CONFIDENTIAL

Smith & Smith
Associates Ltd.

Together | Safeguarding Partnership

MK Together Partnership

Safeguarding Adults Review

Adult 'E'

Authors: **Eliot Smith, Independent Health & Social Care Consultant**
Smith & Smith Associates Ltd.
Date: **16/09/2022**

CONTENTS

INTRODUCTION

"Local Safeguarding Adults Boards must arrange a Safeguarding Adults Review when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is a concern that partner agencies could have worked more effectively to protect the adult" (Department of Health, 2017).

In 2021 the MK Together Safeguarding Partnership considered the case of Adult E who died in hospital on 30 July 2020. In August 2020 her case was referred to the MK Together Partnership for consideration of a Safeguarding Adult Review under the category of suspected self-neglect. In line with local policy and procedure a rapid review was completed which identified learning, in particular for health organisations.

The purpose of a Safeguarding Adult Review (SAR) is to determine what the relevant agencies and individuals involved in this case might have done differently that could have prevented Adult E's death. This is so that lessons can be learned from the case and those lessons applied in practice to prevent similar harm occurring again.

Background to the case

Adult E died in hospital at the age of 57-years-old. Adult E had a significant medical history which included historical and recent conditions, including ischemic heart disease, chronic obstructive pulmonary disease, chronic fatigue syndrome, dropped head syndrome, and partial paralysis following surgery. In March 2019 surgical options were considered to address the head drop, which was having a debilitating effect on Adult E's quality of life; she was experiencing significant difficulties in breathing and swallowing, she was of low weight, fatigued and in pain. It was known that the surgery would be high risk, but it was felt by Adult E and her mother that risks were worth taking. Following her operation, Adult E was in hospital from 13 August 2019 to 29 August 2019 and 3 September 2019 to 21 October 2019 following a fall as a result of loss of motor power to her lower limbs due to a fracture which was pressing down on her spinal cord. Following further emergency surgery to stabilise her spine Adult E suffered partial paralysis and lost her ability to mobilise independently. During her admissions Adult E often declined bed rest and, against medical advice, would sit in her wheelchair or leave the ward area. Previous redness on her sacrum developed into pressure ulcers which progressively worsened. Adult E was ultimately discharged from hospital to her own home, with five visits per day by two carers, funded through Continuing Healthcare, and the visiting support of her mother. In the community, Adult E was also visited by District Nurses and Tissue Viability Nurses.

Adult E had further admissions to hospital for treatment of infections (November 2019), for severe respiratory failure. Adult E's prognosis at this point was poor and discussions were held about the prospect of imminent death. Adult E received palliative care and medication treatment to maintain her comfort. Discussions with Adult E and her family members revealed disagreements about discharge destination - to home, or to a nursing home. Following assessments of mental capacity and concerns about risk, Adult E was admitted to a Nursing Home. Within days Adult E and her family wanted her to be discharged home, and she returned to her home on 11 March 2020 with funding for her package of care, with her mother's help, and with District Nursing support.

Adult E was a bright woman who knew her own mind. Adult E had a difficult time adjusting to life following her paralysis. Adult E and her mother held on to the belief that Adult E would recover and eventually be able to walk again, despite advice to the contrary. As time went on Adult E became more frustrated and had stated that she often cried herself to sleep, and that being in bed was emotionally the worst place for her. Over the next four months Adult E continued to make her own decisions about bed rest and concordance with care. During this time safeguarding referrals were made, and professionals meetings convened in relation to risks of self-neglect and professional concerns about her pressure areas and associated risks.

Adult E remained at home until 29 July 2020 when she was admitted to hospital having been found unresponsive by carers. Adult E's condition did not improve with treatment, and Adult E died peacefully on 30 July 2020.

Methodology

The review methodology draws on systems learning theory to evaluate and analyse information and evidence gathered from available data and documentary records, practitioners and decision-makers in agencies and teams, national research, and the offer of involvement to Adult E's family.

In line with statutory guidance, professionals within local agencies were given the opportunity to be "involved in the review and invited to contribute their perspectives without fear of being blamed for actions they took in good faith." The approach to practitioner involvement was to hold a collaborative learning workshop to make the most from the expertise of practitioners to understand the safeguarding system in which they operate and to identify the learning from Adult E's case. The scope of this review covered the period from 1 March 2019 to 30 July 2020.

About the Reviewer

This Safeguarding Adults Review has been led by Eliot Smith, an Independent Health and Social Care Consultant who has no previous involvement with this case, or prior connection to the MK Together Safeguarding Partnership, or partner agencies.

Agency involvement

The following agencies were invited to contribute to the review:

Buckinghamshire Healthcare Trust, Stoke Mandeville Hospital
Milton Keynes Clinical Commissioning Group (now BLMK ICB)
Central & NW London NHS Trust, Milton Keynes Community Health Services
Milton Keynes University Hospitals NHS Foundation Trust
Oxford University Hospitals NHS Foundation Trust - John Radcliffe Hospital
Milton Keynes Council
GP
Nursing Home
Wheelchair Service

Family involvement

Adult E was very close to her family who were involved with her in decisions made about her care, and who offered her support while she was living at home. The MK Together Safeguarding Partnership wrote to Adult E's family and invited them to participate in the review. The family did not respond during the review, however, prior to publication of the report, Adult E's mother and brother contacted the MKT team and took the opportunity to read through the report and share their personal reflections and memories of Adult E.

Principles

Safeguarding Adults Reviews must adhere to the six safeguarding principles outlined in Care and Support Guidance (Department of Health, 2020); these are Empowerment, Prevention, Proportionality, Protection, Partnership and Accountability. In addition to these, this Safeguarding Adults Review was conducted in line with the following principles:

- Culture of continuous learning – incidents can provide the opportunity to learn and improve
- Proportionality
- Independence and independent challenge
- Meaningful involvement of practitioners without fear of blame for actions taken in good faith
- Involvement of family members and individuals affected by circumstances of the case
- Awareness of risks of hindsight bias and outcome bias
- Focus on system and teams functioning
- Not a re-investigation of incidents or performance

Terms of Reference

The Terms of Reference for this Review were drafted in consultation with the MK Together Safeguarding Partnership and are based upon the findings of the Rapid Review completed by the Partnership in September 2020.

