encountered barriers to engagement. The purpose of identifying these episodes is not to retrospectively judge individual actions, but to understand how events appeared to practitioners at the time, what informed their decision-making, and how organisational structures and relational dynamics shaped the options available. These KPEs provide the foundation for the analysis that follows and illustrate the complex interplay between Matthew’s health needs, his relational world, and the system around him.

Table 1 Table of Key Practice Episodes

KPE	Description of the Episode	Why It Was Significant at the Time (Practitioners' Perspective)	System / Practice Issues Emerging
1. Early indications of deterioration and missed dialysis (Spring–Summer 2023)	Increasing pattern of missed or late dialysis sessions. Renal team observed changes in weight, appearance and engagement. Attempts to re-establish contact were inconsistently successful.	Staff recognised heightened clinical risk associated with non-attendance. They were concerned but also aware this pattern occurred periodically and often reflected anxiety, routine disruption or reluctance to leave his brother.	Difficulty sustaining engagement; limited ability to complete capacity-informed intervention; no clear escalation pathway when consent and access were absent; reliance on relational continuity.
2. Escalating concerns about home environment and daily living (Summer–Autumn 2023)	Reports indicated worsening living conditions, sanitation issues, clutter and poor nutritional intake. Historically intermittent attempts to improve conditions had not been sustained.	Practitioners saw deterioration as part of a long-term pattern but were increasingly worried about risk of infection and the impact on dialysis adherence.	Barriers to home access; absence of reliable third-party information; limited levers where adults refuse entry; challenge applying self-neglect pathways without engagement.
3. Attempts by renal services to stabilise attendance (Autumn 2023)	Renal unit increased contact attempts, used familiar staff, adapted communication, and explored transport solutions. Some temporary improvements were achieved.	Staff believed relational consistency would improve attendance, as previously. They perceived his presentation as fluctuating but workable with continued rapport building.	Heavy reliance on informal relational strategies; limited multi-agency escalation beyond internal communication; unclear thresholds for triggering safeguarding.
4. Safeguarding referrals and early multi-agency discussion (Autumn–early Winter 2023)	Rising concern triggered several safeguarding contacts about missed treatment, home conditions, and possible influence within the household.	Practitioners hoped safeguarding involvement would facilitate joint visits, mental capacity review, and environmental assessment but struggled with lack of access and no response at the door.	System loop between police, ASC and health when adults do not answer; limited tools without consent; inconsistent understanding of how to manage life-sustaining treatment refusal.

KPE	Description of the Episode	Why It Was Significant at the Time (Practitioners’ Perspective)	System / Practice Issues Emerging
5. Increasing missed dialysis and clinical instability (December 2023–January 2024)	Attendance became more erratic. Physical health deteriorated more rapidly. Attempts to engage at home remained largely unsuccessful.	Frontline practitioners felt a growing sense of urgency. They believed Matthew understood the risks but was unable to act independently, often appearing distressed or reluctant to separate from his brother.	Executive-functioning barrier not well captured in existing capacity frameworks; uncertainty about when to use Mental Health Act or inherent jurisdiction; lack of formalised multidisciplinary risk plan.
6. Final weeks: acute deterioration and loss of contact (Late January–early February 2024)	A cluster of missed treatments prompted repeated welfare checks, but access was not gained. When hospital admission finally occurred, Matthew was critically unwell and died soon after.	Practitioners experienced significant emotional impact. Many expressed that their options felt exhausted and that systemic constraints prevented more assertive intervention.	Lack of mechanism to override barriers to access in cases of life-sustaining treatment; limited pathways when adults decline both assessment and care; no shared high-risk health–safeguarding protocol.

5. Findings

Finding 1: Matthew’s diagnosed mental health conditions significantly influenced his communication, engagement and decision-making

Renal clinicians confirmed that Matthew had a documented history of schizoid personality disorder and schizoaffective disorder, diagnoses known to affect emotional expression, social connectedness, reality-testing and capacity to sustain engagement with services. Practitioners across agencies described longstanding patterns of social withdrawal, flat affect, private interactional routines and highly restricted communication. These traits aligned with clinical expectations of schizoid personality patterns (detachment, reduced affect, preference for limited interpersonal contact) and with aspects of schizoaffective disorder that may include internal preoccupation, disorganisation or fixed beliefs.

These diagnostic features significantly shaped Matthew’s presentation: he interacted minimally, communicated little about his needs or feelings, and struggled with environments or people outside his immediate relational framework. Practitioners’ ability to assess his wishes, understanding of risk or executive functioning was therefore inherently constrained.

