A DOMESTIC ABUSE RELATED DEATH REVIEW (DARDR)

'Gwen'

DHR22

JANUARY 2023

PETER MADDOCKS

INDEPENDENT AUTHOR AND CHAIR OF THE DARDR PANEL

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Contents

Pen picture

1. Gwen[1] was a loving grandmother who, until she became increasingly ill, enjoyed spending time with her extended family and friends many of whom Gwen had known from when she began working. Gwen was described as being "quite feisty at times" with a good sense of humour.

2. Gwen took pride in her appearance, dressing well and taking care of her hair. She enjoyed music and going to bingo. She was involved with a local cricket club. She enjoyed regular holidays, often with members of the family. The family enjoyed regular family social events such as BBQs.

3. The onset of her ill health and dementia increasingly curtailed and diminished Gwen's participation in these activities. Gwen increasingly saw less of her friends. Gwen was able to drive a car until 2016.

4. Gwen became increasingly reliant on needing help with her daily care and support needs. Significant changes were noticed by some of the family such as Gwen not having her hair properly brushed and cared for. Gwen was often dressed in clothes such as track suit bottoms that she would not have worn before she became ill.

5. Gwen met Duncan when they both worked in the local pottery industry where they worked for many years until redundancy. Many other members of the extended family also worked in the potteries.

Introduction

6. This report begins by expressing sincere condolences and sympathy to 79-year-old Gwen and Duncan's adult children and their respective families who lost their parents in dreadful circumstances. On behalf of the Stoke-on-Trent Safer City Partnership which commissioned this domestic abuse-related death review (DARDR)[2] and the people and various organisations contributing to the review, we extend our deepest sympathies and condolences.

7. This DARDR examines the response of organisations and the appropriateness of professional support given to Gwen who was unlawfully killed in January 2023 by Duncan her 78-year-old husband of 54 years. Duncan died by suicide several months later in September 2023.

[1] Pseudonyms are used for all named individuals in this report.
[2] This review was commissioned and run as a domestic homicide review (DHR) under national guidance in place at the time. That guidance has been redrafted and reviews are domestic abuse related death reviews (DARDR). The format of reports will change.

8. In addition to recent agency involvement, the review also examines the past to identify any relevant background or trail of abuse or neglect before the death; whether support was accessed within the community and whether there were any barriers to accessing support. By taking a holistic approach the review seeks to identify appropriate solutions to make the future safer.

9. The key purpose for undertaking a DARDR is to enable lessons to be learnt from deaths where a person dies as a result of violence, abuse or neglect by a person related to the victim, has been in an intimate relationship or is a member of the same household.

10. For lessons to be learned as widely and as thoroughly as possible, professionals need to understand fully what happened in each homicide, and most importantly, what needs to change to reduce the risk of such tragedies happening in the future.

11. The review considers the contact and involvement by different professionals and organisations with Gwen and Duncan from January 2018 when Gwen's health began to significantly deteriorate until the date of Gwen's death in January 2023.

Timescales

12. The Chair of the Stoke-on-Trent Community Safety Partnership commissioned the DARDR in March 2023. The review began work in April 2023. The CPS and police were awaiting the outcome of pathology and toxicology reports before a decision about charging was made. Duncan's death ended the criminal investigation. The coroner's inquest concluded in January 2025. The verdicts are included in paragraph 31.

Confidentiality

13. The findings of a DARDR are confidential as far as identifying Gwen or Duncan, their family or professionals. Information is available only to officers/professionals and their line managers who participated in the DARDR. Gwen and Duncan are pseudonyms used in the report to protect their identity and provide privacy for their family. They had three adult children. Two of their sons and their partners are given the pseudonyms listed in the table below. Bill and Kate lived on the same property as Bill's parents; they did not want to have contact about the DARDR. Anne in the company of Eddy spoke with the reviewer. The third child and their spouse did not want any contact about the DARDR.

14. Professionals are referred to by their roles such as health care professional, GP, and nurse for example. A glossary is provided as an appendix.

Pseudonym	Relationship	Ethnicity
Gwen	Victim	White British
Duncan	Perpetrator	White British
Bill	Son	White British
Kate	Daughter-in-law	White British
Eddy	Son	White British
Anne	Daughter-in-law	White British

Methodology, scope and terms of reference

15. The circumstances of Gwen's death were reported to the chair of the Safer City Partnership (the community safety partnership who are the responsible authority for the DARDR) shortly after Gwen's death and an early decision was made that the circumstances of her death were likely to come within the scope of a DARDR.

16. The panel confirmed that the criteria for a DARDR were met. Duncan told police he had killed his wife[3]. Gwen suffered from long-term health impediments; she was diagnosed with Alzheimer's and vascular dementia in April 2016. She had become increasingly dependent on Duncan and their son (Bill) and daughter-in-law (Kate) who lived in a separate part of the same property. There was no record of domestic abuse.

17. The methodology of the review complies with national guidance. This includes identifying a suitably experienced and qualified independent person to chair and provide this overview report for publication.

18. The initial scoping panel agreed on the list of services that would be asked to provide an individual management report if their involvement was significant. The detail is provided in paragraphs 27 and 28.

19. The timeline for the DARDR is from April 2018 (when the marked deterioration in Gwen's health was observed) until the date of Gwen's death in January 2023.

20. The review gave careful and regular attention to how family, friends and support networks could be identified and encouraged to contribute to the review.

[3] The circumstances under which a DHR/DARDR must be carried out are described in the legislation and national guidance described in multi-agency statutory guidance for the conduct of domestic homicide reviews (December 2016).

21. Agencies contributing reports or information to the DARDR used the terms of reference set out in national guidance with additional general areas arising from the particular circumstances of this DARDR as described in the following scope of the review. This included

a) Was Gwen appropriately identified as an adult in need of community care services because of her disability, age or illness and might not be able to take care of herself or protect herself from significant harm or exploitation?
b) Were referrals made appropriately? What Care Act assessments were completed and were these timely and effective in identifying Gwen's care and support needs and the capacity of the family to meet those care needs?
c) How were decisions about Gwen's best interest made in meeting her care and support needs and keeping her safe? Was mental capacity considered appropriately?
d) Were arrangements for Gwen's discharge from 12 weeks of residential care back to her home in early November 2022 appropriate and effective? Did the plan address potential safeguarding or safety concerns?
e) How were Gwen's views, wishes and feelings sought, recorded and acted upon?
f) Are there specific considerations around equality and diversity issues arising from Gwen's age, and disability, that require special consideration? Were any reasonable adjustments considered?
g) Was a carer's assessment offered and completed? Did it explore support needs for Duncan or potential stressors?
h) Were Covid, organisational arrangements or working arrangements with other services a factor in how services were provided to Gwen?
i) With the benefit of hindsight, is there anything that might have been done differently?

Involvement of family, friends, work colleagues, neighbours and the wider community

22. Contact with Gwen's family was postponed pending the outcome of pathology reports and a charging decision about the circumstances of Gwen's death. Duncan died before any contact was made with any of the family.

23. A letter was delivered to each of Gwen and Duncan's children and their partners by the FLO providing information about the DARDR and details of support and advocacy including details of AAFDA[4].

24. Two of Gwen and Duncan's children did not want to have any person-to-person contact about or provide information for the DARDR. The reviewer spoke with the spouse of the third child who was also present during the discussion. Information from the discussion is referenced in the report.

[4] Advocacy After Fatal Domestic Homicide

Contributors to the review

25. More than 30 organisations in Stoke-on-Trent and Staffordshire were contacted as part of the scoping for the review, to inquire about any contact and knowledge they had about Gwen or Duncan. Of organisations who confirmed having contact and information, all were asked to provide a chronology. An individual management review (IMR) was requested from organisations with substantial contact or information.

26. The following organisations provided an individual management review:
    a) Midlands Partnership University NHS Foundation Trust (MPFT); provided physiotherapy services to Gwen following her GP referral between April 2018 and October 2019; provided the home carer service via an independent care provider between Gwen's discharge from the care home in November 2022 and Duncan stopped the arrangements less than three weeks later; provided a continence service from late November 2022 until January 2023; provided patient blood testing via the district nursing service in December 2022 and January 2023; provided a musculoskeletal service (rehabilitation and support with mobility) between November 2022 and January 2023; SALT (speech and language therapy) services (dysphasia assessment[5]; Gwen required a level 5 minced and moist diet[6] and level 1 slightly thickened fluids due to swallowing difficulty) between August 2022 and September 2022 while Gwen was in the care home and again between December 2022 and January 2023 when Gwen was at home;
    b) North Staffordshire Combined Healthcare NHS Trust (NSCH); Gwen was initially referred by her GP to the memory clinic and a diagnosis of Alzheimer's and Vascular Dementia was confirmed in August 2016; regular consultations confirmed a gradual deterioration in symptoms; the last contact was in October 2022; Gwen also participated in a research study *Journeying through Dementia*[7]*;*
    c) Stoke-on-Trent Clinical Integrated Care Board (ICB) provided primary health care through the same GP practice for Gwen and Duncan; there were more than 39 contacts with Gwen and 19 for Duncan between 2018 and 2023; not judged unusual given their ages and health conditions; Duncan had later been seeking consultations about his health; Gwen was transferred to another GP practice while she was resident for 12 weeks at the care home;
    d) Stoke-on-Trent City Council Adult Social Care Services (ASC); the initial referral for OT service was in April 2018; Gwen's visual impairment was noted in the Disability Register in July 2022 and a request for care and

[5] Dysphasia is a language disorder that affects the ability to produce and understand spoken language. It can cause reading, writing, speech and gesturing. It occurs when the areas of the brain responsible for turning thoughts into spoken language are damaged and can't function.
[6] Food is soft, tender and moist. It requires very little chewing and no biting.
[7] https://lab4living.org.uk/projects/journeying-through-dementia/

support via the visual impairment team; DoLS referral[8] in July 2022 when Gwen was transferred from hospital to a residential care home and was assessed to lack the mental capacity to decide about being cared for in the care home; the first social worker was allocated August 2022 until transferred to a second social worker in September 2022 after professional relations broke down with Duncan; DoLS assessor visit to Gwen October 2022; last ASC contact on the day of Gwen's discharge home;

e) Care Home[9]; Gwen was admitted from the hospital in August 2022 until her discharge home in November 2022; care staff completed a range of assessments including a mental capacity assessment, Abbey Pain Scale Tool[10], moving assessment, weight, choking assessment (high-risk) continence assessment (double incontinence) dependency toolkit (Gwen required considerable support, limited ability to communicate or understand or retain information, memory assessment (consistent forgetfulness and confusion, regular disturbance of behaviour, functioning or interaction, history of falls with a high risk of falls with balance problems standing, walking or sitting;
f) University Hospital North Midlands NHS Trust (UHNM); Gwen had outpatient appointments from 2018 due to changes in her decreasing mobility; in February 2019 Gwen was diagnosed with possible normal pressure hydrocephalus[11]; lumbar treatment was provided in April 2019; and these appeared to have been a good effect on Gwen's mobility and memory improving. However, the positive effects only lasted for a limited time, with Gwen deteriorating and requiring further lumbar puncture treatments and an insertion of a shunt. Whilst awaiting an assessment for a shunt, in July 2019 it was reported that Gwen's mobility had deteriorated with Gwen experiencing several falls. Gwen was not brought/did not attend UHNM as a result of experiencing those falls. Gwen attended in September 2019 for the shunt insertion, following which it was reported that Gwen had improved again within her presentation up until June 2020

[8] Deprivation of Liberty Safeguards (DoLS) are a set of checks that are part of the Mental Capacity Act 2005, which applies in England and Wales. The DoLS procedure protects a person receiving care whose liberty has been limited (because they are under continuous supervision and are not free to leave because of concerns about their safety) by checking that this is appropriate and is in their best interests.