1. Inter-agency collaboration: How well did agencies work together to coordinate the provision of care and support?
2. Safeguarding: How effective was safeguarding practice in Adult E's case? Does Adult E's case provide learning about how referrals were made and acted upon?
3. Person-centred care and support planning: How were Adult E's views and wishes taken into account in the arrangements for her care?
4. Assessment and care planning: Was the assessment of Adult E's needs holistic? How well did her care arrangements reflect her physical and psychological needs?
5. Family relationships and care in partnership: How effectively did agencies work with Adult E's family and informal care network?

NARRATIVE SUMMARY OF PRACTICE

The time period under review covers the six-months leading to Adult E's unsuccessful surgery in August 2019 until the date of her death on 30 July 2020.

At the beginning of the review period, Adult E was already experiencing significant spinal difficulties, trapped nerve and difficulties in maintaining her posture and mechanical head drop. Surgical options had been discussed regularly since May 2018, and Adult E had been put on a waiting list. By March 2019, Adult E's case had become an emergency and she was referred for anaesthetics and pre-operative assessments. It was clear that the surgical staff believed the surgery to be high risk in the context of her comorbidities, and that proceeding with an operation to correct her head drop was a balanced decision. Adult E's case was discussed in the spinal multi-disciplinary team and there is evidence that staff were considering how to maximise the chance of a successful outcome – taking into account her home situation, care needs and underlying health condition. A Percutaneous Endoscopic Gastrostomy (PEG) was put in place to optimise her diet and nutrition and weight and Adult E was seen by Occupational Therapy and Physiotherapy.

Documentation at this time records the various risks associated with the surgery, possible complications, and the balanced nature of the procedure. Adult E and her mother were included in decisions and valid consent was obtained – Adult E was given all the information she needed, time to process it, and professionals made sure she was confident in her decision to consent which was given freely. In the lead up to the procedure, Adult E was contacted by different health agencies, each of whom had a part to play. There is evidence of good communication between the different NHS Trusts involved.

Adult E's procedure took place on 13 August 2019 and on 29 August Adult E was discharged home, fully mobile and walking with a stick, and with no complications. A few days later Adult E was admitted to hospital after her legs gave way and she lost power and sensation to her lower limbs. Adult E's admission had been initially through the Milton Keynes Hospital, then to the Neuroscience wing at John Radcliffe Hospital in Oxford for further surgery and a return to Milton Keynes Hospital to await a bed at the spinal cord injury centre at Stoke Mandeville Hospital in Aylesbury for rehabilitation.

It is perhaps at this point that the expectations and narratives of Adult E and her mother, and healthcare professionals diverge. Adult E, and her mother were at times frustrated at her loss of independence but convinced that things could start to improve at any moment, and that with the right help and support, and with Adult E's strength of will, she would be able to recover her mobility. Adult E and her mother placed a great deal of hope in the National Spinal Injury Unit (NSIU) at Stoke Mandeville Hospital and appeared to feel that Adult E's lack of progress was an indication of a lack of the correct support. Throughout these admissions Adult E continued to be active, spending a lot of time outside of her room, or off the ward in her wheelchair.

Healthcare professionals found that they had a good level of personal engagement with Adult E, but that she struggled to accept advice in relation to her care and treatment. Professionals were concerned that Adult E did not accept the reality of her situation or prognosis. While Adult E and her mother put their energies into the hope of recovery and rehabilitation, professionals attempted to explain that the prognosis was that Adult E would not walk again, and that clinical management should instead focus on maintaining her skin integrity and supporting the healing of pressure wounds made worse by the lack of bed rest and non-concordance with advice. At various times Adult E's mental capacity had been assessed, and on each occasion, she was found to be competent to make decisions about her care. Adult E's apparent inability to accept advice and her non-concordance with treatment did not appear to be an issue of mental impairment, rather one of acceptance.

On 21 October 2019 Adult E returned home with a package of care funded under Continuing Healthcare (CHC). The package of care was for five home visits daily. The divergence of views and perspectives on Adult E's condition, prognosis, and treatment priorities continued after her discharge home. Between October and December 2019 Adult E lived at home, supported by her mother, the District Nursing service, and her five-times-per-day package of care. Adult E continued to want to live her life and would often cancel appointments or would not be at home.

On 25 December 2019 Adult E suffered respiratory failure and was admitted to hospital with a poor chance of survival – Adult E and her family were informed that she may not survive the admission. At this point Adult E's views remain consistent and as her condition stabilises and improves, she is keen to return home. Adult E's wishes, however, are in conflict with the assessments by the treating team of safe discharge arrangements, and of family views. Adult E's mother and brother are worried for her welfare, and worried that she may be found dead at her home if discharged. At the point of discharge Adult E is assessed to lack mental capacity in relation to safe discharge decisions. A reassessment of mental capacity was reasonable in the context of respiratory failure and possible further hypoxic brain injury. In the context of such dissonance between Adult E's views and those of her family, and in the context of a long-term accommodation decision, it may have been appropriate to instruct an Independent Mental Capacity Advocate[1] to ensure that Adult E's views were influential in the decision-making process.

By February 2020 Adult E was deemed to have improved and was no longer considered end of life. She was also deemed to have mental capacity to make decisions about residence and remained "desperate to go home". Due to her pressure areas and need for care and two-hourly repositioning the prevailing view of professionals remained that returning home was not a safe option. Adult E resided at the nursing home until 11 March 2020 when she returned home with a re-instated package of care, equipment, and community nursing follow-up. Adult E continued to suffer from contractures, and significant pressure damage with risk of sepsis – for which she was in fact, treated in hospital in April 2020. The circumstances of her admission and subsequent discharge from a nursing home demonstrate the challenges practitioners face when working with mental capacity and decision-making amid conflicting views between service users and families – especially family carers. In the case of Adult E, the different views held by Adult E, and her family members about placement, shine a light on the practice of person-centred care, mental capacity, and decision-making, and also of evaluation of available options and best interests.

---

[1] S.38 MCA 2005 places a duty on an NHS body to instruct an IMCA in decisions to arrange accommodation for longer than 8 weeks. It should be noted that this duty only applies when there is no other person whom it would be appropriate to consult. In the case of Adult E this would involve a professional judgement on Adult E's mother's, or brother's suitability.