Practitioners also reflected that opportunities for preventative medical intervention existed earlier in Matthew’s life, including treatment that may have reduced or delayed the need for dialysis. These opportunities pre-dated the review period and sit outside the scope of this SAR. However, the reflection reinforces a central learning of the review: that long-standing patterns of disengagement significantly constrained preventative as well as crisis responses, and that earlier clinical opportunities were similarly shaped by Matthew’s difficulty sustaining engagement with services.

System impact:

Existing cross-system professional intervention pathways, including multi-agency safeguarding arrangements, were not well suited to a situation characterised by limited engagement, restricted access, and escalating clinical risk.

Finding 2: Matthew’s lifelong relational dependency with his twin created a closed relational system that reduced autonomy and complicated safeguarding

From childhood onward, Matthew and his brother functioned as an unusually interdependent unit, with shared routines, idiosyncratic communication and limited engagement outside their dyad. Practitioners described the brothers’ relationship as unlike any other they had encountered, with elements of enmeshment, mutual reinforcement and shared belief systems. Research shows that twins and closely bonded sibling dyads may develop highly exclusive relational systems, sometimes including private languages and a reduced capacity for independent functioning.

The twin relationship appeared to provide Matthew with emotional safety but also created barriers to external support. His willingness to leave the home, attend dialysis or engage independently was strongly influenced by his brother’s presence, routines or preferences. Practitioners found it extremely difficult to assess Matthew alone, limiting the system’s ability to understand his own perspective or identify potential influence. Practitioners emphasised that this was not a situation of partial engagement but one of sustained lack of access, with repeated unsuccessful attempts to see Matthew independently or assess the home environment.

System impact:

While the Mental Capacity Act 2005 provides a robust framework for supporting decision-making, including where individuals require assistance to engage, the practical application of safeguarding and health pathways still relies heavily on an adult being accessible, communicative, and able to participate in assessment processes. In Matthew’s case, relational dependency and communication barriers significantly constrained how these frameworks could be operationalised.

Finding 3: Escalating risk associated with missed life-sustaining treatment was recognised by practitioners, but systems lacked a shared escalation pathway

Renal teams repeatedly identified the severe risks associated with Matthew’s missed dialysis sessions and invested significant effort in re-engaging him. However, the system lacked a coordinated protocol for managing repeated non-attendance where the consequences were life-threatening. National SARs have highlighted similar gaps where a person appears to understand the clinical risk but is unable to act on that understanding due to cognitive, psychological or relational barriers[13]. Policy guidance emphasises the need for multi-agency escalation frameworks in cases where non-engagement with essential healthcare is likely to cause death or serious deterioration[14].

In Matthew’s case, individual services escalated concerns internally, but there was no single multi-agency risk forum or high-risk pathway designed for life-sustaining treatment. This meant risk was sometimes held in parallel rather than synthesised across agencies.

System impact:

A coordinated, multi-agency high-risk health/safeguarding pathway was not triggered, limiting opportunities for assertive intervention.

Finding 4: Chronic self-neglect, hazardous home conditions and deterioration in daily living were known but remained insufficiently addressed due to lack of access and limited legal levers

Concerns about the home environment had been present for many years. The household reflected a pattern of entrenched self-neglect, characterised by emotional dependence on routine, avoidance of external involvement and difficulty sustaining behavioural change. National evidence identifies that individuals who self-neglect often prioritise emotional or psychological safety over physical wellbeing, and may resist intervention even when risk is severe[15].

Comparable SARs consistently show that “no access” and “refusal of assessment” can create systemic paralysis in self-neglect cases, preventing professionals from determining risk or applying supportive interventions[16] [17].

[13] West Sussex SAB (2021). SAR Mr B — non-attendance for dialysis and executive functioning barriers.

[14] ADASS (2019). Self-Neglect and Multiple Exclusion: Practitioner Guidance.

[15] Braye, S., Orr, D., & Preston-Shoot, M. (2015). Self-Neglect Policy and Practice: Building an Evidence Base. SCIE.

[16] Norfolk SAB (2018). SAR “Jo” — no-access and under-recognition of risk.

[17] Haringey SAB (2020). SAR Ms X — non-engagement and environmental risk.