[9] The care home is not identified to preserve the privacy of the family.

[10] The Pain Scale is an instrument designed to assist in the assessment of pain in residents who are unable to clearly articulate their needs.

[11] Normal pressure hydrocephalus (NPH) is an abnormal buildup of cerebrospinal fluid (CSF) in the brain's ventricles (cavities). It occurs if the normal flow of CSF throughout the brain and spinal cord is blocked in some way. This causes the ventricles to enlarge, putting pressure on the brain. Symptoms of NPH include:
Progressive mental impairment and dementia
Problems with walking
Impaired bladder control
The person also may have a general slowing of movements or may complain that his or her feet feel "stuck." Because these symptoms are similar to those of other disorders such as Alzheimer's disease, Parkinson's disease, and Creutzfeldt-Jakob disease, the disorder is often misdiagnosed. Many cases go unrecognized and are never properly treated.

when Gwen had deteriorated. Gwen required admission in July 2020 for a revision of the shunt following which in September 2020, Duncan reported that Gwen had improved however did express concerns about Gwen's memory. It was explained that this may be multifactorial and that Duncan to seek advice from Gwen's GP. Gwen attended UHNM once in 2021; she attended in July 2022 following a stroke when there appeared to be a marked deterioration in her condition. Gwen was discharged to an assessment bed at a care home due to this change in her presentation. Subsequent contact following this admission up until 2023 was via outpatient appointments. **Duncan** attended UHNM once in January 2022 via an outpatient appointment following a referral from his GP. Historically Duncan had attended the clinic in 2012 due to pain symptoms in his legs, and at that time, he was discharged from the service with the view to conservative management. During the attendance in January 2022, Duncan stated he had no pain in his legs however his balance had recently become unsteady and although he could walk, he did require the use of a stick. Duncan did not require treatment and advice was provided. However, he said that he was becoming increasingly forgetful at times and he consumed around 21 units of alcohol per week. Duncan was advised to continue with his prescribed medications, to exercise, and to continue with smoking cessation. The outcome of the appointment, along with the information Duncan disclosed was communicated to Duncan's GP via the routine clinic outcome letter.

27. Summary information was provided by

a) Staffordshire Police; had no contact other than for investigation of the homicide of Gwen and the death of Duncan;
b) West Midlands Ambulance Service; responded to three 999 calls about Gwen; transported Gwen to hospital in July 2022 when she became unwell due to low blood pressure; responded to an emergency call from her son on the day of Gwen's death when he found her deceased at home.

The review panel membership

28. The panel was chaired by the author of this report. The first meeting of the panel was in June 2023.

Organisation	Job title or role	Attendance
Independent reviewer	Peter Maddocks Chair and report author	5/5
Midlands Partnership NHS Foundation Trust (MPFT)	Head of Strategic Safeguarding Safeguarding Nurse	3/5 2/2
North Staffordshire Combined Healthcare	Named Nurse for Safeguarding	5/5
Staffordshire Police	Major Crime Policy and Review Team Senior Investigating Officer (SIO) Family Liaison Officer (FLO)	4/5 4/5 4/5
Stoke-on-Trent Clinical Integrated Care Board (ICB)	Deputy Designated Nurse for Safeguarding Adults. Named GP for Safeguarding	5/5 2/2
Stoke-on-Trent City Council Adult Social Care Services	Principal Social Worker and Safeguarding Lead	4/4
Victim's Care Home	Manager	3/4
University Hospital North Midlands	Lead Nurse - Safeguarding	5/5
Stoke-on-Trent Community Safety Partnership	Partnerships and Reviews Officer	5/5
Staffordshire and Stoke-on-Trent Adult Safeguarding Board	Board Manager	5/5

The New Era Domestic Abuse Support Service (Area Manager) fulfilled the role of Critical Reader for the review.

The author of the overview report and chair of the review panel and the statement of independence

29. Peter Maddocks is the independent author of this report and chaired the panel. He has worked in local authority, voluntary and national services in senior and practice roles. These have included working with families and children harmed by domestic abuse including work on policy and service development as well as direct work. He is a qualified and registered social worker who continues to participate in regular professional training (including BIA) and development that

includes domestic abuse. He has completed domestic homicide reviews with other community safety partnerships in England. He has completed other DARDRs in Stoke on Trent. He has never worked for any of the organisations that contributed to this review nor has he held any elected position in Stoke-on-Trent or Staffordshire. He is not related to any individual who either works or holds an elected office in Stoke-on-Trent or Staffordshire.

Parallel reviews

30. There were no parallel reviews. The criminal process was terminated when Duncan died before a decision had been made about what charges would be prosecuted. The coroner's inquest in January 2025 concluded that Gwen was unlawfully killed by Duncan by a combination of compression of Gwen's neck, smothering and mirtazapine toxicity. Duncan died by suicide due to ethanol (alcohol) poisoning and a paracetamol overdose leading to an unrevivable multi-organ failure.

Equality and diversity

31. Gwen and Duncan were white British and English-speaking. They were married for 54 years. There is no record of any formal or informal religious affiliation or faith for either of them. They were both born in Stoke-on-Trent and their extended family live in the city.

32. The Equality Act 2010 defines age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation as protected characteristics. The Act makes it illegal to discriminate against a person because of any of the protected characteristics.

33. Gwen lived with a disability being diagnosed with dementia in 2016 causing progressive cognitive and physical impairment. Dementia is an umbrella term used to denote progressive conditions that develop as a result of degenerative changes in the brain. Dementia primarily affects older people and is characterised by the loss of cognitive, social and behavioural functions that impact a person's mood and personality and the ability to think, speak, comprehend, reason, communicate, remember and perform basic self-care functions like dressing and eating.

34. As dementia progresses, the associated behavioural and functional disabilities necessitate the provision of increased daily assistance and care to the individual. Hence, the role of caregivers in providing care can be and was significant in Gwen's circumstances[12].

[12] Alzheimer's Association (2023) '2023 Alzheimer's disease facts and figures'. Alzheimer's and Dementia
Cahill, S., O'Shea, E. and Pierce, M. (2012) Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy. DSIDC's Living with Dementia Research Programme. Dublin: Trinity College School of Social Work and Social Policy and Irish Centre for Social Gerontology, National University of Ireland (Galway)

35. Gwen's age and cognitive decline made her increasingly dependent on Duncan. An area of particular inquiry for the DARDR was how professionals ensured that it was Gwen's voice, views, wishes and feelings being sought, understood and considered rather than relying on Duncan or other family members. Lessons are identified later in the report.

36. Research evidence suggests that domestic abuse occurs more often when someone is suffering from dementia and is more prevalent in relationships with a pre-morbid history of domestic abuse[13].

37. The circumstances of Gwen's death, her age and her diagnosis of Alzheimer's and its impact on her cognitive and physical health represent an intersection between two distinct issues of domestic abuse and abuse of older people. Government guidance and policy draw distinctions between definitions of elder abuse to define abuse by family members whilst having separate and distinct definitions of domestic abuse[14].

38. Dementia increases vulnerability to abuse although the prevalence is the subject of variation between different research studies. Of the 15 studies reviewed by Downes et al[15], the prevalence rate of some form of abuse, usually encompassing measures of both physical and psychological abuse and sometimes neglect, ranges from 27.9 per cent to 55 per cent. Of the types of elder abuse examined, psychological abuse was consistently the most prevalent form of abuse of people with dementia, ranging from 27.9 per cent to 62.3 per cent. Reports of the prevalence of physical abuse of older people with dementia ranged from 1.4 per cent to 23.1 per cent. Five studies examined the prevalence of neglect with prevalence figures ranging from 4 per cent to 15.8 per cent.

39. Several studies measured the prevalence of either physical abuse, psychological abuse or neglect in older people living at home with dementia. Several UK studies cited by Downes[16] demonstrated a high rate of abuse in older people with dementia, with over half of the caregivers self-reporting abusive behaviour. In a representative cross-sectional sample of 220 family

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[13] Beth McCausland, Lucy Knight, Lisa Page & Kylee Trevillion (2016) A systematic review of the prevalence and odds of domestic abuse victimization among people with dementia, International Review of Psychiatry, 28:5, 475-484, DOI:10.1080/09540261.2016.1215296 https://doi.org/10.1080/09540261.2016.1215296

[14] Penhale, B. (2003) 'Older women, domestic violence, and elder abuse: a review of commonalities, differences, and shared approaches', Journal of Elder Abuse & Neglect, 15(3-4), pp. 163-183.
Policastro C, Finn MA. Coercive Control and Physical Violence in Older Adults: Analysis Using Data from the National Elder Mistreatment Study. J Interpers Violence. 2017 Feb;32(3):311-330. doi: 10.1177/0886260515585545. Epub 2016 Jul 10. PMID: 25976315.

[15] Downes. C et al (2013) Abuse of Older People with Dementia: A Review UCD NCPOP Health Service Executive p8

[16] Downes. C et al (2013) Abuse of Older People with Dementia: A Review UCD NCPOP Health Service Executive p10

caregivers of older people with dementia, a prevalence rate of 52 per cent was reported for abuse while one-third of carers met the criteria of significant abuse. The authors measured abusive behaviour by the same carers one year later and found that it had increased over time with two-thirds of carers reporting abusive behaviour compared to around half of the carers at baseline.

40. In an earlier UK study, a lower prevalence rate was reported for abuse in a purposive sample of 86 caregivers of older people with Alzheimer's disease (27.9 per cent).

41. Cognitive decline is associated with diminished financial capacity and older people with dementia often rely on caregivers to manage their financial affairs and this is where there can be a conflict of interest. For example, older people need to fund care and support services in the face of opposition from family members who may have a vested interest in how those financial resources are spent. A complicating factor in the financial abuse of older people with dementia is the fact that, unlike other forms of abuse, there is often no visible sign of abuse. Moreover, financial abuse is often not recognised as abuse by relatives due to an assumed sense of expectation and entitlement to the assets of the older person.

42. Research studies demonstrate the particular vulnerability of financial mismanagement for older people with dementia. For example, one study investigated the use of substitute decision-making arrangements in the case of 25 community-dwelling older people with dementia who had lost financial competence and found that only one person's financial affairs were being administered appropriately.

43. The creation of a legal definition of economic abuse from 2023 (Domestic Abuse Act 2021) has implications for future risk assessments. Economic abuse is behaviour that has a substantial and adverse effect on a victim's ability to acquire, use or maintain money or property or to obtain goods or services (including receiving appropriate care in later life).