During the chronology period there were significant difficulties and delays in accessing physiotherapy. Analysis provided by one of the NHS Trusts involved in the review concludes that “the complexity both of Adult E’s health needs and of physiotherapy service provision, combined with the impact of the Covid-19 pandemic led to delays in her receiving physiotherapy. It is not possible to ascertain the impact that earlier physiotherapy would have had on Adult E’s physical health or her psychological adjustment to her condition or what impact this would have had on her concordance.”

Between May and June 2020 Adult E’s pressure wounds continued to deteriorate despite her package of care and input from District Nurses. By this point Adult E was receiving 2-3 visits weekly from district nurses. When the deterioration of her pressure wounds was explored with Adult E, she disclosed that she hadn’t been concordant with bed rest, and that she had been cancelling care calls. Adult E admitted that that she had been arranging her care for first thing in the morning and last thing at night in order to still have full days out. New wounds were also noted, which had resulted from her legs being strapped to her wheelchair at Adult E’s request due to spasms. Advice was given to Adult E, and care and treatment continued. Between 15 and 17 July 2020 the concerns about non-concordance with care calls, bed rest, and repositioning became the subject of three safeguarding alerts raised with the Local Authority in relation to self-neglect. These were screened on 27 July confirming the action plan of a mental capacity assessment by health, and a professionals meeting discussion. No other actions were noted.

Adult E and her mother held strong views about her recovery, and rehabilitation potential, which were not held by professionals. It is worth noting that professionals worked hard on engagement with Adult E and on her acceptance of her prognosis. Professionals took a pragmatic approach offering both ultimate advice in relation to the need for bed rest, but also working with compromise solutions to minimise harm in the face of non-concordance.

FINDINGS

The methodology of this review uses the case of Adult E as an opportunity to examine the organisational context and environment in which professionals worked and made decisions. The purpose of the review is to understand what agencies may have done differently, to learn lessons, and to improve the system-response in future cases to prevent future harm or deaths.

General findings

Adult E's case was challenging for all agencies and professionals who were working with Adult E and her mother to help them adjust to Adult E's health conditions and the outcome of her spinal injury and paralysis. Practitioners involved in her care recognised a difference in the prognosis reality, and Adult E and her mother's beliefs that she could defy the odds, recover, and that she would be able to walk again. This difference in belief, perception, and acceptance of Adult E's prognosis was at the heart of this case, with issues of non-concordance and non-adherence with medical advice, and the catastrophic impact this had on Adult E's health and wellbeing. On a personal level, Adult E was described as engaging, someone with whom it was possible to develop a positive relationship and rapport; someone who would appear to accept and welcome the advice of the professionals involved in her care. However, she was also reluctant to heed the advice given – or to adhere to treatment plans, even when collaboratively made.

Adult E's case was the subject of a rapid review by the MK Together Safeguarding Partnership, identifying a number of initial findings about the coordination of care and communication across agencies. These initial findings and the learning from the rapid review formed the basis for the terms of reference for the Safeguarding Adults Review. The findings of this review are structured around those terms of reference, based upon the review of appropriate legal and policy frameworks, relevant and applicable research and evidence-based practice, documentary evidence from Adult E's case, and the involvement of professionals involved in her care.

Organisations and key professionals within the MK Together Safeguarding Partnership area have also reflected on the key learning themes identified in this review. There are significant challenges in different systems' design. Separate funding streams for social care and continuing care can result in differences in the way systems handle case coordination, information sharing and care planning, and reviews. In most cases these different systems operate independently of each other. The risk that organisations are unable to work together effectively increases at points of intersection. This may be due to needs, complexity, or safeguarding concerns. Work has taken place to create pathways and failsafe measures at points of intersection; for example, a joint Multi-Agency Safeguarding Hub (MASH)-Continuing Healthcare (CHC) pathway has been developed to aid communication of cases shared for information, and those that are shared for action.

Other discussions focused on safeguarding systems and the way safeguarding is managed when enquiries are caused to 'health' partners, effectively becoming health safeguarding – a concept that does not exist in statutory frameworks or guidance but appears to in culture and practice.

TOR 1: Inter-agency collaboration

How well did agencies work together to coordinate the provision of care and support?

Adult E was in receipt of care from a number of health providers in the community, in hospital, and through outpatient services. The complexities of Adult E's underlying conditions and health needs meant that she was seen and supported by a number of different professionals with different specialisms and areas of expertise. Within the current commissioning landscape of the NHS, this also meant that her care was provided by different NHS Trusts using different recording systems. As noted in the rapid review different electronic patient records systems meant that clinical information was not readily available across the system and the geography. Complexities in the commissioning and provision of specialist services, including local and national services, can also have an impact on referral pathways and the multi-disciplinary nature of healthcare, treatment, rehabilitation, and recovery.

In such a system clear and consistent communication becomes even more important – not only between professionals, but between organisations, and with services users and their families. The agencies involved in providing NHS care to Adult E relied on different communication methods and systems to coordinate her multi-disciplinary care. These included letter correspondence, telephone communication, and multi-disciplinary team (MDT) meetings.

In evidence provided to the review professionals valued an 'MDT' approach, they felt involved, and voiced positive views about the effectiveness of inter-agency collaboration. This demonstrates that a joined-up approach can be beneficial to patient care and can allow professionals to feel part of a wider "team around a patient", each with a role to play. When these systems worked well, Adult E's care was coordinated, and professionals felt confident in the roles and responses of colleagues. When these systems failed, referral pathways became more difficult to navigate and gaps appeared, resulting in delays, and missed opportunities. In learning events, it has been suggested that the risk of system failure may increase when there is no agency involved with the ability to provide a lead professional, or case coordination role, especially in complex cases. In many cases it will be unrealistic for any one agency to adopt a long-term case coordination role, but what we learn from Adult E's case is that case coordination, or at least joint care planning and review may be crucial at certain times – especially when needs or risks change significantly. At these times a greater priority could be placed upon communication of changes to care or treatment such as changes to treatment plans following admissions to hospital or a change to level of care following a CHC Review. This may be achieved through sharing of discharge summaries, and joint review processes.