This pattern is consistent with findings from Cumbria Safeguarding Adults Board’s recently published thematic Safeguarding Adults Review on self-neglect[18], which identified persistent no-access and refusal of assessment as critical points at which safeguarding systems can stall, risk becomes normalised, and responsibility fragments across agencies.
The thematic review highlights the importance of recognising no-access itself as a safeguarding signal requiring collective oversight, rather than repeated single-agency responses. This pattern occurred repeatedly in Matthew’s case: practitioners could not gain access to the home, safeguarding enquiries could not progress, and the absence of consent limited statutory options.

System impact:

Existing legal mechanisms and procedural pathways were insufficient to resolve persistent non-engagement in a context of life-threatening risk.

Finding 5: Structural constraints limited the effectiveness of safeguarding responses despite strong professional commitment

Across all agencies, practitioners demonstrated persistence, compassion and concern for Matthew. Despite this, their efforts were constrained by systemic limitations, including:

- Difficulty conducting assessments due to communication, relational and mental health factors
- Reliance on consent-based safeguarding pathways where consent was rarely given
- Limited mechanisms to override barriers to access
- Unclear thresholds for capacity reassessment in the context of personality disorder and fluctuating mental state
- Absence of a shared high-risk protocol
- Incomplete historical records reducing organisational memory

National analyses of Safeguarding Adults Reviews identify these same structural barriers as recurring themes in cases involving self-neglect, personality disorder, complex relational systems and non-engagement[19] [20].

System impact:

The pattern of risk in this case reflects system limitations rather than individual practitioner action.

[18] Cumbria Safeguarding Adults Board. Thematic Safeguarding Adults Review: Self-Neglect. The thematic review identified persistent no-access and refusal of assessment as critical points at which safeguarding systems can stall, risk may normalise over time, and responsibility can fragment across agencies, highlighting the need for collective oversight rather than repeated single-agency responses.

[19] Preston-Shoot, M. (2020). National SAR Analysis 2017–2019.

[20] SCIE (2021). Understanding Themes in Safeguarding Adults Reviews.

6. Recommendations

Before setting out the recommendations, it is important to recognise that this case involved a series of dilemmas well documented in national policy, case law and Safeguarding Adults Reviews. Professionals were operating within a tightly constrained legal landscape shaped by the Mental Capacity Act 2005 (MCA), the Mental Health Act 1983 (MHA)[21], the limits of the High Court’s inherent jurisdiction, and the statutory principles governing adult safeguarding. These frameworks, while essential for protecting autonomy, can significantly restrict professional action where risk is escalating but the adult is assessed as having capacity, declines support, and presents with entrenched patterns of non-engagement[22] [23].

Matthew had been assessed repeatedly by renal clinicians as having capacity to make decisions about dialysis, and the MCA requires practitioners to respect capacitous refusals, even when those refusals carry a risk of serious harm or death[24]. An earlier period in Matthew’s life involved legally compelled dialysis, but once he was later assessed as having capacity, the legal authority to compel treatment ceased. Case law confirms that capacitous adults may refuse life-sustaining treatment, and neither anxiety, ambivalence, impaired motivation, relational dependency nor personality disorder automatically negate capacity if the person can understand, retain, use and weigh relevant information[25].

Similarly, the Mental Health Act provides no straightforward route for intervening in such circumstances. Although Matthew had diagnosed schizoid personality disorder and schizoaffective disorder, detention under the MHA requires evidence of mental disorder and that detention is necessary for assessment or treatment of that disorder, not for compelling treatment for a physical illness. The MHA cannot be used to enforce dialysis[26]. Inherent jurisdiction also offers limited scope: it is designed for situations involving coercion, undue influence or circumstances that critically compromise free decision-making. The relationship between Matthew and his brother was highly interdependent and unusual, but there was no evidence of coercion in the legal sense.

These constraints do not imply that professionals missed opportunities or failed to act. On the contrary, they highlight a known structural reality in safeguarding: some adults experience life-threatening risk within a legal and ethical space where compulsion is neither available nor justified, even when practitioners recognise severe deterioration[27]. In Matthew’s case, staff across health, adult social care, mental health and police services demonstrated persistence, compassion and professional skill. What was limited was the system’s ability to intervene lawfully against a capacitous refusal, not practitioners’ willingness or competence.

The opportunities for improvement therefore lie not in compulsion, but in multi-agency visibility, shared formulation and clear legal guidance. Earlier coordinated escalation may have brought different fragments of risk together sooner; mental health involvement, even when compulsory powers were not indicated, could have provided valuable formulation, engagement strategies and

[21] The Mental Health Act 1983 is referenced here for completeness, reflecting practitioner consideration of available statutory frameworks, rather than as a route that was clinically or legally indicated in Matthew’s case.

