

Pauline SAR

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West of Berkshire Safeguarding Adults Board

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Pauline

- Pauline lived alone in her own home. She had several known conditions that impacted on her ability to manage daily living activities, including a diagnosis of Alzheimer's disease, cataracts and arthritis, but remained very active and physically able.
- She was a local well-liked character. She was friendly, chatty and cooperative;
- She was also fiercely independent and proud of her ability to manage. She was resistant to support, especially social care services. She frequently and repeatedly made clear to professionals involved in providing care and treatment that she wanted to remain independent. Her home was much more than bricks; it symbolised regaining and retaining control over her life.
- Her neighbours carried out regular checks (often daily). One neighbour also acted as keyholder and emergency contact and facilitated access to Pauline including passing key messages from professionals to Pauline regarding medication management, health appointments etc. Concerns had been raised by her neighbours and a number of professionals over recent years that, as she had grown increasingly frail with age, behaviours which may have been present throughout her life (e.g. non-concordance with medication, hoarding out of date foods) posed increased risk to her health.
- Pauline died at home in November 2021, having fallen and fractured her neck.



Deciding to commission a Safeguarding Adult Review

WBSAB instigated this review initially believing Pauline's case may have met the criteria for a review under s44 Care and wanted to explore if practitioners had worked together to reduce the risk of harm through 'self-neglect'.

S.44 duties arise for adult with needs for care and support (whether or not the local authority has been meeting any of these needs) if:

- There is reasonable concern about how the SAB, partner agencies or other persons with relevant functions worked together to safeguard the adult AND
- The adult died as a result of abuse or neglect (or suspected abuse or neglect) or suffered serious harm.

Whilst members of the SAB reasonably commissioned the review on the information available following initial enquiries, it quickly became apparent that practitioners from across many agencies had worked constructively with Pauline, each other and her neighbours to balance carefully her need for protection against her wider wishes.

As such, the panel concluded that this review continue (in line with s44(4) Care Act) as a discretionary SAR to highlight the good frontline practice that took place despite severe pressures experienced by all services during the Covid pandemic and to support system leaders build on that good practice.



The period under review is from 01.03.2020, shortly before the national 'lockdown' to prevent further spread of Covid-19 was announced, until Pauline's death on the 29.11.21.

WBSAB asked that the following themes be examined through this SAR:

- Are the care management and safeguarding pathways used to support adults with dementia suitable for adults who are, or are at risk of, self-neglecting?
- What legal frameworks could have been applied in this case, what were the challenges in agencies applying them?
- What are the barriers facing professionals when considering Mental Capacity and best interest decisions in risk management?
- Was the engagement between front line staff and Pauline's neighbours appropriate?
- What was the impact Covid had on this case and what lessons can be learnt in the event of any future pandemics?

Key lines of enquiry



It is estimated that 5,430 people over 65 are living with dementia in the West Berkshire area, of those 3616 have a formal diagnosis. The West Berkshire Dementia Action Alliance has published an action plan to deliver on the those aims, including a commitment to 'work towards necessary improvements to enable people with dementia and their carers to live independently in their community for as long as possible.'

In 2020 a National SAR Analysis found in 45% cases (n104) adults had died or suffered serious harm due to self-neglect. A Practitioner briefing identified:

- Practitioners must pay close attention to mental capacity, carrying out capacity assessments where indicated, esp. when an adult consistently disregards high levels of risk to themselves or others. This includes impaired executive brain function on decision-making.
- Comprehensive risk assessments are an essential component of practice
- Poor case coordination and information-sharing, workforce pressures, availability of commissioned resources and absence of management scrutiny, training and guidance, compromise good outcomes as they directly influence how practitioners approach their work with an individual. Practitioners' awareness of these systemic factors can assist them to take appropriate actions, for example to contribute actively to interagency coordination and information-sharing, and to escalate difficulties to the appropriate domain.

Currently there are 463 references within the National Chairs Network's SAR Repository to cases where self-neglect and dementia was a factor in death or serious harm of an adult with care and support needs.

What the research tells us:



System findings

There is evidence of appropriate multi-agency referrals, information sharing and shared risk assessment in line with duties under s3 NHS Act and the Care Act. Practitioners demonstrated persistent, compassionate concern particularly with regards to her ability to take her medication and manage her nutrition, given her practices of keeping out of date food. The approaches adopted by agencies were in line with the local self-neglect policy and reflect the aspiration that practitioners understand the person beyond the self-neglect.