Holistic and creative commissioning

Throughout the time period under review there were specific difficulties within the system in relation to the provision of physiotherapy. The outcome for Adult E was that she failed to receive physiotherapy promptly and her case highlights the risk of a complex commissioning framework and criteria-based approach. It should be noted that internal reviews have already identified learning and actions taken to address some of the local and specific issues in the case. The wider system learning in relation to the provision of key allied health therapies and specialist treatments is in relation to involvement of the wider system and commissioning in the holistic provision of care.

Finding 1: Holistic and creative commissioning

Context and underlying issue
Individuals with complex needs may receive care and treatment from a complex network of commissioners and providers, often through bespoke care and treatment arrangements delivered across health and social care, and from local and nationally commissioned services.

Impact on system
When individuals' circumstances mean their care crosses organisational and commissioning boundaries there is a risk that inflexible commissioning and criteria-based approaches may stand in the way of effective receipt of services without individual case management and creative commissioning decision-making.

Recommendation

- *Commissioning arrangements should be as clear and streamlined as possible:* The arrangements for an individual's package of care should be shared with a greater priority placed upon sharing discharge summaries and reviews.
- *Making the most of reviews:* Where possible review meetings should include all agencies involved in a person's care. Non-statutory agencies and providers should be invited to contribute and be a part of review processes alongside service users and their families.

Oversight of packages of care and disengagement

Documentary evidence and submissions and evidence from practitioners reflects favourably on the effectiveness of professionals meeting together, however there were also limitations in this process. Meetings and cross-disciplinary discussions focused on the formulation of treatment plans and sharing of information between professionals, but less so on the quality and reliability of the package of care.

With the benefit of hindsight, it has become clear that Adult E was not receiving her five calls per day as intended. A pattern had emerged where this was not escalated or visible to commissioners of the package of care, or to the wider professional network. Calls were requested for early in the day, and later in the evening, and were cancelled or missed during the day. The outcome of this could potentially be long periods without care, and the associated risks were at risk of being hidden.

Community nurses were also asked to make appointments and schedule their interventions around Adult E's daily schedule. For a significant period within the review chronology this dynamic was unseen. A lack of coordination or oversight of the pattern of care provision meant that the risks associated with missed or under-provided packages of care could not be effectively managed or taken into account in treatment decisions.

Finding 2: Oversight of packages of care and disengagement

Context and underlying issue

Decisions about treatment and risk were made in the context of a belief that Adult E was receiving all the care that had been commissioned. The wider professional network had better oversight of the provision of statutory-clinical services than over the direct provision of commissioned care.

Impact on system

The tendency for multi-agency meetings and discussions to be held between practitioners from the statutory bodies[2], without colleagues from commissioned services[3] left gaps in awareness, review, and monitoring, of the package of care. This limited the effectiveness of the clinical-professional network and meant that care and treatment decisions were made with the false sense of safety that Adult E was regularly receiving up to five care calls per day. Multi-disciplinary networks need to have relevant information and participation from all agencies, formal and informal carers, and services users to be effective.

Recommendation

- *Case coordination:* At certain times in a service user's life there may need to be an identified case coordinator allocated to provide oversight. Where a person is supported by multiple agencies, and where there is a context of safeguarding concern or risk, the lead practitioner should provide oversight over the general adherence to a care or treatment plan.

TOR 2: Safeguarding

How effective was safeguarding practice in Adult E's case? Does Adult E's case provide learning about how referrals were made and acted upon?

Safeguarding is about protecting an adult's right to live in safety, free from abuse and neglect (Department of Health, 2020). The statutory framework for safeguarding adults is the Care Act (2014) with statutory guidance – the Care and Support Guidance (2020). Safeguarding systems have traditionally focused upon the statutory criteria – previously under No Secrets guidance and now under the Care Act, under section 42.

Section 42 of the Care Act 2014 places a duty on local authorities to cause or make enquiries for any adult who:

a) Has needs for care and support
b) Is experiencing, or is at risk of, abuse or neglect, and
c) As a result of those needs is unable to protect himself or herself against the abuse or neglect, or risk of it.

---

[2] Including: CCG, NHS Trusts, and the Local Authority

[3] The domiciliary care agency

Pressure ulcers and safeguarding enquiry

In Adult E's case safeguarding referrals were made in the context of pressure areas, and later self-neglect. Historically there has been much debate around the relationship between safeguarding and quality. Pressure areas may be an outcome or symptom of poor care, and ultimately neglect. In 2018 the Department of Health and Social Care published the Safeguarding Adults Protocol on pressure ulcers and the interface with a Safeguarding Enquiry (DHSC, 2018). The aim of the protocol was to standardise the safeguarding approach to pressure area risks, and to "*provide a national framework, identifying pressure ulcers as primarily an issue for clinical investigation rather than a safeguarding enquiry led by the local authority. Indicators to help decide when a pressure ulcer case may additionally need a safeguarding enquiry are included*." (DHSC, 2018).

The protocol reflects statutory guidance that states that safeguarding "is not a substitute for providers' responsibilities to provide safe and high quality care and support" (Department of Health, 2020), but that there are occasions when pressure ulcers may be an indication of poor practice, neglect or abuse. Included in the protocol is a scoring-based "adult safeguarding decision guide for individuals with severe pressure areas". The decision guide asks a number of questions about clinical condition, deterioration, care planning and risk assessment. Answers are scored 0, 3, 5, or 15. A total score of 15 indicates a concern for safeguarding which should result in a referral to the local authority, local investigation processes, and clear recording of the concern in the person's record.

In Adult E's case there is evidence of the decision guide being completed with a total score of under 15, which did not meet the decision guide for a safeguarding concern for neglect. While there is one question related to mental capacity and "compliance[4]" this is not sufficient to score for a safeguarding concern. This relates to the focus of the protocol guide on identifying neglect rather than self-neglect. As a result, Adult E's case was not referred for safeguarding when arguably her pressure ulcers were a sign of self-neglect (a form of abuse under Care Act 2014) although not neglect.

---

[4] See TOR 3 for a discussion on the language and concepts of compliance, adherence, and concordance.