[22] Department of Health & Social Care. (2022). Making Decisions: A Guide for People Who Work with Adults Who May Lack Capacity.

[23] Cooper, A., & Preston-Shoot, M. (2021). Adult Safeguarding and the Law. Jessica Kingsley Publishers.

[24] Mental Capacity Act 2005, s.1–s.4

[25] Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67. LBX v K, L and M [2013] EWHC 3230 (Fam); CC v KK & STCC [2012] EWHC 2136 (COP).

insight into executive functioning; and earlier legal consultation could have clarified the narrow range of options more decisively, reducing drift and supporting practitioners navigating ethically challenging circumstances.

These recommendations therefore do not propose routes that the law does not permit, nor do they suggest that the outcome was preventable through statutory intervention. Instead, they focus on strengthening system-wide mechanisms for responding when adults with complex mental health presentations, relational dependency and entrenched self-neglect decline life-sustaining treatment despite having capacity. They aim to ensure that practitioners in similar future cases are supported by clear structures, shared understanding and coordinated decision-making.

In setting out these recommendations, the review recognises that this was not a case in which practitioners failed to act. Rather, it was one in which the limits of statutory frameworks, legal thresholds and the scope of available powers created an unusually narrow space for intervention. The purpose of the recommendations is therefore not to propose routes that the law does not permit, nor to suggest that compulsion would have been justified or effective, but to strengthen the system’s ability to respond when adults with complex mental health presentations, relational dependency and entrenched non-engagement decline life-sustaining treatment despite having capacity.

Recommendation 1: High-risk non-engagement with life-sustaining treatment

The Safeguarding Adults Board should assure itself that existing multi-agency risk and escalation arrangements, including Multi-Disciplinary Team (MDT) forums, high-risk meetings and risk enablement processes, can be confidently and flexibly used where an adult with capacity persistently disengages from life-sustaining treatment and risk is escalating. This recommendation builds on existing escalation and multi-agency arrangements, including the Cumbria Safeguarding Adults Board’s Escalation and Resolution Guidance and its ongoing development of practitioner MDT guidance[28].

This should include clear shared understanding that practitioners have the authority to convene multi-agency discussions outside standard templates where circumstances are exceptional, access is persistently limited, and risk is identified through repeated indicators, patterns of deterioration, and converging professional concerns over time.

The focus should be on bringing together health, adult social care, mental health, primary care and police perspectives early enough to support collective formulation, creative problem-solving and relationship-based approaches, rather than reliance on linear pathways or single-agency escalation.

To support consistent embedding in practice, the Safeguarding Adults Board should seek assurance that cases involving persistent non-engagement with life-sustaining treatment, repeated no-access, or converging indicators of escalating risk are explicitly recognised as appropriate for consideration within existing MDT and high-risk forums.

This should include clarity about how such cases are identified, recorded and reviewed within current arrangements, and how learning from these discussions is shared, so that reliance on individual discretion or informal escalation is reduced.

[28] Cumbria Safeguarding Adults Board. (2024). Escalation and Resolution Guidance and MDT practice development. Cumbria Safeguarding Adults Board.

Recommendation 2: Mental health formulation and advisory support

The Safeguarding Adults Board should assure itself that mental health services are routinely able to contribute advisory input and formulation in complex cases where adults with diagnosed mental health conditions, personality disorder, communication differences or executive functioning difficulties are declining essential medical treatment.

This contribution should not be limited to consideration of compulsory powers, but should include advice on engagement strategies, relational dynamics, psychological barriers to treatment adherence, and how mental health presentations may affect an adult’s ability to act on understood risk.

Such input should be accessible through existing Multi-Disciplinary Team (MDT) and multi-agency discussion forums, supporting other services to respond in psychologically informed ways even where the adult is assessed as having capacity and statutory thresholds for compulsion are not met.

Recommendation 3: Legal advice embedded in multi-agency practice

The Safeguarding Adults Board should ensure that existing Multi-Disciplinary Team (MDT) and escalation guidance explicitly supports practitioners to seek timely legal advice in cases where an adult with capacity is refusing life-sustaining treatment and risk remains extreme.

This should include clear expectations that each agency is responsible for accessing its own legal advice, and that legal input is used to clarify the lawful options and limits under the Mental Capacity Act, Mental Health Act and inherent jurisdiction, rather than to extend compulsion where legal thresholds are not met.