44. In summary, the prevalence rates of elder abuse by people with dementia are substantially higher when compared to the rates of elder abuse reported for the general population of older people living at home. The evidence indicates that there may also be a concurrent clustering of different types. Physical abuse rarely occurs in isolation from psychological abuse.

45. The literature provides evidence of several risk factors and correlates of elder abuse in people with dementia, which may be summarised as relating to the characteristics of the older person with dementia, the caregiver's characteristics, the carer-recipient relationship and the care environment.

46. A systematic review conducted by Johannesen and Logiudice (2013)[17] identified eleven studies of community-dwelling older people with dementia and found that greater cognitive impairment, problematic behaviour, psychiatric illness or psychological problems, poor relationships within the family and a shared living arrangement were risk factors in at least some of the studies reviewed.

47. Other risk factors identified in the research include physical and psychologically aggressive behaviour as a symptom of dementia was a strong predictor of abuse associated with caregiver burden[18]. Health-related factors in the care of a person with dementia that are associated with abuse include poor psychological health, anxiety, depressive symptoms, alcohol abuse, and lower self-esteem[19].

48. The quality of the relationship between the older person with dementia and the caregiver has been identified as a risk factor for abuse and is of particular relevance to the DARDR. Numerous studies have found caregiver abuse was associated with a poor premorbid relationship and a poor current relationship. Caregiver abuse of the person with dementia was associated with premorbid abuse of the carer by the older person with dementia.

49. Environmental risk factors include the extent of involvement and duration or volume of caregiving tasks where the symptoms of dementia are more severe. Some studies found that less use of services increased the likelihood of abuse. A perceived lack of support and isolation on the caregiver's part were related to abuse.

50. In summary, factors which were most commonly identified as contributing to the risk of elder abuse of people with dementia included caregiver burden, caregiver's psychopathology, abuse or aggression towards the caregiver by the individual with dementia and the quality of the pre-existing relationship between the individual with dementia and the caregiver.

Dissemination

51. Family members will have a copy of the published report. They received copies of the draft report and were invited to discuss and comment. The organisations and people who participated in the review will receive a copy of the published

[17] Johannesen, M. and Logiudice, D. (2013) Elder abuse: A systematic review of risk factors in community- dwelling elders. Age and Ageing, 42 (3), pp. 292–298 cited by Downes, C et al.
[18] Caregiver burden can be defined as the strain that is experienced by a person who cares for a chronically ill, disabled, or older family member. The burden of care is used to describe the side effects of care that are extremely problematic for the patients and their families. It is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience.
[19] Downes. C et al (2013) Abuse of Older People with Dementia: A Review UCD NCPOP Health Service Executive p13

overview report. The report will be shared with the Staffordshire and Stoke-on-Trent Domestic Abuse Commissioning and Development Board and the Staffordshire Police, Fire and Crime Commissioner. Each member of the Community Safety Partnership will receive a copy; these are the Probation Service, Stoke-on-Trent City Council (children's services, public health and housing), Stoke-on-Trent Integrated Care Partnership, Staffordshire Fire and Rescue Service (SFRS), Staffordshire Police, Youth Offending Services (YOS) and the voluntary sector members. Additionally, a copy of the report will be provided to the Staffordshire and Stoke-on-Trent Adult Safeguarding Board and the Stoke-on-Trent Health and Wellbeing Board.

52. The commissioning body and the independent author for this DARDR thank the various people and organisations who participated in the DARDR process.

Background information and chronology

53. Gwen was diagnosed with dementia in August 2016 following a referral to the Memory Clinic. She was still driving in 2016. She continued to have regular medical consultations and reviews with the GP. In September 2017 the GP noted that Gwen's preferred place of care was her home.

54. Gwen's very low and depressed mood was discussed with the GP in April 2018 and she was prescribed anti-depressant medication which was reviewed three weeks later in April 2018. Duncan was noted to be Gwen's "main carer" at this stage.

55. A care coordinator contacted Gwen a fortnight later following a referral from the GP and subsequently completed an assessment at her home noting that she said little during the assessment, relying heavily on Duncan and "seems happy to do so". Duncan was receiving a DWP carer's allowance[20] and was advised about applying for an attendance allowance. He was providing a lot of personal care to Gwen who needed help using the bathroom and lavatory. Gwen was unable to climb the stairs. Gwen said that she wanted a DNAR in place saying she "would be better off out of the way". Gwen and Duncan were both described as very frustrated and declined being referred for carers to support Gwen or to complete a PHQ9[21]. Gwen was described as tearful and Duncan said he was fine but just wanted help on things he could do to help Gwen.

56. The GP made a referral to the OT service to assess what aids could be fitted to help around the home.

[20] Department of Work and Pensions (DWP)

[21] The PHQ-9 is the depression module, which scores each of the nine DSM-IV criteria (Diagnostic and Statistical Manual of Mental Disorders) as "0" (not at all) to "3" (nearly every day). It has been validated for use in primary care. It is not a screening tool for depression but it is used to monitor the severity of depression and response to treatment. However, it can be used to make a tentative diagnosis of depression in at-risk populations.

57. In June 2018 Gwen was randomly selected and contacted to participate in a research study of people living with dementia. When the research team assessed Gwen in July 2018, they were very concerned about a marked deterioration in her symptoms since she was seen by the Memory Clinic. Gwen seemed to be displaying symptoms of Parkinson's or severe side effects from medication. The family felt that the GP had not acted on these concerns and was extremely worried about Gwen.

58. The concerns were raised with the GP and the Memory Clinic who requested a re-referral. In a subsequent assessment at their home, Duncan was noted to be supporting Gwen throughout and she seemed to be happy for him to be present due to her poor memory and was "grateful for everything he was doing for her".

59. Ducan expressed his concern regarding Gwen's deterioration, mainly physically. She was unable to easily rise from a chair and could not mobilise easily. He said this had developed over six months. There was a discussion about the effects of advancing dementia on Gwen's mobility and vision (macular degeneration).

60. Duncan discussed his concern about the prescribed Memantine having an impact on Gwen's gait and affecting her ability to stand. Additionally, when Gwen stood up, she appeared confused about what she could do to help herself. Duncan wanted to try a reduction in Memantine to see if this made any difference to Gwen's mobility. There was a discussion about support that Duncan could access in his caring role and organisations that could support him. Duncan said he was aware of who to contact and had information should he need it.

61. In September 2018 the GP noted that Gwen needed Duncan's help to walk. Duncan was concerned that Gwen's memory was getting worse and she was shaking and unable to walk properly. Duncan and Gwen wanted to know if she had Parkinson's. Duncan was still not happy with Gwen taking Memantine due to side effects. She had become more incontinent, tired, and forgetful and her gait was imbalanced.

62. Gwen was referred for a neurology assessment that concluded there were features of the disease and a trial of L-dopa medication was started[22]. An MRI[23] was arranged. A series of tests were conducted. Gwen was orientated to time and date, was able to complete simple maths, and spelling was variable. For

[22] Levodopa is a medication used to control bradykinetic symptoms apparent in Parkinson's disease.
[23] Magnetic resonance imaging (MRI) is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body in this case to look at the structure of the brain.

clarity, this is not a capacity assessment as described in the Mental Capacity Act (MCA) and is discussed later in the report.

63. Following a review of the MRI scan in February 2019, the working diagnosis for Gwen was possibly normal pressure hydrocephalus (this is where there is an abnormal build-up of fluid within the brain, however pressure within the brain remains at a normal level. This can lead to effects on a person's mobility, and memory to name a few).

64. Duncan reported there had been no improvement to Gwen's mobility after commencing medication from her previous appointment. It was recorded that Gwen's mobility remained slow and her memory remained poor. It was recorded that Gwen was keen to be able to walk better. The plan was to determine whether this was a cause of Gwen's memory and mobility issues and whether this could be treatable.

65. A referral was made to neurosurgery to consider a possible shunt insertion (this is where a thin tube is inserted into the brain which drains the fluid to the abdomen). It was also arranged for Gwen to attend for a lumbar puncture (this is where a sample of the fluid is taken from the lower spine to test it and also to remove it).

66. A primary healthcare worker (not a GP) visited Gwen at home in April 2019 who was well and in good spirits and relying heavily on Duncan. She was struggling to get about using mobility aids; Duncan took her out in a wheelchair.

67. In May 2019 the family reported that Gwen had been "brighter" since her lumbar puncture procedures, and Duncan noted a significant improvement in her mobility. A referral was made to neurosurgery to assess for a shunt which was fitted in September 2019[24].

68. At the follow-up appointment in October 2019 attended with Duncan it was recorded that Gwen seemed to be brighter than before her procedure and that her mobility had significantly improved. Gwen was able to remember things more than before the procedure and could walk longer distances aided by Duncan. It was noted that her poor vision (due to macular degeneration) did not help her to engage in the activities (unspecified) that she wanted to, however, Gwen was noted to be happier following the procedure. Duncan informed staff that he was very pleased with the outcome. The clinician felt that further improvements could be had, however, informing Gwen and Duncan that if anything, the improvement would be a slow process and agreed to review in six months.

[24] A shunt is a flexible tube placed into the area of the brain called the ventricles, where cerebrospinal fluid (CSF) is accumulating. The purpose of the shunt is to remove the excess fluid which causes increased pressure within the brain.

69. The annual dementia review by primary health care in November 2019 was a home visit with a primary health care staff member other than a GP where Gwen and Duncan were both present. On examination Gwen's 'state of mind was normal, patient condition the same'. Gwen was 'well kempt, the patient looks well, in a good mood, her son living next door visiting regularly.... husband is happy with the plan, to come back if any concerns'.

70. In the dementia review, it was noted that the "patient has made a living will and that lasting power of attorney (LPA) for health and finances is husband. Preferred place of care noted as home". The short reference to LPA conflates the two distinct categories of LPA for health and welfare decision-making and the separate LPA for property and finance. In reality, Duncan had LPA for finance but not for health and welfare which is discussed later in the report.

71. The home visit with the health care assistant (HCA) in January 2020 for a health screening for patients over 75 years old found Gwen well, still showing improvement since having her shunt fitted. Duncan 'helps with all ADLs (activities of daily living) at present, showering her and washing her hair. Since Gwen's shunt had been fitted, she was more able to do these things on her own' encouraged Duncan 'to sit in the bathroom with her but prompted Gwen to wash herself a little bit more'. 'Patient happy, no concerns re welfare, son lives upstairs, aware to contact the surgery if any changes'.

72. At the neurology review in March 2020, Duncan reported that there had been a significant improvement in Gwen's gait following the shunt insertion, up until February 2020 when Gwen's gait had deteriorated. Gwen was walking up to half a mile into Stoke but had become quite "shuffly" (sic) again. A CT scan was arranged and contact was made with the neurosurgery service to revise the shunt which was done in late July 2020. Gwen did not attend the scheduled review appointment in December 2020.

73. In June 2021 Duncan consulted the GP about suffering from prostate problems (nocturia getting up 2-3 times per night). He was drinking more beer than previously because of the lockdown. Duncan was not willing to come into the surgery, he just wanted tablets without any further investigation or treatment, and declined PSA/U&Es and PR (prostate) examination despite explaining that symptoms could be a result of an enlarged prostate/prostate cancer. Medication was prescribed.

