

Pauline

Pauline lived alone in her own home. She was a local well-liked character; friendly, chatty and cooperative, but fiercely independent and someone who, despite increasing frailty associated with aging, remained very active and physically able. Pauline died at home in late 2021, having fallen resulting in fatal injuries. Pauline had several known conditions that impacted on her ability to manage daily living activities, including a diagnosis of Alzheimer's disease, cataracts and arthritis. Concerns had been raised by Pauline's neighbours and a number of professionals over recent years that, as she had grown increasingly frail with age, and her choices which may have been present throughout her life (e.g. not taking medication, hoarding out of date foods) posed increased risk to her health.

Detailed case analysis clarified Pauline did not die because of abuse or neglect and partners had complied with their duties to assess and offer support in a manner that complied with her human rights.

The report found issues explored in this case were prevalent across health and social care agencies in the West of Berkshire. There was evidence of good practice from professionals throughout. Findings and recommendations for the SAB are explained within this learning summary.

Balancing risks and rights: Pauline's neighbours and practitioners she encountered, made appropriate multi-agency referrals, shared information effectively and jointly assessed. They 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with regards to her ability to take her medication and manage her nutrition, given her practices of keeping out of date food.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 risks to Pauline remaining within her own home were well understood, but consideration was also given to the harm that compelling her to receive care against her will would cause. There was multi-agency cooperation to assess risk and her capacity to make decisions and keep herself safe. Practitioners reasonably concluded it was unnecessary and disproportionate to use legal powers to compel her to receive treatment using the powers of the Mental Health Act or Mental Capacity Act. The approaches adopted by agencies were in line with the local self-neglect policy and duties under the NHS Act and Care Act.

Practitioners from across agencies spoke of high levels of case experience where an adult lacked capacity to understand the risks faced by their degenerative condition but was not yet at high risk of harm to warrant close supervision of the nature that is available within a residential setting. There was a misperception, for some practitioners, that the legal framework acted as a barrier to providing a proportionate, gradual approach to interventions. Practitioners need organisational support when facing inherently risky, but finely balanced decisions on managing foreseeable risks for people reluctant to accept support.

Caring Communities have a valuable role: People with dementia wishing to remain at home for as long as possible, have the easiest course when they have family, friends or neighbours supporting this choice. Pauline's neighbours had for many years acted as a protective factor. They paid attention to her comings and goings, checked in with her (often daily) and acted as a link between her and practitioners, reminding her of appointments and the need to take her medication. If alerted that she had become confused whilst out shopping, they helped her return home. The kindness shown to her by practitioners and her wider community, was very moving.

Practitioners spoke of the importance of regular contact with Pauline's neighbours when seeking to mitigate risks for Pauline given her reluctance for formal support. They also explained the importance of maintaining important professional standards, for example Pauline's confidentiality. Case records suggest care was taken to ask only pertinent information from her neighbours to enable a dynamic evaluation of risks. For example, the memory nurse during one failed home visit (as Pauline had gone out) checked if neighbours felt she was coping, whether they felt she may have lost any weight, dressed appropriately for the weather, left home at night when the risks might be greater for her. In asking these questions, she provided guidance on changes in behaviour or presentation her neighbour might want to look out for as that would prompt more detailed enquiries by professionals. Practitioners also respected the boundaries to the level of support her neighbours felt able to provide, for example understanding that whilst one neighbour was happy to have a key and pass messages, she did not wish to be more closely involved in Pauline's care plans. It was reasonable, therefore, that her neighbours were not offered carer assessments or involved more closely with care planning responsibilities.

Pauline Safeguarding Adults Review, Learning Summary



Good record keeping is essential to good risk enabling care: Professionals recognised that, whilst there was common understanding and agreement of her capacity, formal assessment reports were not completed in line with policy. Whilst this didn't impact on Pauline's care, they understood it was almost inevitable that as her condition deteriorated the matter would have to be considered by the Court of Protection. As such, the lack of formal capacity assessments and risk management plans could have made it more difficult to justify urgent interventions or look to provide Pauline with a care and support plan that may have impacted on her liberty, as they may not have been able to demonstrate the less restrictive actions to mitigate risks had been exhausted. It is also notable, despite agreement Pauline lacked capacity regarding care decisions, that an Independent Mental Capacity Advocate or Care Act Advocate had not been appointed to support her within those assessment, care planning and safeguarding discussions. There are, therefore, opportunities to improve recording and monitoring systems to ensure improved compliance with important procedural safeguards embedded within the MCA and Code of Practice.

Lesson learnt from Covid should not be forgotten: It is possible that the enforced isolation, necessary to prevent the spread of the Coronavirus during the pandemic, hastened Pauline's cognitive decline. However, what is clear from the case files and discussions with those involved in this review was that at the time of her death she was still well nourished and mobile. She also still valued her independence and wished to remain at home and that this was made possible by the close attention paid to her wellbeing by practitioners and a committed network of neighbours. The ingenuity employed by practitioners during the pandemic who found creative ways to engage and stay connected to older adults should be built on within strategic commissioning plans. The pandemic was undoubtedly a very difficult time to have additional vulnerabilities, but there was also remarkable effort from volunteers and key workers to reduce harm to adults with care and support needs. There are opportunities to build on the community engagement work at neighbourhood levels with practical advice on providing compassionate, safe opportunities for social interaction for adults with dementia who wish to retain their independence but, like Pauline, truly value their place within their community.

Recommendations

Recommendation 1: The SAB should consider raising awareness of the good practice and compassionate care shown to Pauline.

Recommendation 2: The SAB 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 health and adult social care.

Recommendation 3: The SAB 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 value their place within their community.

Recommendation 4: The SAB 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.

Recommendation 5: The SAB should seek assurance from the relevant partners agencies that they have effective procedures to monitor compliance with duties to carry out and record capacity assessments for those with known cognitive impairments.

Recommendation 6: Consideration should be given to whether the 'connected care' system should be adopted more widely across adult social care and health partners to enable greater information sharing, and its able to flag key documents such as capacity assessments.