The Board should seek assurance that practitioners across agencies are confident about when and how to access legal advice, and that learning from such cases is shared through existing governance, guidance and professional development activity.

Recommendation 4: Strengthening guidance on executive functioning, relational dependency and family dynamics

The Safeguarding Adults Board should strengthen existing practice guidance to support practitioners in recognising and responding to cases where an adult’s ability to act on understood risk is constrained by executive functioning difficulties, relational dependency, communication barriers, or closed family or sibling systems.

This guidance should assist practitioners to identify when such factors warrant enhanced scrutiny, multi-agency discussion or specialist consultation, even where the adult is assessed as having capacity. It should support professionals to analyse relational dynamics, including co-dependency and shared vulnerability within family or sibling relationships, and to consider how these dynamics may shape engagement, decision-making and help-seeking behaviour over time.

This work should build on learning from existing Cumbria Safeguarding Adults Reviews, including the Robyn SAR[29], which demonstrated the value of moving beyond binary assessments of coercion to a more nuanced understanding of relational constraint, and of translating complex safeguarding learning into practical prompts, briefings and reflective tools that support professional judgement. Dissemination should take place through guidance updates, practice briefings and

[29] Cumbria Safeguarding Adults Board. (Year). Safeguarding Adults Review: Robyn. Cumbria SAB.

learning sessions, rather than through the creation of new procedural frameworks. This approach aligns with Cumbria SAB’s current efforts to develop MDT practice guidance and routine learning events for practitioners.

Recommendation 5: Entrenched self-neglect and persistent no-access

The Safeguarding Adults Board should continue to support and seek assurance on current work to strengthen multi-agency responses to entrenched self-neglect and situations of persistent no-access, recognising that sustained inability to see or engage an adult can significantly constrain assessment and safeguarding action even as risk escalates.

This should include assurance that existing mechanisms; including self-neglect strategies, Risk Enablement Panels and Multi-Disciplinary Team (MDT) discussions, are used to coordinate joint planning, share information and review cumulative risk where adults cannot be meaningfully seen or assessed over time.

Consistent with learning from Cumbria’s thematic self-neglect Safeguarding Adults Review, persistent no-access and repeated failed attempts to engage should be recognised as active safeguarding concerns requiring collective oversight and review, rather than allowing risk to fragment across services or normalise through repetition. This recommendation recognises that relevant work is already underway locally and focuses on consistent application and impact.

Recommendation 6: Flexibility and partnership problem-solving in exceptional cases

The Safeguarding Adults Board should promote and expect active, relationship-based partnership working in cases that sit outside standard safeguarding templates or pathways, particularly where risk is longstanding, engagement is limited, and outcomes are deteriorating.

While Cumbria has established mechanisms to support multi-agency working, including escalation pathways and Risk Enablement Panels, this case highlights that these mechanisms alone are not sufficient if they are not accompanied by timely, collective problem-solving. Practitioners and agencies should feel both supported and expected to bring partners together proactively, to share concerns, challenge assumptions and jointly explore options where usual approaches are not leading to change.

This includes recognising when exceptional circumstances require professionals to move beyond linear processes and single-agency ownership, and instead sit together to think differently about how help and support might be offered, how engagement barriers might be addressed, and how risk can be held collectively rather than in parallel. This learning reflects feedback from practitioners and family members about the need for earlier, more coordinated system responses in complex cases.

Recommendation 7: Embedding learning through practitioner development

The Safeguarding Adults Board should ensure that learning from this Safeguarding Adults Review is embedded through existing practitioner development activity, such as lunch-and-learn sessions, briefings or facilitated learning events, rather than necessarily through the creation of additional frameworks or structures.

This learning should focus on supporting practitioners to navigate the complex interface between mental health, safeguarding and autonomy, particularly where adults are assessed as having capacity but continue to make decisions that place them at extreme risk. It should include

reflection on executive functioning, relational dependency, engagement barriers, and the limits of statutory intervention.

Consideration should be given to involving mental health expertise in the delivery of this learning, to support psychologically informed practice, ethical decision-making, and practitioner confidence when working in cases where lawful options are constrained and outcomes may remain uncertain.