74. A review by the GP practice of Gwen's dementia advance care plan noted that Duncan was looking after her and "coping okay". Their son and daughter-in-law were helping. No additional help was needed at that time. The family was managing to look after Gwen.

75. A review of Duncan's hypertension by an HCA (health care assistant) in August 2021 noted that he was coping well. He had recently been struggling with his

balance and thought it could be related to his history of vertigo; there were no reports of any falls and he used his umbrella when walking to help him balance. Duncan had not taken any medications for his vertigo for some time. Alcohol advice was given and Duncan said that he had alcohol-free nights.

76. In September 2021 Duncan consulted the GP about dizziness and was still experiencing nocturia as well as helping Gwen to the toilet. He declined a referral to the urologist.

77. In January 2022 Duncan was referred to the vascular surgery clinic due to pain in his legs. He reported having become unsteady and that he required the aid of a walking stick. He also reported becoming increasingly forgetful and was consuming about 21 units of alcohol a week. There is no record of further follow-up about Duncan's memory problems or changes and the context of his drinking.

78. The HCA well-being assessment of Gwen's long-term condition in February 2022 was done via a telephone discussion with Duncan. It was noted that there were no safeguarding concerns and that Duncan "can cope". The well-being assessment in April 2022 was face to face and nothing had changed.

79. In June 2022 Gwen attended an ophthalmology appointment. Gwen did not talk much during this appointment. There is no record of how Gwen was encouraged or helped to communicate. Duncan said that they had agreed not to go ahead with right eye cataract surgery as they understood a prognosis was unforeseeable due to Gwen's advanced age-related macular degeneration. A certificate of 'vision Impairment for people who are sight impaired" was issued for Gwen recording that she had support with her care needs from someone, she had difficulties with her physical mobility and hearing, and she was diagnosed with dementia. No recorded consideration was given to gaining Gwen's views and wishes about surgery for her cataract.

80. In July 2022 Gwen was admitted to hospital for 25 nights with a suspected urinary tract infection. She was dehydrated and was diagnosed with a stroke and an increased level of confusion and she was discharged to a care home.

81. The Transfer of Care form completed by the hospital included the review completed by the Older Person's Outreach Team at the request of Track and Triage at the hospital due to concerns about Gwen's mobility and confusion and whether it was safe for her to return home. Concerns had also been raised about Gwen's nighttime needs increasing which included incontinence, restlessness, poor sleep and walking around the ward at night.

82. Duncan wanted Gwen to return home so he could care for her however the Outreach Team were concerned about his ability to manage due to Gwen's care and support needs particularly overnight.

83. The referral forms recorded that Gwen could not consent to the referral to Outreach (she lacked capacity). On arrival at the care home, Gwen was assessed as lacking capacity. The home made a DoLS (deprivation of liberty safeguards) referral[25]. The issue of decision-specific mental capacity assessment as required under the Mental Capacity Act (MCA) is discussed later in the report.

84. Gwen was very confused and had difficulties swallowing which required a change to medication by the GP from pills to patches. The care home staff noted that Gwen had a lump in one of her armpits and raised this with the GP and Duncan. He did not want Gwen to be referred to a clinic as he did not want her to be moved to different places and he just wanted her home. There is no record of Gwen's views being sought.

85. In late August 2022, a social worker was allocated and a referral was made to the SALT (speech and language therapy) service due to Gwen's difficulties in chewing and swallowing.

86. Duncan visited Gwen daily at the home. In late August 2022, he talked with a staff member while Gwen was receiving personal care from other staff. He discussed how long they had been married and when asked how he thought Gwen was doing replied that he wanted Gwen home. He thought her walking difficulty was because she had lost her strength and he had bought her an exercise machine. He was asked what he would do if Gwen began choking on food and he replied he would call an ambulance. He said that his son and daughter-in-law were out at work during the day.

87. There was further discussion between the care home and adult social care (ASC) during August 2022 about Duncan's wish to have Gwen return home and concerns on the part of the nursing staff that he did not understand or accept the extent of Gwen's needs and noting that Duncan became very upset in any discussion about this.

88. An MDT (multi-disciplinary team) meeting in early September 2022 discussed plans for Gwen's care. The meeting was erroneously advised that Duncan had LPA for Gwen's health and well-being (it was property and finance). He was described as frustrated and angry and stated that he could do what he wanted because of the LPA (this is discussed later in the report).

[25] The Deprivation of Liberty Safeguards (DoLS) was an amendment to the Mental Capacity Act (MCA) 2005 which are intended to be changed by the Liberty Protection Safeguards (LPS), the Law Commission's proposed replacement for DoLS which have yet to be enacted.
DoLS ensures people who cannot consent to their care arrangements in a care home or hospital are protected if those arrangements deprive them of their liberty. Arrangements are assessed to check they are necessary and, in the person's, best interests. Representation and the right to challenge a deprivation are other safeguards that are part of DoLS process.

89. The meeting ended prematurely with Duncan saying he did not wish to speak to ASC. A follow-up phone call by the service to talk with Duncan confirmed that Duncan had no wish to talk and that he would report the social worker for harassment. He did not need social care involvement and would do what he felt was right to help Gwen. ASC allocated a new social worker following this call.

90. In early September 2022, Duncan confirmed that he only had LPA for finance and property and not for health and welfare.

91. In mid-September 2022 the care home recorded that an MDT met due to the family having concerns about Gwen's return home and Duncan not being able to cope. ASC recorded that Gwen would be responsible for funding care arrangements which Duncan did not agree with and that he wanted to pursue whether Gwen was eligible for continuing health care funding without a financial liability for Gwen and the family. No other detail is recorded or provided to the DARDR.

92. In late September 2022 Duncan had a long conversation with staff at the care home talking about recent events including the assessment of Gwen and his concern about paying for care saying that he was not convinced that two carers were needed for Gwen at home (despite being needed at the care home). Duncan was keen for Gwen to return home and felt that he could best manage her care by himself. He asked to be more involved in care while Gwen was in the care home and would like to assist staff with personal care of Gwen and be more involved with assisting with meals. Duncan was spending up to four hours each day and was now thinking of reducing this. Duncan did not feel that anything could be done immediately to resolve his issues as they were `generally ongoing`

93. A planned MDT in early October 2022 had to be postponed due to the home closing to visitors because of an outbreak of covid.

94. Gwen was presenting the care staff with a range of confused and agitated behaviour, ripping or taking off her clothing and attempting to eat her continence pads. This was discussed with Duncan in early October 2022. He acknowledged being worried about Gwen and hardly sleeping because he was used to her being at home; this leaves it unclear whether it was more that he was missing Gwen or whether he was worried about her condition and needs. He continued to say that Gwen needed to be at home and that she would calm down. He said that he would speak to Gwen to tell her that she is "a naughty girl".

95. It was explained to Duncan that she would not remember her behaviour and was advised that they would increase their level of supervision and monitoring for Gwen.

96. Duncan continued to tell staff that he would be able to look after Gwen at home and that he did not want to pay for carers to visit their home. He did not accept that care was needed and that he could provide care for Gwen although two carers continued to be needed to look after Gwen in the home.

97. At the end of October 2022, the DoLS assessor visited Gwen at the home. A meeting had been arranged for the same day to discuss Gwen's discharge from the home.

98. The rescheduled meeting in October 2022 agreed that discharge would be arranged when a care package had been agreed upon with the care provider. Duncan became "very frustrated" saying that he would facilitate the assessment once Gwen was home. Equipment such as hoists was ordered to be delivered to their home. Training would be arranged for Duncan to help with safe lifting for Gwen.

99. Gwen was discharged home on the 3rd of November 2022. Carers visited the home four times a day (which continued until the 20th of November 2022 when Duncan refused any further visits). Gwen had been deregistered from the GP Practice while she was in the care home; she was re-registered on the 10th of November 2022 when Duncan went to the practice asking for medication for Gwen.

100. On the 16th November 2022 Duncan spoke to his GP about Gwen not being able to swallow and was concerned that the medication was different to what had been administered in the home. The GP appeared to be unaware of the care arrangements that had been made for Gwen (who had been de-registered when she was admitted to the care home). There is no record of enquiry.

101. The care provider visited Duncan and Gwen at home to review the care plan and package. It is recorded that signposting to social care was declined by the family. They accepted a referral to continence service and physio. No concerns were raised regarding the family's ability to offer appropriate care. Gwen and Duncan's son and daughter-in-law live in the same house and their daughter lives down the road. It is not clear who other than Gwen and Duncan were seen. There is no specific record of Gwen's' views being sought and recorded or her ability to express anything about her needs, wishes and feelings.

102. At the end of November 2022, the dietician service spoke to Duncan. Gwen had been referred to the dietician before she left the care home because of "unintentional weight loss". Duncan told the dietician that Gwen was eating everything he gave her and he declined a consultation with the dietician and the referral was closed. There is no record of Gwen's weight at this stage. A discharge letter was issued and sent to the referring GP practice (for the care home), and not the current and longer-term GP with whom Gwen had been

registered after her discharge home. This is an area of learning for UHNM as contact should have been with Gwen's current GP to ensure that they were cited on the outcome of the assessment.

103. The outcome letter sent to the GP indicated that Duncan voiced no issues and it could be interpreted that he declined a review due to Gwen's intake being good. This could be misleading and have resulted in the GP not conducting a follow-up in the belief that there were no issues with Gwen's care.

104. The outcome letter also did not record any of the concerns that Duncan voiced to the staff member. The GP may have been prompted to follow up with Duncan if this information had been included in the outcome letter.

105. There is no further record of exploration of Duncan's frustrations or discussion with the local authority about Gwen's care and support needs.

106. There is no evidence that a follow-up review was undertaken by the dietetic team. It may be that a follow-up call could have initiated another assessment of Gwen's nutritional intake and Duncan might have been more open to discussion.

107. A routine medication review by the pharmacist in late December 2022 via a telephone consultation was declined by Duncan who became very agitated and verbally aggressive. He refused a telephone consultation demanding a home visit which was arranged. He accepted a SALT referral being made.

108. On the 5th of January 2023, a face-to-face appointment with the neurology Parkinson nurse recorded that Gwen engaged a little in the conversation during the assessment and could experience lucid moments during the day. There appeared to be no consideration for a follow-up review following this, taking into consideration that Gwen might be able to have engaged better in the assessment.

109. During the assessment, the nurse was told that the family were providing Gwen with care and support to meet all of her care needs with no paid carers. There were positive areas identified that the family voiced they were trying hard to keep Gwen physically fit. However, there are also some difficulties and concerns identified such as Gwen's sleeping pattern. There was no evidence that Gwen's care and support needs were discussed in the context of clarifying if the family were able to continue to meet Gwen's needs, or if they required support.

110. Gwen was given a covid vaccination in early January 2023 48 hours before she died.

Overview

111. Gwen and Duncan were married for 54 years. The mental and physical decline of an intimate or close member of a family is profoundly distressing.