Finding 3: Interpretation of Safeguarding Adults Protocol on Pressure Ulcers

Context and underlying issue

The DHSC Protocol on the interface between pressure ulcers and safeguarding enquiry is designed to indicate when pressure ulcers are an indication of neglect and therefore should be referred for safeguarding enquiry under section 42 of the Care Act 2014. The decision guide, which is widely used to triage for referral to the local authority, does not support referrals where pressure ulcers are a result from self-neglect or non-concordance with care.

Impact on system

Reliance on the pressure ulcer decision guide may mean that pressure ulcers which may be an indication of serious self-neglect may mean that safeguarding referrals are not made when they should be.

Recommendation

- *The DHSC Protocol Decision Guide:* Local guidance should highlight that in the context of self-neglect, professional judgement should be exercised and that safeguarding referrals may be required even when the decision-guide score is under 15.

- *DHSC Protocol Decision Guide, National learning:* The MK Together Safeguarding Partnership should consider escalating this finding to the DHSC as a national learning issue. The Chief Social Worker's office at the DHSC should consider revising the protocol in the context of self-neglect, and its current focus on compliance rather than concordance.

Self-neglect and safeguarding enquiry

Self-neglect is defined under Care and Support Guidance as covering "a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding" (Department of Health, 2020). The statutory guidance includes self-neglect as a category of abuse for the purposes of a section 42 enquiry, but the most up-to-date guidance does note that self-neglect may not prompt a section 42 enquiry. The most current MK Together Safeguarding Partnership multi-agency safeguarding policy[5] does not directly refer to self-neglect, rather defines abuse within the context of interpersonal relationships – "harm that is caused by anyone who has power over another person" and includes organisational abuse (MK Together, 2021a).

As part of their suite of policy and procedure, MK Together has published specific guidance on self-neglect and hoarding. This guidance provides a local framework for responding to self-neglect with a focus on multi-agency risk management and response. The guidance is consistent with the safeguarding legal frameworks and the multi-agency policy and includes a decision-making tool which uses example prompts to indicate the level of multi-agency response: to "Resolve, Consult, or Report" (MK Together, 2021b).

---

[5] The current multi-agency policy was revised and is effective from 1 January 2021.

The guidance is clear and well-structured and enables staff to apply objective evidence to the threshold decision to refer a case to the local authority. Factors to indicate a report include, among others, danger to life and ignoring critical ill-health, where consultation is advised in the context of refusal of medical treatment and care, and partially accepting medical advice. In the case of Adult E there is evidence that professionals convened regular multi-agency team meetings, however it was not until July 2020, when risks appeared to escalate, that safeguarding referrals were made. There may have been earlier opportunities to have referred Adult E's case to safeguarding, including by the care agency who were under-providing care at Adult E's request, and in May 2020 strapping her legs to her wheelchair, again at Adult E's request, due to spasm and her feet slipping off the footplates. Adult E's insistence on unsafe working practice should have been referred by the care agency. This information could have been useful to the multi-disciplinary team and may have aggregated to a greater level of concern.

The practice demonstrated in the case of Adult E is broadly consistent with the local policy framework as a multi-disciplinary approach was followed. The aggregation of concern, self-neglect, and risk would arguably have met the report criteria of the decision-making tool, and the statutory criteria for enquiry under section 42 Care Act 2014. During the practitioner's event there was a lot of discussion about safeguarding enquiries and their interface with other processes such as the multi-disciplinary team. There was a strong feeling that MK Social Care are responsive, but that an enquiry would not necessarily have added to existing interventions; safeguarding enquiries were seen as more of a parallel process. It was felt that a multi-disciplinary approach was "a much better and more effective way of highlighting and managing risks". The reflections of the practitioners' event highlighted the opportunity to bring together clinical processes and statutory safeguarding. Section 42 Care Act 2014 provides the local authority with the power to cause other bodies to make enquiries, however in the case of Adult E, perhaps the best outcome would have been achieved through a joining of processes, or a joining of the local authority to the multi-disciplinary network. This reflects the partnership principle of safeguarding, where the sum is greater than the parts.

Finding 4: Safeguarding and the Multi-Disciplinary Team

Context and underlying issue
When safeguarding concerns or risks relate primarily to the provision of healthcare there can be a tendency to separate clinical care from local authority safeguarding duties. Safeguarding enquiries may be seen as either health or social care driven – but rarely both.

Impact on system
Partnership is a core principle of safeguarding, and multi-agency working a strength of the local system. However, when safeguarding enquiries or concerns are categorised according to 'health' or 'social care needs' there is a risk that one or other process may lose expertise and knowledge.

Recommendation

- *Joined-up Safeguarding:* In complex cases of self-neglect, the default approach for safeguarding and risk management systems should be inclusion of both relevant health organisations and adult social care.

TOR 3: Person-centred care and support planning

How were Adult E's views and wishes taken into account in the arrangements for her care?

Adult E's case was challenging for all agencies and professionals working with Adult E. Professionals spent significant time with Adult E and her mother to help them adjust to Adult E's health conditions and the outcome of her spinal injury and paralysis. There was a difference in the professional perception of Adult E's prognosis reality, and Adult E and her mother's beliefs that she could defy the odds, recover and that she would walk again.

Culture and practice in healthcare – consent, compliance, and concordance

Human interactions and professional-patient relationships are critical to effective health care and the nurturing of concordance in treatment. On a personal level, Adult E was described as engaging, someone with whom it was possible to develop a positive relationship and rapport; someone who would appear to accept and welcome the advice of the professionals involved in her care. However, she was also reluctant to heed the advice given – or to adhere to treatment plans, even when collaboratively made. The reasons for this may have been multi-factorial and complex; Adult E may have disagreed with the advice, she may have failed to grasp the seriousness of the risks presented by her worsening pressure wounds, she may have hoped and believed for something different, she may have had trouble adjusting to her paralysis and reduced abilities, and it is known that she found bed rest and limiting the amount of time out of bed emotionally very difficult.

It is a fundamental principle of medical law and ethics that professionals should get the patient's consent, where it is "the patient, rather than the doctor, who has final say on whether a proposed treatment can go ahead" (Herring, 2018). This principle holds true in nursing culture and practice where there has been a move away from concepts of compliance and non-compliance to a more collaborative focus on concordance. Where compliance refers to whether a patient correctly follows medical advice, concordance describes the process of interaction between patient and professional leading to a shared understanding and formulation of a treatment plan where decisions are made together. There is also a question of adherence – the extent to which the patient is able to follow the agreed treatment plan. In the case of Adult E, healthcare professionals were faced with dilemmas between issues of compliance and concordance, neglect and self-neglect, and mental capacity and competence. Evidence provided by practitioners who worked with Adult E indicates that she would "appear very accepting of plans and convince staff that she was taking the advice on board, but there was no sign of actual compliance".