Table 2 Table of Recommendations at a glance

No.	Theme	Recommendation summary
1	High-risk non-engagement	Assure that existing **Multi-Disciplinary Team (MDT) forums, high-risk meetings and risk enablement processes** are used flexibly and confidently in cases of persistent non-engagement with life-sustaining treatment, repeated no-access, and converging indicators of escalating risk, with clear expectations about identification, recording and review.
2	Mental health advisory input	Ensure **mental health services provide early advisory and formulation support** in complex cases, including guidance on engagement, relational dynamics and executive functioning, even where Mental Health Act thresholds are not met and the adult is assessed as having capacity.
3	Legal advice and practitioner confidence	Embed expectations within **MDT and escalation guidance** that agencies seek **timely, agency-specific legal advice** in cases involving refusal of life-sustaining treatment, and provide Board assurance that practitioners are confident in understanding lawful options and limits.
4	Executive functioning and relational dependency	Strengthen existing guidance to support practitioners to recognise and respond to **executive functioning difficulties, relational dependency and closed family or sibling systems,** drawing explicitly on learning from Cumbria SARs (including the **Robyn SAR**) and disseminating this through practical briefings and reflective tools.
5	Entrenched self-neglect and no-access	Continue to support and assure current work on **entrenched self-neglect and persistent no-access**, ensuring sustained lack of access is recognised as an **active safeguarding concern** requiring collective multi-agency oversight rather than repeated single-agency responses.
6	Flexible partnership problem-solving	Promote and expect **active, relationship-based partnership working** in exceptional cases where standard pathways are insufficient, supporting practitioners to come together proactively, challenge assumptions and engage in collective problem-solving when risk is complex and longstanding.
7	System learning and practitioner development	Embed learning from this review through **existing practitioner development activity** (e.g. lunch-and-learn sessions and facilitated learning), focusing on the mental health–safeguarding interface, autonomy, executive functioning, relational dependency and ethical decision-making where lawful options are constrained.

7. Conclusion

Matthew’s death occurred in the context of long-standing health needs, enduring communication and interaction differences, diagnosed personality and mental health conditions, and a deeply enmeshed relational world that shaped every aspect of his engagement with services. His circumstances were marked by complexity rather than neglect, and by longstanding patterns of behaviour that were exceptionally difficult for professionals to influence, even when risk became acute.

Throughout the review period; and indeed across many years, there was consistent evidence of compassionate, persistent and thoughtful practice. Practitioners across agencies described using flexible, creative and relational approaches to engagement, including adapting communication styles, maintaining continuity of staff, varying contact methods, and persisting with outreach despite repeated barriers. These efforts reflect high levels of professional curiosity and commitment, even where outcomes remained constrained by structural and legal limits. Renal clinicians, GP staff, adult social care practitioners, mental health professionals, police and community responders all invested sustained effort in trying to engage Matthew, monitor deterioration, and support his attendance for life-sustaining treatment. Practitioners spoke with depth, honesty and reflection about their work with Matthew, and it is clear that many held a genuine commitment to his wellbeing. The GP practice, in particular, demonstrated remarkable continuity and understanding of the twins’ lifelong presentation, and the renal team showed considerable persistence, adapting approaches repeatedly in the face of non-attendance. Frontline staff across all agencies worked with professional curiosity, empathy and respect.

Despite this, the system as a whole faced significant structural limitations. The combination of a capacitous adult declining essential medical treatment, long-standing mental health diagnoses, entrenched patterns of self-neglect, relational dependency, and persistent non-engagement created a situation in which the statutory frameworks available to practitioners offered very few lawful routes for intervention. These constraints did not arise from practitioner inaction but from the boundaries of the Mental Capacity Act, Mental Health Act and inherent jurisdiction, and from the inherent difficulty of safeguarding someone who has capacity but cannot be persuaded to accept treatment.

This review has therefore focused not on individual practice, but on the system conditions that shaped what was possible. It acknowledges the professionalism, persistence and humanity shown by those who worked with Matthew, and recognises the emotional and ethical challenges involved in supporting someone whose autonomy ultimately resulted in life-threatening harm. The aim of the recommendations is to strengthen structures around future cases of similar complexity; promoting earlier multi-agency visibility, stronger formulation, clearer legal guidance, and better support for practitioners, while respecting the fundamental legal and ethical limits on overriding capacitous refusal.

Matthew’s life and death highlight the profound challenges that arise when autonomy, vulnerability, mental disorder, relational dependency and serious medical risk converge. This review seeks to honour him by supporting learning that improves the system’s ability to respond to adults whose lives sit within this difficult and often uncomfortable space, and by recognising the considerable efforts of those who tried, with care and persistence, to keep him safe.

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