112. There were no reports or concerns recorded about domestic abuse. The family members who spoke to the reviewer described Duncan as controlling many aspects of the marriage such as finances. The reviewer was told that Duncan had been determined that all of any money and property would be passed to his family and not go to the state. They did not describe Duncan as an abuser although felt that Gwen was much more controlled than she realised but that she had seemed happy with the lifestyle that they had together.

113. An increasing number of services and professionals became involved with Gwen and Duncan as Gwen's symptoms progressively deteriorated and she was identified as an adult at significant risk with increasingly complex care and support needs by August 2022.

114. The circumstances under which Gwen died by homicide are not fully accounted for given Duncan died before evidence was given to a court.

115. As Gwen's health and need for care and support became increasingly complex Duncan remained determined to have Gwen living at home. Before her admission to a care home from hospital in August 2022 after she had become very poorly Duncan was talking to his GP about his increasing health issues including poorer balance and was finding it difficult to accept that Gwen's condition would continue to deteriorate.

116. Whilst in the hospital and the care home, the level of Gwen's needs became clear to care and medical staff. Gwen needed ongoing support and assistance with medication, repositioning, eating washing and dressing. Gwen presented with agitated and unsettled behaviour, removing her clothes and incontinence pads. Gwen had difficulty swallowing. These were symptoms of Gwen's diagnosed condition which Duncan found difficult to understand other than being wilful or naughty behaviour.

117. When Gwen was discharged from the care home Duncan booked a holiday to Spain as an incentive for her to start walking which she could not achieve and was another example of Duncan not accepting or understanding Gwen's condition.

118. The care assessment and care plan while in the care home indicated that Gwen had little vocalisation, had limited facial expression or change in body language to indicate for example her wishes or feelings. She was not independently mobile and could present a risk sometimes to a carer assisting because of her unpredictable behaviour. Recording in the home showed that Gwen was

sometimes unable to understand instructions, was usually confused and had difficulty with her balance. She was assessed as a high risk of choking. Gwen needed help going to and getting up from bed. She had lost weight before her admission to the care home but gained weight while she was there. Gwen was doubly incontinent and needed assistance to get to and use the toilet.

119. The level of risk to Gwen from her deteriorating condition was recorded in a variety of assessments while at the care home. This included the risk of falls due to Gwen's difficulty in balance whether standing or sitting; the high risk of choking due to Gwen's difficulty in swallowing, and erratic movements that presented a risk to carers as well as to herself.

120. A dependency assessment at the care home revealed that Gwen could participate in activities and interests if she had assistance and support. Gwen had limited ability to communicate or understand communication over periods (raising queries about her ability for example to retain and weigh information). Gwen was assessed as being at high risk of falls due to her difficulty with balance whilst standing, walking or sitting. She required two carers to help with many aspects of daily living to remain safe and prevent accidents and injury.

121. Gwen's memory difficulties were manifested in her forgetfulness and confusion and are conditions that render a person particularly vulnerable to abuse and the ability to disclose information. Her behaviour had an impact and caused disruption to other people in the home; this was not wilful or naughty behaviour but a reflection of her diagnosed condition.

122. Duncan's health was also declining having reported problems with his balance, forgetfulness and use of alcohol. Duncan's refusal to accept information about Gwen's condition and risk and that her need for care and support was becoming more complex was a significant risk factor. His uncooperative behaviour, robust language and loss of temper with professionals were also risk factors, especially in considering how he would respond to Gwen's presenting behaviours and needs[26].

123. Not much is recorded about Duncan's health or his ability to meet Gwen's needs although there were several attempts by different professionals to talk empathetically with him about this. From the consultations with his GP, it is evident that Duncan's health was being affected by his age and there is some evidence for example of using alcohol more and his stress and lack of sleep.

124. None of the services knew much about how much Gwen's life changed as a result of her increasingly poor health. For example, she had friends and

[26] The agency reports provided several examples of where Duncan became upset and angry with different professionals. Examples included telephone contact with primary health care professionals about appointments or prescriptions, refusing to speak to a social worker who attempted to talk about Gwen's care and support needs and how they could be best met. At least one meeting was disrupted by Duncan not being willing to hear or listen to any plans for Gwen other than for her to return home.

pursued hobbies or social activities that were curtailed in later life. From the discussion with Anne and Eddy, it is apparent that Gwen was very sociable although Duncan had often been with her during those social activities. Anne had concerns about the clothing Gwen was wearing in the later stages of her illness along with the care of her hair did not reflect Gwen's choices and pride in her appearance before she became ill and more dependent on Duncan.

125. Almost without exception, Gwen was not seen by any professional without Duncan being with her; this was the case from the first consultations about a diagnosis. Much of the record of contact described what Duncan said or reflected views, wishes and feelings he had on behalf of Gwen.

126. No information was sought or recorded about the relationship between Gwen and Duncan before her diagnosis. Duncan had almost complete control of interaction with professionals, he influenced the narrative about their relationship and had control over the economic resources that he and Gwen jointly owned and could have been used to provide care and support for Gwen.

127. As Gwen became frailer and more vulnerable Duncan became more determined to influence and determine what care arrangements were made for Gwen. He incorrectly told professionals that he had LPA for health and welfare and used this to say that he could determine what happened. He was often verbally obstructive and dismissive with professionals especially social workers when they were trying to raise legitimate concerns about how he would be able to meet Gwen's complex needs. He displayed little insight or understanding about how Gwen's mental and physical health had been adversely impacted by her condition. His opposition to care arrangements was motivated by liability for cost. In none of the discussions with Duncan was there any opportunity to explore the fact that any financial resources were as much Gwen's as his.

128. A clearer understanding of Duncan's attitude to Gwen's deteriorating condition and need for care and support could have been attempted. Was he lonely or scared about what was happening to his spouse after so many years? Had his behaviour changed? Was his attitude the behaviour of a man who was used to control his spouse and all of their resources? What were the views of other family members involved in any day-to-day care and support?

129. The issue of Gwen's mental capacity to make specific and critical decisions was not the subject of specific capacity assessments as required under The Mental Capacity Act (MCA). The application for a DoLS assessment was not concluded before decisions were made about Gwen's discharge home. The DoLS would not have determined long-term care arrangements for Gwen but it does provide a legal breathing space for other legal processes to resolve best interest welfare issues for example through referral to the Office of Public Protection or hearing in the Court of Public Protection. The effort to make local best-interest decisions was disrupted by Duncan's opposition.

130. Duncan halted the carer support for Gwen that had been agreed upon before her discharge home in November 2022. With or without hindsight that was a moment of heightened risk given the level of Gwen's needs and Duncan's difficulties with issues such as balance and forgetfulness.

131. The family members who spoke to the reviewer were not involved in the discussions about arrangements for Gwen before she was discharged from the care home although had visited her. They had tried to talk to Duncan when they thought for example Gwen was being dressed in clothes such as track suit trousers that she would never have worn when she was able to make her own choices. They were unaware of the details about risk assessments or how difficult the discussions were between Duncan and professionals and wished they had been aware of this. They had assumed that Gwen would remain in residential care. They say that if they had been aware of more details especially after Gwen was discharged, they would have raised a safeguarding concern.

132. Other than the care agency that was providing the carers nobody else was notified about the significant development of the carer support being cancelled by Duncan three weeks after Gwen's discharge until the nurse in the neurology department saw Gwen for a scheduled appointment and Duncan said the family were caring for Gwen. It is not clear that the nurse had any detail about the care plan that had been put in place with paid carers and there was no discussion about Gwen's support needs and how the family was meeting these.

133. The following analysis is within the context of reflecting on whether Gwen's best interests were appropriately and fully considered, whether relevant law and safeguarding processes were used to assist that decision making and whether there was enough awareness and curiosity about the vulnerability of someone in Gwen's circumstances to being a victim of abuse including control and economic abuse.

Analysis

134. Adult safeguarding and protection from domestic abuse are the focus of learning. Key themes identified in national reviews are reflected in the circumstances of this DARDR. One in four women killed by their partner is aged 65 or older. Where older victims are killed by their partners there is a higher incidence of suicide by the perpetrator. Older couples are typically not known to the police or other services for domestic abuse (in contrast to younger adults). Older victims often have serious physical and or mental health needs. In most cases, the perpetrator is the caregiver[27].

[27]Bates et al Vulnerability Knowledge and Practice Programme (VKPP) Domestic Homicides and Suspected Victim Suicides During the Covid-19 Pandemic 2020-2021 https://cdn.prgloo.com/media/02d412c416154010b5cebaf8f8965030.pdf

135. Risk in older age is complex and multi-faceted. Cognitive and physical changes can create risk in terms of choking, eating, falling, forgetfulness, being able to meet day-to-day care and personal needs, isolation, abuse, neglect and exploitation.

136. Domestic abuse is a hidden crime that is not confined to any particular age or demographic group. The onset of conditions in older age represents additional barriers for abuse to be disclosed or recognised.

137. Domestic abuse in older relationships occurs in a range of contexts which include domestic abuse that has "grown old" with the relationship having started earlier in life and persisted; the onset of domestic abuse in later life where the relationship had not been abusive earlier on; new partnerships in later life when divorce or widowhood have occurred.

138. Evidence of domestic abuse in older age where there have been no earlier concerns reported or observed does not mean that the abuse did not start early in a relationship. There are many barriers facing victims in talking about abuse and for older people this can be cultural; what is understood as abuse today was perhaps not defined as abuse in previous generations; older people often come from a tradition of not talking about what happens in the privacy of a relationship or home.

139. The prevalence rates of abuse for people with dementia are substantially higher when compared to the rates of abuse reported for the general population of older people living at home.

140. Cognitive decline is associated with diminished financial capacity and older people with dementia often rely on caregivers to manage their financial affairs including making arrangements for their care and support. A complicating factor in the financial abuse of older people with dementia is the fact that, unlike other forms of abuse, there is often no visible sign of abuse.

141. The intersectionality of older age and health with domestic abuse is therefore an area for particular exploration in this review. The review explores how professionals determined Gwen's best interests and assessed risk.

Was information appropriately sought or known about Gwen and Duncan's relationship? This includes how Gwen's declining health had an impact and any discussions Gwen and Duncan may have had about prior decisions between themselves or with other family members.

142. None of the services provided any recorded evidence of information being sought from Gwen or Duncan about their relationship over and above the length of time they had been married. This includes the Care Act assessment which provides detail about family composition and length of marriage but no further

detail including any discussion about advance decisions that are referenced by the GP practice.

143. There are several references by different professionals about how Gwen and Duncan appeared to have a good relationship based on the length of time they had been together and Gwen appeared passively content for Duncan to speak and deal with professionals. There are multiple references to Gwen appearing to be well cared for and Duncan's assertions that they did not need support. The memory clinic described Duncan as concerned about Gwen and that Gwen "was grateful to Duncan for how much he helped her". Family members appeared to act in Gwen's best interest and although Duncan sought advice there is evidence that the advice was not what he wanted to hear. A significant issue appeared to be his belief that there would be a medication solution to halting and reversing Gwen's decline.