This approach may be reflective of the prevailing culture in healthcare. Brought into focus by public health responses to the Covid-19 pandemic, concepts of consent, concordance and compliance, and duty of care describe a different environment of practice when compared to the social policy and legal frameworks in social care. One of the aims of social care interventions is itself support for people to be more independent and have more autonomy and control over their outcomes. In most cases the best health and social care outcomes are achieved when service users are genuinely involved and influential. In the case of Adult E healthcare professionals worked hard to work with her in a collaborative way offering her their ultimate advice – of bed rest and full adherence to medical advice, but with a compromise offer of treatment and adaption. What may appear to be a compromise may for the individual be a balance of optimal health and wellness against quality of life.

Decision-making and autonomy

In most instances Adult E's views were taken into account and then advice was given accordingly – even if a compromise on the ultimate advice. Adult E's concordance – or adherence – was then measured against the frameworks for self-neglect and in the context of risk. On one occasion Adult E's views and wishes were in direct conflict with her family's. Adult E had collapsed at home and had been admitted with severe respiratory failure. Her prognosis on admission was poor but having stabilised and recovered sufficient to be considered for discharge Adult E and her family were consulted about discharge destination. Options included a return home with support from her family and her package of care, or admission to a nursing home. Adult E's views on discharge were very clear – she wished to go home and did not wish to go into a nursing placement. This option was predicated, however, on the ability and willingness of her family members to continue to visit and provide care and support. The views of the family were that a return home was too risky – Adult E's mother and brother did not want to visit one day and find Adult E dead. The family view was therefore that Adult E should be discharged to a nursing home, and this view was consistent with the assessments of the treating team who also considered a nursing placement the less risky option.

The legal framework applied to this decision-making process was the Mental Capacity Act 2005. Adult E had been assessed to lack capacity and as a result the decision about discharge destination needed to be made using best interests. Those making this decision on Adult E's behalf were required to weigh up the available options against best interests' considerations (section 4 MCA 2005). Assessments of mental capacity and best interests determinations are made on balance of probability and on the professional's reasonable belief that the option chosen is in the person's best interests – within the meaning of the Mental Capacity Act 2005. While the views and wishes of the person should be accorded significant weight in a best interests determination, they are not automatically determinative. Adult E was discharged to a nursing home which although against her expressed wishes may have still been within her best interests under section 4 MCA 2005.

TOR 4: Assessment and care planning:

Was the assessment of Adult E's needs holistic? How well did her care arrangements reflect her physical and psychological needs?

In relation to her physical healthcare needs Adult E's needs were well assessed. Adult E was known to primary care, community health services, and received specialist interventions from inpatient specialist services. Her health conditions were well known, and she had received an assessment of her physical healthcare needs. Adult E's care arrangements had been through the continuing healthcare process and a package of care of five calls per day had been commissioned by the Continuing Healthcare Team within the Clinical Commissioning Group. Decisions about Adult E's ongoing physical health management benefited from review through a multi-disciplinary team process and the communication between professionals was good – although less so with the care agency.

The delivery of services, such as physiotherapy, was problematic at times complicated by multiple physiotherapy providers, eligibility criteria, and the Covid-19 pandemic. Covid-19 restrictions, resource reallocations and redeployment also had an impact on the delivery of non-critical services. While assessments and care arrangements were effective for Adult E's physical health needs, there is learning in relation to the psychological and mental health impacts of her spinal injury and adjustment to her partial paralysis. Research into the psychological consequences of spinal injury suggests that early psychological help is important with some evidence for the benefits of Cognitive Behavioural Therapy (CBT) in cases where individuals experience difficulties in adjusting to life after traumatic injury (Craig, et al., 1999). In Adult E's case she had been referred to psychology fairly late on in her journey, and only prior to her death had there been discussions about her need for psychological interventions. The majority of Adult E's professional contacts focused on physical health and deteriorating pressure wounds and she may have benefited from a more formal approach to her psychological needs and an offer of psychological interventions.

Finding 5: Access to psychological therapies

Context and underlying issue

A number of personal, social, and environmental factors may predict how well a person adjusts to traumatic spinal injury. Not all individuals will need psychological therapy, however it is important that services are able to identify when individuals are struggling to adjust to life after traumatic injury.

Impact on system

An individual's mental health and psychological needs may be less medically apparent but just as crucial to rehabilitation, acceptance, and adjustment. A failure to address an individual's psychological barriers to acceptance and treatment needs can have a significant impact on that individual's ability to balance adverse aspects of necessary treatment against perceived quality of life.

Recommendation

- *Psychological needs:* Greater emphasis should be placed upon the psychological needs of individuals adjusting to life after traumatic injury. Advice and specialist expertise should be available to universal services and primary care to ensure that a patient's psychological needs are prioritised.

TOR 5: Family relationships and care in partnership:

How effectively did agencies work with Adult E's family and informal care network?

Adult E was close to her family and her mother and brother in particular were very involved in her care. Adult E's mother and brother visited her regularly and her mother was present at many consultations and appointments, supporting Adult E to make decisions about surgical options and treatment. In many ways Adult E and her mother were united in their views and beliefs about Adult E's abilities and potential. Adult E's mother expressed belief in her daughter, that she would be able to walk again, and a shared frustration at services when Adult E was not making the progress that they hoped she would.

Interactions with Adult E's family were focused on managing expectations and seeking greater concordance or adherence with treatment plans and advice. There were occasions when Adult E's mother would agree with the advice being offered to stay in bed but was unable to put this into practice. Adult E’s mother loved her deeply and was distressed to see her upset. Adult E’s mother was committed to her daughter’s wellbeing and at times, to make her daughter happy and alleviate her distress, she would facilitate her going out and remaining active. This dynamic became the focus of carer intervention.