There was also evidence of multi-agency cooperation to address the complexity and uncertain of managing foreseeable risks given Pauline's reluctance to accept support.

However, practitioners found their ability to offer solutions that *'connect relevant legal rules with the professional priorities and objectives of ethical practice'* was at times thwarted by:

- misperceptions of how legal frameworks operate;
- cumbersome processes for multi-agency assessment and risk management; and
- A lack of shared understanding of when Pauline's ability to keep herself safe might permit more invasive support, including clear agreements on who and when would undertake relevant capacity assessments and how these should be shared and recorded across the relevant services working to support her.



Human rights-based approach to safeguarding and risk management

National and local guidance advocates a human rights-based approach to safeguarding and risk assessment, moving away from paternalistic protections of those with care and support needs to supporting people to understand their legal rights, make informed decisions about risk based on potentially differing viewpoints and manage risk from a person centred, strength-based perspective!

“ The healthy and moral human instinct to protect vulnerable people from unwise, potentially catastrophic decisions must never be permitted to eclipse their fundamental right to take their own decisions where they have the capacity to do so.”

Hayden J, LB Tower Hamlets v PB [2020]

‘The freedom to choose for oneself is a part of what it means to be a human being.’

Peter Jackson in Heart of England v JB [2014]

“Emphasis must be on sensible risk appraisal. Seeking a proper balance and being willing to tolerate manageable or acceptable risk as the price appropriately to be paid in order to achieve some other good. What good is it making someone safer if it merely makes them miserable?”

Munby J, Local Authority X v MM [2007]



Humanity in the Courts...

Best interests considerations are *“not an academic issue, but a necessary protection for the rights of people with disabilities. As **the Act and the European Convention make clear, a conclusion that a person lacks decision-making capacity is not an ‘off-switch’ for his rights and freedoms.** To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. It would therefore be wrong in principle to apply any automatic discount to their point of view.*

*...I am quite sure that it would not be in Mr B's best interests to take away his little remaining independence and dignity in order to replace it with a future for which he understandably has no appetite and which could only be achieved after a traumatic and uncertain struggle that he and no one else would have to endure. **There is a difference between fighting on someone's behalf and just fighting them.***

Peter Jackson in Wye Valley NHS Trust v B [2015]

In considering best interests assessments decision-makers must consider *“welfare in the widest sense, not just medical but social and psychological; ...they must try and put themselves in the place of the individual patient”:*

Aintree NHS Trust v James [2013] UKSC 67



WBSAB and relevant partners, in collaboration with the West Berkshire Dementia Action Alliance should review the local dementia strategy to ensure there are clear pathways between voluntary, community and faith sector organisations, primary care, specialist services provided by BHFT and adult social care. This should provide guidance on:

- Holistic needs assessments and risk mitigation at the point of diagnosis and at regular intervals as the condition progresses. An adults wishes must be clearly recorded, respected and correct legal processes followed to bring together multi-agency risk, care and treatment plans.
- The availability and range of assistive technology, including links to local direct payments and personal health budget policies as possible mechanism to fund that support and maintain independence for as long as possible;
- The availability of temporary respite, step up/ down and supported living options and guidance on the use of MCA and Deprivation of Liberty Safeguards to prevent overreliance on s2 MHA powers.
- Access to local sources of information, advice and assistance for adults living with dementia and their carers that support with appointing lasting powers of attorney and advanced decision making;
- Provide guidance, modelled on the local MHA protocol, of steps agencies should take when they are unable to make contact with an adult living in the community with dementia. Including guidance on wider powers of entry and what level of risk would trigger the necessity to use police powers under the Police and Criminal Evidence Act 1984 ['PACE'].



- WBSAB should consider a public awareness campaign that provides practical advice on providing compassionate, safe opportunities for social interaction for adults with dementia who wish to retain their independence and value their place within their community.
- WBSAB should provide guidance to first responders, primary care, trusted assessors and community health and social care review teams on availability of TEC and application of a least restrictive approach within best interest decision making for adults living with dementia.
- WBSAB should seek assurance from the relevant partners agencies (adult social care and NHS bodies) that they have effective procedures to monitor compliance with duties to carry out and record capacity assessments for those with known cognitive impairments.
- Consideration should be given to whether the 'connected care' system should be adopted more widely across RBC and health partners to enable greater information sharing between health and social care is enabled to flag key documents such as capacity assessments.