144. During a health screening with Gwen in April 2018 it was recorded that she wanted a DNAR (do not attempt resuscitation) in place and said "she would be better out of the way". Her statement that she would be better off out of the way was not explored (at least this was not recorded as being done) and such a statement can reflect a variety of circumstances although other recording describes concerns about Gwen becoming more debilitated and having a diminished quality of life.

145. Duncan's assertion that he had an LPA for health and well-being as well as for property and finance was used more than once to say that he alone had decision-making authority about arrangements for Gwen. He had an LPA for property and finance and this was not clarified for several months. The law expects a person with LPA to act in the best interests of the person rather than being given carte blanche to make any decision.

146. The issue of LPA is important to clarify as a matter of routine and a simple process of checking with the Office of Public Protection would provide the information[28].

147. Although there were attempts to talk to Duncan about Gwen's condition it is not clear that at any stage it was important for the professionals and Duncan to understand that it was not for any one single person to decide what was in Gwen's best interests or explain the various processes for Duncan to use to challenge decision making ranging from raising a complaint through to Court of Protection procedures discussed in the conclusion of this report.

[28] https://www.gov.uk/view-lasting-power-of-attorney

Was Gwen appropriately identified as an adult in need of community care services because of her disability, age or illness who might not be able to take care of herself or protect herself from significant harm or exploitation?

148. Gwen suffered from long-term health impediments. She was diagnosed with Alzheimer's and vascular dementia in April 2016. She had become increasingly dependent on Duncan along with their son and daughter-in-law (Bill and Kate) who lived on the same property. There is little recorded discussion with them about their views, wishes and role in arrangements for Gwen.

149. During Gwen's health screening appointments, she was flagged for "severe frailty" and the regularity of reviews including for her dementia and medication included opportunities to discuss referrals and signposting to other services and support. Much of this was discussed with Duncan who for the most part declined referrals. When consent was forthcoming referrals were made for example to the OT service. The GP practice provided clear recorded evidence about Gwen's need for care and support and in addition to regular reviews also provided information and signposting to other support services. The GP had a signed copy of Gwen's' advance decision about not being resuscitated.

150. The Care Act assessment does not include a record of Gwen's capacity to protect herself from risk or exploitation despite several references to her diagnosis of dementia and difficulty in following or participating in the conversation. There is no description of what was done to facilitate communication with Gwen.

151. There is a little recorded discussion with Gwen's son and daughter-in-law about their day-to-day role in care and support for Gwen and the level and type of support they could provide over the generalised assertions of being supportive. They both worked and were not in the house 24/7.

152. There is no discussion about the impact on and capacity of, Duncan to look after Gwen. The physical and emotional stress was a factor that deserved some reflection in terms of carer needs and Duncan's interaction with professionals with whom he could be argumentative, obstructive and dismissive. If he behaved like this with professionals what was his interaction with Gwen and other family members?

153. Although the GP records included reference to no safeguarding issues being raised this is within the context of Duncan being ever present with Gwen and often speaking on behalf of Gwen and making decisions on her behalf.

154. Gwen's health had declined sufficiently in August 2022 when she was admitted to the hospital and discharged to the care home and this was an opportunity for a variety of assessments to be completed which provided further evidence about severe risk from choking, difficulty in swallowing, falls and unpredictable behaviour. She had lost weight that she began to regain after admission and

required two carers to help her with daily care and support needs. She needed the correct equipment to help her safely mobilise and reposition; this equipment was declined by Duncan.

155. The risk to Gwen from not having her care and support needs met adequately was significant and was an issue the DoLS is expected to address when a person cannot make specific decisions for example about where and how their care and support needs can be met.

156. Given the level of opposition by Duncan to any plan other than Gwen returning home, and his very different view about the level of complexity of Gwen's care and support needs, it would have been good practice to have considered arranging advocacy for Gwen and as part of the DoLS process considering the appointment of a paid RPR (relevant person's representative) or IMCA (independent mental capacity advocate) under section 39 of the MCA[29].

157. The reason this was not done at the time appears to be a belief that the family were motivated by Gwen's best interests and there was no conflict of interest (although in reality there was in terms of how for example the cost of care would be met).

158. The law sets out specific measures for ensuring the best interest of an adult at risk with care and support needs are identified. In this case, although the DoLS process was initiated and there were attempts to convene best-interest meetings the outcomes were effectively dictated by Duncan.

159. The DoLS process was not in compliance with legal timescales that describe an urgent DoLS can be made for seven days when a person is identified as being deprived of their liberty and cannot make a decision (in the hospital and in the care home as far as Gwen was concerned) and then a further 28 days to complete the six standard authorisation assessments which include the BIA assessment (which the most time consuming).

160. The BIA requirement is made up of four distinct conditions.

    a) That the person is or is to be detained in a care home or hospital;
    b) That it is in the Best Interests of the person to be detained in the hospital or care home;

[29] The role of a Relevant Person's Representative (RPR) is to maintain contact with the person and to represent and support them in all matters relating to the deprivation of liberty safeguards (DoLS). This support has to be completely independent from the providers of the services they are receiving. Section 39 of the Mental Capacity Act 2005 sets out the different IMCA roles: Section 39A IMCAs are instructed when there is an assessment in response to a request for a standard authorisation made by the care home/hospital, or a concern about a potentially unauthorised deprivation of liberty.
Section 39C IMCAs cover the role of the RPR when there is a gap between appointments, this might be due to the RPR being unwell and unable to continue in their role for some time.
Section 39D IMCAs support the person, and/or their RPR, when a standard authorisation is in place.

c) That, to prevent harm to the person it is necessary to detain them in the care home or hospital; and
d) That the detention is a proportionate response to the likelihood and seriousness of harm

161. The BIA assessment had not been completed before Gwen was discharged. The BIA assessment is required to assess the needs and best interests of Gwen who was unable to decide between continuing to receive residential care the BIA assessment has the power to authorise continued care (and deprivation of liberty) and can make specific conditions if required to safeguard the best interests of Gwen. If the dispute with Duncan could not be resolved he had recourse to the Court of Protection[30].

162. The lessons for practice are discussed in the conclusions of this report, particularly about the importance of clarity about mental capacity and how decisions are made about best interests and legal routes when best interest is disputed or cannot be resolved in discussion with a spouse or significant family member.

163. Within the context of a DARDR, the reason and motivation for a spouse opposing or refusing to engage in discussion about what is in the best interest of their partner is important. In this case, there was a manifest conflict of interest about the funding of care arrangements for Gwen who was being prevented from using matrimonial assets[31] held with her spouse to meet her care needs.

164. The point is made by more than one of the agencies' IMR authors to the DARDR that the impact of cognitive and physical decline is immensely distressing and the psychological and emotional distress on both spouses requires empathetic professional responses. However, behaviour that could be motivated by a need to control and the potential for abuse of an adult with complex care and health needs requires professional curiosity and legal literacy in safeguarding adults at risk.

Were referrals made appropriately? What Care Act assessments were completed and were these timely and effective in identifying Gwen's care and support needs and the capacity of the family to meet those care needs?

165. The Care Act assessment has been commented on in the previous section about how it could have been a more effective process.

166. The GP practice made a referral to ASC in April 2018 for advice and help with equipment and adaptations. This was the only referral to ASC. The GP practice

[30] The Court of Protection make decisions on financial or welfare matters for people who can't make decisions at the time they need to be made (they 'lack mental capacity').
[31] Matrimonial assets are financial assets that have been acquired during marriage

made appointments to see Gwen about social prescribing which is usually expected by the ICB to include considering whether referrals or signposting to other services is needed for meeting care and support needs. There is evidence of Gwen being referred to other clinical services such as the Memory Clinic. Although there is evidence of the primary health care staff discussing and providing information to Duncan in particular about support there is no specific record of considering a referral to ASC.

167. The ability of the family to meet Gwen's care and support needs was never formally assessed. Gwen's admission to the care home in August 2022 provided an opportunity to record in detail the extent and complexity of her care needs. Acknowledging Duncan's distress at being separated from Gwen he was unable to engage in discussion with social workers or care staff. Although he relied on the fact that his son and daughter-in-law lived on the same property there is no detail about how much they were involved in any day-to-day care of Gwen and there is a reference to them both working although no clarification about how this impacted their availability to assist Gwen and Duncan.

168. When Duncan halted the carer involvement there was no referral from the care agency to ASC despite the transfer of care documentation requiring the agency to contact ASC before carer arrangements were changed or removed. The absence of a referral to ASC removed an opportunity to complete an urgent assessment under the Care Act which would have included any immediate risk to Gwen's safety. There is no process for ASC to check or monitor the delivery of a care package.

169. The care home completed a referral to the DoLS team to request authorisation for the placement when Gwen was admitted and assessed as not having the mental capacity to consent to her admission and care.

How were decisions about Gwen's best interest made in meeting her care and support needs and keeping her safe? Was mental capacity considered appropriately? Did the arrangements include consultation with all relevant family members and were their expressed views consistent with what was in Gwen's best interests?

170. Except for UHNM who say that a mental capacity assessment was completed about the implementation of a DNAR advance decision none of the services provided a record of a mental capacity assessment being completed with Gwen.

171. There was a common assumption from August 2022 that Gwen did not have mental capacity. The UHNM describe the best interest decision-making process for the DNAR involving a discussion with Gwen's son who wanted her to have a peaceful death and did not wish to prolong her suffering.

172. There is little record of any direct discussion with Gwen or description of attempts to ascertain her views and there is a general reliance on Duncan speaking on Gwen's behalf for all the professionals who had contact with Gwen. The information that is recorded describes Gwen's appearance and her functional ability.

173. Two examples from the information provided to the DARDR are illustrations of how the mental capacity of Gwen and Duncan deserved closer attention than was evidenced.

174. The only direct recording of Gwen's views about what she wanted to happen was for her to say she wanted to go swimming and when asked more specifically about whether she wanted to go home simply said yes. All other recording about Gwen is about how she is observed such as not looking distressed or smiling or becoming less agitated when Duncan visits.

175. Duncan was assumed to have capacity throughout all contact with him. When for example he was asked what he would do if Gwen was choking (given the high level of risk to Gwen) he simply replied he would call an ambulance.

176. Mental capacity is a significant issue for safeguarding adults at risk. It has very significant implications for how best interest decision-making is conducted and safeguarding potential victims of abuse whether from an intimate partner or a family member. This is not making allegations or comments about Duncan or other members of the family but drawing attention to why professionals need to ensure that good standards and laws are followed.

177. The DoLS process requires a mental capacity assessment to be completed by a person:
    a) Approved under section 12 of the Mental Health Act 1983 (specifically trained and qualified in the use of the Act); or
    b) A registered medical practitioner with at least 3 years post-registration experience in the diagnosis or treatment of mental disorders; and
    c) Have completed the Deprivation of Liberty Mental Health Assessors training programme; and
    d) When completed more than 12 months ago, undertaken further training relevant to the role within the last year.

178. The MCA says that a person is unable to make a particular decision if they cannot do one or more of the following four things.
    a) Understand the information given to them.
    b) Retain that information long enough to be able to make a decision.
    c) Weigh up the information available to make a decision.
    d) Communicate their decision; this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.