Adult E’s mother visited regularly to offer care and support and there were signs that she may have had her own needs as a carer. Section 10 Care Act 2014 places a duty on the local authority to assess “whether the carer does have needs for support, and what those needs are” (section10 Care Act 2014). Supporting family carers can help to add another voice to the discussion about care needs, change, and treatment options. A carer’s needs may be practical or emotional and in the context of Adult E’s spinal injury and partial paralysis, it was not only Adult E who had to adjust to her new level of ability. In such cases there can be significant psychological or mental health impacts on close family and carers.

Medical crises can also cause carers significant distress; Adult E’s severe respiratory episode represented a significant change in circumstance. Adult E’s prognosis was poor and, initially, she was not expected to survive her admission. The emotional impact of this on Adult E’s family was not explored. Despite Adult E’s underlying health conditions and risk factors – she had diagnoses of ischaemic heart disease, chronic obstructive pulmonary disease and was a smoker – her admission may have been a shock for Adult E and her family. It is not clear what support was offered to help them come to terms with this new reality.

Finding 6: Carer’s engagement

Context and underlying issue

Informal carers play a significant part in individual’s care and support, and the decisions made about their treatment. Carers can also support individuals’ adherence to advice, especially when this advice conflicts with their lifestyle and quality of life factors. While the focus is often on the cared-for person, the needs of carers themselves can be significant and worthy of deducted assessment and interventions – practical and psychological, and emotional.

Impact on system

Informal carers can play a crucial role in caring for and supporting individuals who have a dependency on others for health or social care needs. Recognising the practical, psychological, and emotional needs of carers is likely to improve outcomes for both the carer and the cared-for person.

Recommendation

- *The needs of carers and relatives:* A greater emphasis should be placed upon the needs of carers. The MK Together Safeguarding Partnership should use this review as an opportunity to raise awareness of carers’ assessments and the services available.

ADDITIONAL LEARNING

In addition to the formal terms of reference, the MK Together Safeguarding Partnership has identified other areas for consideration during the course of the review, including the theme of mental capacity and influences on clinical decision-making, and practice developments, such as the Vulnerable Adult Risk Management (VARM) process.

Mental Capacity

At the centre of this case was the issue of non-concordance, or non-adherence, to medical advice. Adult E's persistent failure to adhere to medical advice and healthcare professionals' recommendations was seen as unwise decision-making. The Mental Capacity Act 2005 provides a legal framework for decision-making for individuals who may have a degree of mental impairment. Decisions are "conclusions or resolutions reached after consideration" and the Mental Capacity Act 2005 provides a framework for assessment of someone's ability to consider the relevant information in the process of consideration.

At its heart, the Mental Capacity Act is a rights-based piece of legislation, enshrining in section 1 principles of autonomous decision-making and self-determination, the concept of person-centred best interests, and the preference for options that are less restrictive of an individual's rights and freedoms. The Mental Capacity Act self-determination principles state that all persons are assumed to have capacity unless established otherwise, that a person should not be treated as lacking mental capacity until all practicable steps have been taken to help them make a decision, or merely because they make an unwise decision.

In applying these principles to practice it is important to objectively consider the evidence of each situation and decision-making process. The code of practice to the Mental Capacity Act states that an individual's mental capacity should be assessed when *"the person's behaviour or circumstances cause doubt as to whether they have the capacity to make a decision"* (Department of Health, 2007). Adult E's mental capacity in relation to care and treatment was not formally assessed until the decision she faced was to return home or move to a nursing placement. At other times during the review period members of staff who worked with Adult E believed she was capable of making decisions in relation to health and care treatment, although her mental capacity was not assessed. The prevailing view of professionals was that although Adult E was making arguably unwise decisions this was more an aspect of lack of acceptance of the advice than lack of mental capacity about the decision.

Multi-Disciplinary Meetings and Multi-Agency risk management processes

The MK Together Safeguarding Partnership like many Boards across the country has designed and implemented a multi-agency risk management process to support individuals who are deemed to be at high risk, but who do not fall within existing multi-agency processes such as formal safeguarding processes. The MK Together Safeguarding Partnership process is called Vulnerable Adult Risk Management (VARM). The VARM is supported by policy[6],

---

[6] As an aside policy documentation would benefit from a publication date and version control.

practice guidance, information for agencies and Chairs coordinating the specific VARM process, and a leaflet for people who meet the criteria for discussion and participation in the VARM process. The VARM is a case-specific structured risk management process which can be led by any organisation. The VARM criteria is that the adult at risk does not fall within existing multi-agency processes and that **all** the following conditions are met:

1. The person has the mental capacity to make decisions and choices about their life.
2. There is a risk of serious harm (physical or psychological) which is life-threatening and/or traumatic and which is viewed to be imminent or very likely to occur, or death by self-neglect, fire, deteriorating health condition, non-engagement with services, or where an adult is targeted by the local community, is the victim of hate crime or anti-social behaviour or the victim of sexual violence.
3. There is a public safety interest.
4. There is a high level of concern from partner agencies.

Notwithstanding the condition about public safety interest, the VARM process has been designed to address risks of serious harm or death as a result of self-neglect, risk-taking behaviour or chaotic lifestyles, or the refusal of services. A VARM process could have been considered for Adult E – a process she would have been able and expected to participate in, although it may not have been necessary in the context of the Multi-Disciplinary Team process that was in place.

Fundamentally the question is whether a non-statutory multi-agency process was preferred to formal safeguarding enquiry under section 42 (Care Act 2014). In the case of Adult E, the team elected for the MDT process which provided a multi-disciplinary forum for discussing and managing risk, but which does not have service user participation as robustly built into its operation.