179. A lack of mental capacity can be temporary or enduring and relates to a particular decision at a point in time.

180. The type of decisions that are covered by the MCA range from day-to-day decisions such as what to wear or eat, to more serious decisions about where to live, having an operation or what to do with a person's finances and property. The MCA applies to situations where a person may be unable to make a particular decision at a particular time because their mind or brain is affected, for instance, by illness or disability, or the effects of drugs, prescribed or otherwise or alcohol.

181. For example, a person such as Gwen may lack the capacity to make some major decisions, for instance about specific medical treatment, but this does not necessarily mean that they cannot decide what to eat, wear and do each day. In other words, it is not about a general or global capacity to make decisions.

182. Most professionals deferred to Duncan's expressed wishes and views and he also asserted (incorrectly) that he had an LPA that gave him absolute authority about what happened in making care and other arrangements for Gwen; in effect, he believed he held a trump card.

183. LPA does not give absolute authority to make any decision; all decision-making has to be based on clarity about what are the best interests of the person about whom a decision is being made if they have been assessed as being unable to make that decision for themself.

184. Family will not always agree about what is in the best interests of an individual as occurred in this case. Professional decision-makers will need to demonstrate in their record keeping that they have made a decision based on all available evidence and taken into account all the conflicting views. If there is a dispute, the following things can assist in determining what is in the person's best interests;

a) Involve an advocate who is independent of all the parties involved; if the DoLS assessment had been completed and had concluded that Gwen's best interest was remaining at the care home a relevant person's representative (RPR) could have been considered.
b) Get a second opinion.
c) Hold a case conference/best interest meeting.
d) Go to mediation
e) Make a safeguarding referral to the Office of Public Protection which has the power to appoint a visitor where there is a dispute.
f) Make an application to the Court of Protection for a ruling.

185. The best interest meeting that was attempted is described as ending prematurely and being disrupted by Duncan's opposition to any plan that did not involve Gwen returning home and his resisting any support arrangements.

186. The change to Gwen's medication in October 2022 provided a measure of improvement to some of her physical symptoms. Although Duncan was very encouraged by this development the improvement was limited to Gwen's *functional* ability rather than achieving any improvement in her *cognitive* ability or to process and retain information for example. This was something that an effective mental capacity assessment would have explored if such an assessment had ever been completed. None was despite a common assumption that Gwen lacked capacity at the point at which she was discharged from the hospital to the care home.

Were arrangements for Gwen's discharge from 12 weeks of residential care back to her home on the 3rd of November 2022 appropriate and effective? Did the plan address potential safeguarding or safety concerns given that domiciliary and other support offered to Duncan and the family to enable Gwen to return home was subsequently declined?

187. It is not reasonable to make an informed comment on whether the views of the family were in Gwen's best interests without the completion of a mental capacity assessment, DoLS authorisation (or refusal) or a completed best interest process. This is why these processes are so fundamental; they are not administrative procedures but are the vehicle for consulting, examining and analysing information that underpins what decisions will protect and promote the best interest of the person; in this case Gwen.

188. Meetings which took place with the family did not result in agreement with professional recommendations until the recommendation was changed to meet with the family's agreement.

189. The decision for Gwen to go home was a capitulation to the continuing opposition of Duncan and the misdirection of Gwen's temporary functional ability that the family interpreted as Gwen returning to an earlier level of less dependency are factors that deserved to be dealt with more assessment rigour at the time.

190. This included Gwen's level of dependency and risk because of a variety of factors, including Duncan's inability or unwillingness to accept Gwen's increasingly complex care needs. Duncan's physical frailty including his problems with balance and memory combined with his refusal to pay for Gwen's care were all visible and real sources of risk to Gwen. Additionally, Duncan's dismissive or obstructive interaction with professionals, his description of Gwen being naughty and for example pretending to sleep when he tried to feed her, and his need to control Gwen's opportunity to be consulted or what financial

resources could be used were further concerns given Gwen's almost absolute dependency on Duncan.

191. The "Transfer of Care" (TOC) document for the care home carer specified that the provider was to make contact with adult social care before any care arrangement was amended or removed. There is no record of contact being made with ASC to advise that the care had been cancelled. Reliance was placed on the care agency and the provider informing social care of any change in provision as per the discharge process. This did not happen.

192. There was no ongoing action plan, risk assessment or safeguarding process which identified the ongoing risk of Duncan potentially not being willing to pay for care (for which a cost would be inevitable) should Gwen require care at the end of her initial support at home. It is documented within Gwen's case notes that Duncan did not feel the need to pay for carers just to "change her nappy" as he could do this himself. It was also documented that Gwen would be over the financial threshold for financial support towards care provision although a financial assessment was not completed.

193. There is no process for ASC to "check" whether a person or family maintained the care after discharge. The responsibility remains with the care provider at this point. As eligibility had been completed under the Care Act an annual review process had been triggered but this would not activate a follow-up call/check within the period between discharge and Gwen's death.

194. Gwen's admission to residential care meant that she was registered with the GP practice providing primary health care services to the home and was de-registered from her long-term GP. Neither of the GP practices was directly involved in the discharge planning for Gwen; this is not unusual. There was no consultation with the GP Practice about Duncan's health and ability to meet the complex and demanding range of care and support needs that Gwen had.

How were Gwen's views, wishes and feelings sought, recorded and acted upon?

195. There is little recorded information about how Gwen's views, wishes and feelings were sought over the above recording that she seemed happy or content or appeared to agree with Duncan.

196. Information that is provided about Gwen's views, wishes and feelings being sought provides evidence of Gwen's cognitive difficulties. For example, she is asked where she would like to go when she leaves the care home and replies swimming although when asked if she wanted to return home to Duncan, she answered that she would. There is no evidence of anybody talking with Gwen about options for example remaining in a care home or discussing other options with her. There is no recorded evidence of reasonable adjustments for example being made to assist Gwen in such discussion or complying with code of

practice expectations that assistance is given to assist a person in their understanding.

197. Although it was known that Gwen had memory concerns and was diagnosed with dementia, no recorded consideration was given to gaining Gwen's views and wishes about surgery for her cataract. Gwen's vision impacted her ability to engage in activities that she wished to undertake. Therefore, this procedure may have provided Gwen with an improvement in her sight however as indicated by the clinician, the outcome of the surgery was unforeseeable due to Gwen's macular degeneration.

Are there specific considerations around equality and diversity issues arising from Gwen's age, and disability, that require special consideration? Were any reasonable adjustments considered?

198. The GP practice made reasonable adjustments such as arranging to visit Gwen at home when getting the surgery was problematic.

199. Most appointments by health and social care professionals to see Gwen were scheduled by professionals without little recorded consideration or discussion about whether Gwen was more able to engage in any discussion or interaction at different times of the day or to attempt more than one contact with Gwen.

200. The care assessment and care plan indicated that Gwen had little vocalisation, had limited facial expression or change in body language to indicate for example her wishes or feelings. There is no record of what care, health and social care staff did beyond relying on Duncan to effectively speak on Gwen's behalf.

201. For example, ensuring the location for a discussion is calm and quiet, whether it was a time of day when Gwen was more able to communicate more clearly.

202. Communication is not just talking. Gestures, movement and facial expressions can all convey meaning or help get a message across. Body language and physical contact become significant when speech is difficult for a person with dementia.

203. When someone has difficulty speaking or understanding, particular measures can be attempted: patience and remaining calm, which can help the person communicate more easily; keeping the tone of voice positive and friendly, where possible; talking at a respectful distance to avoid intimidating them; being at the same level or lower than they are (for example, if they are sitting) can also help; patting or holding the person's hand while talking to them can help reassure them and make them feel closer; using eye contact; minimising distractions or other people including family trying to take over; repeating back what is thought or understood about what they might be communicating;

watching their body language and listening to what they say to see whether they're comfortable with the discussion and approaches being attempted.

Was a carer's assessment offered and completed? Did it explore support needs for Duncan and/or other family members or potential stressors?

204. Duncan declined offers to refer or signpost him to any support for carers. The reason for this reluctance is not known. Duncan was resistant to any discussion about the level of care that Gwen needed and some of this may have been based on Duncan having been able to meet Gwen's needs at an earlier stage in her developing disease combined with unrealistic optimism about functional improvements that were observed in Gwen in October 2022 as a result of changed medication. There is no recorded evidence that details from the various assessments completed by care staff with Gwen were discussed with the family.

205. The GP Practice provided evidence of Duncan's needs being considered on several occasions and asked if he could manage to meet Gwen's care and support needs. They made clear that he could contact the practice if their needs changed which relied on Duncan's self-reporting. The GP Practice would have benefitted from being made aware of the records of assessments with Gwen when in residential care; the evidence that she was gaining weight, the care and risk assessments, and the fact that she was at high risk of choking and falls. Putting this information alongside Duncan's changing health and difficulties for example with sleeping would have helped inform assessments.

206. The UHNM identified an outpatient appointment in July 2019 when Duncan and his daughter were concerned about Gwen's rapid deterioration. Although there was a good clinical response in responding to Gwen's symptoms and ensuring appropriate treatment was in place there could have been improved curiosity to determine what support needs Gwen had and how the family could continue to meet them and for this to have been a prompt to discussing sources of support.

207. The UHNM acknowledge that improvements are needed in staff identifying and considering the needs of people caring for patients receiving hospital treatment and signposting them to support services. For example, there were multiple contacts with the memory clinic between 2018 and 2023 when there were opportunities to provide clearer advice about support services which may have been received better by Duncan coming from staff that Gwen and he were seeing regularly.

208. There was no contingency plan for support to Duncan when Gwen returned home in the event of the carer arrangements breaking down.

Were Covid, organisational arrangements or working arrangements with other services a factor in how services were provided to Gwen?

209. In the agency reports for the DARDR Covid was not considered to be a factor in how services were provided to Gwen (or Duncan). The panel were mindful that during the pandemic there was no opportunity for face-to-face contact with Gwen or Duncan.

210. The DoLS assessment was not completed. These arrangements are the responsibility of the Supervisory Body which is the local authority who are responsible for authorising (or refusing if not in the best interest of the person) and assessing deprivations of liberty outside of the Court of Protection. As part of their function, they have responsibility for monitoring and evaluating the DoLS process. Additionally, they have a function in providing feedback and learning on improving care and safeguarding arrangements in care homes and hospitals. This case raises issues for the local authority as a Supervisory Body and for any managing authority operating care, nursing and hospital settings.

211. Working arrangements between ASC, the care home and other health services such as the GP were not coordinated or the responsibility of one service or professional. There is no comment in the reports provided to the DARDR about whether staff had access to sufficiently reflective and challenging supervision and oversight. All of the professionals are working in services that are under very severe workload pressures and simultaneously doing complex work. The level of challenge from Duncan at times would have been difficult to manage and contributed to work being reallocated adding further complexity.

212. Duncan's inability to understand or accept the level of Gwen's needs and the risks associated combined with his reluctance to pay for care and support should have been subject to a specific assessment of risk.

With the benefit of hindsight, is there anything that might have been done differently?