SUMMARY OF RECOMMENDATIONS

No.	Finding	Context and underlying issue	Impact	Recommendation
1.	Holistic commissioning and case escalation	Individuals with complex needs may receive a bespoke package of care and treatment delivered across health and social care, and from local and nationally commissioned services.	When individual's circumstances mean their care crosses organisational and commissioning boundaries there is a risk that criteria-based approaches, and complex commissioning arrangements may stand in the way of receipt of services. To address this risk individual case escalation may be necessary to ensure that eligibility.	*Commissioning arrangements should be as clear and streamlined as possible* The arrangements for an individual's package of care should be shared with a greater priority placed upon sharing discharge summaries and reviews. *Making the most of reviews* Where possible review meetings should include all agencies involved in a person's care. Non-statutory agencies and providers should be invited to contribute and be a part of review processes alongside service users and their families.
2.	Oversight of packages of care and disengagement	Decisions about treatment and risk were made in the context of a belief that Adult E was receiving all the care that had been commissioned. The MDT had better oversight of the professional-clinical resources being provided than over the direct provision of care through the commissioned service.	Gaps in awareness, review, and monitoring, of package of care inhibited the ability of the MDT to respond effectively and in a timely way to dynamic changes in risk.	*Case coordination* At certain times in a service user's life there may need to be an identified case coordinator allocated to provide oversight. Where a person is supported by multiple agencies, and where there is a context of safeguarding concern or risk, the lead practitioner should provide oversight over the general adherence to a care or treatment plan.

No.	Finding	Context and underlying issue	Impact	Recommendation
3.	Interpretation of Safeguarding Adults Protocol on Pressure Ulcers	The DHSC Protocol on the interface between pressure ulcers and safeguarding enquiry is designed to indicate when pressure ulcers are an indication of neglect and therefore should be referred for safeguarding enquiry under s.42 Care Act 2014. The decision guide, which is widely used to triage for referral to the local authority, does not support referrals where pressure ulcers are a result from self-neglect or non-concordance with care.	Reliance on the pressure ulcer decision guide may mean that pressure ulcers which may be an indication of serious self-neglect are not recognised as such and safeguarding referrals are then not made when they should be.	*The DHSC Protocol Decision Guide* Local guidance should highlight that in the context of self-neglect, professional judgement should be exercised and that safeguarding referrals may be required even when the decision-guide score is under 15. *DHSC Protocol Decision Guide, National learning* The MK Together Safeguarding Partnership should consider escalating this finding to the DHSC as a national learning issue. The Chief Social Worker's office at the DHSC should consider revising the protocol in the context of self-neglect, and its current focus on compliance rather than concordance.
4.	Safeguarding and the Multi-Disciplinary Team	When safeguarding concerns or risks relate primarily to the provision of healthcare Local Authorities often use their power to cause an enquiry to be made, often led by safeguarding teams from Clinical Commissioning Groups (CCG) or an involved NHS Trust. Enquiries may be seen as either health or social care driven but may achieve better outcomes when health and safeguarding processes are combined.	Statutory safeguarding enquiries conducted through existing health team or governance processes may offer a broader range of perspectives and expertise to the management of safeguarding concerns and risk.	*Joined-up Safeguarding* In complex cases of self-neglect, the default approach for safeguarding and risk management systems should be inclusion of both relevant health organisations and adult social care.

No.	Finding	Context and underlying issue	Impact	Recommendation
5.	Access to psychological therapies	A number of personal, social, and environmental factors may predict how well a person adjusts to traumatic spinal injury. Not all individuals will need psychological therapy, however it is important that services are able to identify when individuals are struggling to adjust to life after traumatic injury.	An individual's mental health and psychological needs may be less medically apparent but just as crucial to rehabilitation, acceptance, and adjustment. A failure to address an individual's psychological barriers to acceptance and treatment needs can have a significant impact on that individual's ability to balance adverse aspects of necessary treatment against perceived quality of life.	*Psychological needs* Greater emphasis should be placed upon the psychological needs of individuals adjusting to life after traumatic injury. Advice and specialist expertise should be available to universal services and primary care to ensure that a patient's psychological needs are prioritised.
6.	Carer's engagement	Informal carers play a significant part in individual's care and support, and the decisions made about their treatment. Carers can also support individuals' adherence to advice, especially when this advice conflicts with their lifestyle and quality of life factors. While the focus is often on the cared-for person, the needs of carers themselves can be significant and worthy of deducted assessment and interventions – practical and psychological, and emotional.	Informal carers can play a crucial role in caring for and supporting individuals who have a dependency on others for health or social care needs. Recognising the practical, psychological, and emotional needs of carers is likely to improve outcomes for both the carer and the cared-for person.	*The needs of carers and relatives* A greater emphasis should be placed upon the needs of carers. The MK Together Safeguarding Partnership should use this review as an opportunity to raise awareness of carers' assessments and the services available.

REFERENCES

Chapman, H., 2018. Nursing theories: adherence and concordance. *Nursing Times,* 114(2), p. 50.

Craig, A., Hancock, K. & Dickson, H., 1999. Improving the long-term adjustment of spinal cord injured persons. *Spinal Cord,* Volume 37, pp. 345-350.

Craig, A. R. et al., 1990. Psychological Consequences of Spinal Injury: a Review of the Literature. *Australian and New Zealand Journal of Psychiatry,* 24(3), pp. 418-425.

Department of Health, 2005. *Mental Capacity Act 2005.* London: TSO.

Department of Health, 2007. *Mental Capacity Act 2005: Code of Practice.* London: TSO.

Department of Health, 2014. *Care Act.* London: TSO.

Department of Health, 2020. *Care and Support Statutory Guidance (online version, updated 12 February 2018).* London: TSO.

DHSC, 2018. *Safeguarding Adults Protocol: Pressure Ulcers and the interface with a Safeguarding Enquiry,* London: Chief Social Worker for the Department of Health and Social Care.

Herring, J., 2018. *Medical Law and Ethics.* 7th ed. Oxford: Oxford University Press.

Kennedy, P., Evans, M. & Sandhu, N., 2009. Psychological adjustment to spinal cord injury: The contribution of coping, hope and cognitive appraisals. *Psychology, Health & Medicine,* 14(1), pp. 17-33.

MK Together, 2021a. *MK Together Safeguarding Adults – Interagency Policy & Procedure V4.1,* Milton Keynes: MK Together Partnership.

MK Together, 2021b. *Milton Keynes Interagency Safeguarding Adults: Self-Neglect and Hoarding Guidance V2,* Milton Keynes: MK Together Partnership.

Ridd, M., Shaw, A., Lewis, G. & Salisbury, C., 2009. The patient–doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *British Journal of General Practice,* 59(561), pp. 116-133.

Wilkinson, D., Herring, J. & Savulescu, J., 2020. *Medical Ethics and Law: A cirriculum for the 21st Century.* 3rd ed. London: Elsevier.