213. Completion of a Mental Capacity Act assessment should have been completed and there were several times when this should have happened. The DoLS process should have included a mental capacity assessment and if that had determined that Gwen did not have mental capacity and her deprivation of liberty had been authorised as being in her best interests that would have determined that Gwen remained at the home subject to the period of authorisation that was specified. It would not be a long-term solution which would either see progress in locally resolving the dispute or taking the matter to the Court of Protection for a ruling. If agreement about Gwen's best interest could not be achieved an application to the Court of Protection should have been made for a judge to rule what was in Gwen's best interests. If the authorisation under the DoLS had been agreed it would have been for Duncan

to make that application and he could have been advised and supported in doing this.

214. Any best-interest decision had to be informed by a detailed discussion of Gwen's care and support needs alongside a consideration of what the least restrictive options were for keeping Gwen safe.

215. An IMCA[32] or other advocate should have been appointed to ensure that Gwen's views were independently considered rather than relying just on what Duncan or any other family member thought was in Gwen's best interests.

216. Duncan should have been given information about how to raise a formal complaint as a means of having independent scrutiny of the concerns he was raising with the services.

217. A contingency plan that included how the arrangements were to be supported and monitored should have been agreed.

218. The care agency should have contacted ASC as a matter of urgency when the carers were prohibited from continuing with the care plan.

219. If all of the services including the neurology service had been part of or given a copy of the care plan there would have been a clearer opportunity for the nurse to have raised the issue with ASC in January 2023 just before Gwen died.

220. Duncan should have been offered a carer assessment although they may have been aware that he had declined signposting to carer support services when this had been raised by other services.

221. A safeguarding referral could have been made to the Office of Public Protection to help the decision-making[33].

Conclusions

222. Families dealing with the reality of dementia find it frightening and bewildering as the person they have known is changed by their disease.

223. The relationship between dementia and domestic abuse is complex. People with dementia have cognitive symptoms that can make them more at risk of abuse or neglect and make it even more difficult for them to protect themselves. Carers can also be at risk of neglect and abuse especially if they are overburdened, isolated, lonely or experiencing severe stress. Dementia

[32] An IMCA is an advocate who has been specially trained to support people who are not able to make certain decisions for themselves. IMCAs do not make decisions and they are independent of the people who do make the decisions.

[33] https://www.gov.uk/government/organisations/office-of-the-public-guardian/about

changes both spouses. There has been some discussion about a potential specific link between dementia and spousal domestic abuse associated with the onset of Alzheimer's[34].

224. Abuse and safeguarding interventions for people with dementia are complex because of the additional concerns around cognitive capacity as it relates to decision-making. Dementia can affect a person's memory, comprehension, and judgment; as a consequence, it can impair a person's decision-making capacity in some areas of their lives.

225. It is challenging for health and social care professionals to determine whether it is appropriate to take action on behalf of older people with dementia, especially in cases where intervention is warranted, but consent is not granted or is disputed. Healthcare and other professionals are bound by professional ethics to respect an individual's autonomy and yet they are obligated to protect vulnerable older people from abuse and neglect. The matter is further complicated by the fact that it is often difficult to make judgments about cognitive capacity or decisional capacity, as a person's cognitive status may fluctuate.

226. The difficulties and changes that Gwen's condition was imposing made her unable to care for herself or to protect herself from harm. Gwen was an adult at risk with several areas of vulnerability which are reflected in DARDRs and SARs in other parts of England. Women in Gwen's circumstances are adults at risk from the increasing complexity of their needs and conditions. As they become less mobile and more dependent on a spouse or family members and their ability to communicate and process information becomes more difficult their level of vulnerability to any form of abuse is elevated.

227. Dementia and cognitive disease are substantial risk factors for abuse of older people from domestic abuse, elder abuse and exploitation.

228. The discharge of Gwen to the care of Duncan represented a very considerable risk. It is not for the DARDR to say that a particular decision is right or not; it is the role of the DARDR to highlight where expected processes were not followed that could have made decision-making more robust and informed and to learn from that.

229. The level of Gwen's care and support needs combined with Duncan's rejection of support combined with the financial motivation and lack of understanding and insight that Gwen had a deteriorating condition that was getting worse would place any carer under very considerable levels of stress and was something he was struggling with in his interactions with professionals. Duncan

[34] Fok-Han Leung, Kara Thompson, Donald F. Weaver; Evaluating Spousal Abuse as a Potential Risk Factor for Alzheimer's Disease: Rationale, Needs and Challenges. Neuroepidemiology 1 July 2006; 27 (1): 13–16. https://doi.org/10.1159/000093894

acknowledged that he was becoming forgetful in conversations with health professionals and was drinking more alcohol than previously.

230. The concerns about how Gwen's care and support needs would be met if she returned home were reflected in the discussions various social care professionals attempted with Duncan. This was met with concerted opposition from Duncan to any plan other than his. His unwillingness to meet the cost of care support was an important factor (and was economic abuse) although he also showed a lack of insight and understanding about Gwen's condition and the implications for developing more complex care and support needs and the risk from issues such as choking and falling for example. Not all avenues were tried to resolve the differences.

231. Advocacy could and should have been used as part of the DoLS process; the complaints process could have been offered as a way of looking at his concerns. The DoLS process should certainly have been completed more robustly and if agreement could not have been reached it should have been referred to the Court of Protection.

232. The Care Act 2014 states Safeguarding is 'Protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult's well-being is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action.'

233. The care plan did not go much beyond a commitment for two carers to visit four times a day. Important partners such as the GP were not made aware of Gwen's discharge until Duncan requested medication and had no details about what the plan involved.

234. The service providing the carers told nobody else about Duncan stopping access less than three weeks after the discharge. There was no contingency to deal with this eventuality even though Duncan had flagged very clearly that he was opposed to any support coming into the home.

235. Duncan's health problems and difficulties with balance combined with his short temper and obstructive responses when he did not get his way should have been given much greater attention.

236. Important processes such as the DoLS were not completed; this is not about whether the right bit of paperwork was completed or not. The Deprivation of Liberty Safeguards (DoLS) is a crucial aspect of the UK's mental health care and social services system providing legal protection for adults at risk and ensuring that the human rights of a vulnerable group are upheld.

237. When it works as intended the process guarantees that the care and treatment being provided are in the best interest of the individual through a process of interlinked assessments. It serves as a safeguard against potential abuse or neglect.

238. Regrettably, it is a system that is beset with a time-consuming and bureaucratic process that results in delays in decision-making. It is a potentially complex process and can be resource-intensive. However, once an authorisation is agreed upon by the Supervisory Body nobody can overturn the care arrangement until the DoLS process has assessed whether the person can decide on their care (and therefore the DoLS process no longer applies) or the BIA assessment is completed and concludes what arrangements are in the best interest of the person.

239. A corporate review of the DoLS was being completed by the local authority and this report recommends that findings from the DARDR be considered as part of that process.

240. If the BIA assessment in this case had concluded that continuing care at the home was in Gwen's best interests that could not have been overturned unless and until it had been referred to the Court of Protection for a judicial ruling which would have been binding on all parties or the disagreement about what was in Gwen's best interests had been resolved locally.

241. The fact that the DoLS process was not completed is the issue; the BIA may or may not have decided that it was in Gwen's best interest to be cared for at home although the assessment would have had to set out in detail how the differing needs and risks were to be addressed. The Supervisory Body had the option of making a referral to the Court of Protection.

242. The report has commented earlier on occasions other than the DoLS when a Mental Capacity Act (MCA) assessment could and should have been completed.

243. The MCA is based on best practice and creates a single, coherent framework for dealing with mental capacity issues and a system for settling disputes, dealing with personal welfare issues and the property and affairs of people who lack capacity.

244. The MCA puts the individual who lacks capacity at the heart of decision-making and places a strong emphasis on supporting and enabling that individual to make their own decisions. If they are unable to do this it emphasises that they should still be involved in the decision-making process as far as possible.

245. Mental capacity is central to the MCA and should be a daily part of health and social care decision-making. Professionals can often assume that capacity is a

global condition in terms of making specific decisions. They can also mistake functional ability for cognitive health; in this case, some of Gwen's physiological symptoms were improved temporarily by changes in her medication but did not achieve improvements for example in her cognitive condition. Some of Duncan's frustration with Gwen's behaviour is interpreted as her being "naughty" or "pretending to sleep".

246. Assessing capacity requires a distinction between and consideration of 'decisional' capacity and 'executive' capacity. Although not in the MCA Code of Practice these contextual terms when assessing the decision-making capacity of talking-the-talk (decisional capacity) and walking-the-walk (executive capacity) (being able to process and carry out a decision).

247. Executive functioning is an umbrella term used to identify a wide range of cognitive functions commonly thought to be situated in the frontal lobes of the brain. This includes, for example: insight, attention, planning, organisation, initiation, generating ideas, inhibition, control of behaviours and emotions, problem-solving, evaluation, judgment and decision-making skills. If and when these are damaged through injury or disease such as Alzheimer's this can cause executive dysfunction.

248. Crucially in Duncan's case (who had begun talking to the GP about his problems with balance and memory), it means that the person might have good awareness or insight about a particular problem and be able to engage in talking about it but then have great difficulty in organising themselves to initiate or manage a situation or solution. In Duncan's case, he displayed very little awareness or insight about Gwen's condition (talking the talk) let alone addressing how her needs could be adequately and safely met.

249. Abuse in older age can be difficult to identify. This is particularly so in the case of older people with dementia where cognitive decline can present a barrier to disclosure and mask any abuse. Thus, healthcare and social care professionals have a critical role in preventing abuse and intervening when necessary.

250. The DARDR was told that local thematic audits routinely consider whether the voice wishes, and feelings of people with limited vocalisation and cognitive function are promoted throughout documentation completed by social work team members. This includes consideration of written evidence throughout the documentation being measured against a set of standards, from any initial contact to best-interest decision-making and recommendations.

251. Given that the risk of abuse is higher in vulnerable older people, such as those with dementia, health and social care professionals in particular need to be equipped with both the knowledge and the tools to recognise the *potential for* as well as the *warning signs* of abuse in this group.

252. Routine screening for both subjective and objective evidence of abuse, careful interviewing and observations for forensic biomarkers of abuse are all important professional disciplines.

253. Although several approaches and techniques to screening for elder abuse among people with dementia are discussed in the literature, no validated screening instruments for use with older people with dementia have yet been reported[35]. Indicators of abuse and behavioural signs of distress are marked out as something that health and social care professionals should pay particular attention to in older people with dementia.

Lessons to be learnt

254. Things that make a difference include;

a) Professional curiosity; the DNAR in place with Gwen saying she "would be better off out of the way" for example; what was Gwen's life like before she became so incapacitated; what had been the dynamics of the relationship; awareness of the cultural and social context of Gwen and Duncan's relationship; issues such as control of money and decision making; did this reflect longer-term patterns of behaviour in this relationship
b) Avoiding making assumptions that a spouse and family always make the right decision in the best interest of a person; minimising risk is wrong and potentially dangerous;
c) Considering potential conflicts of interest within families and whether there are differing perspectives about what is in the best interest of family members;
d) Understanding that people with dementia will have cognitive symptoms that make them more at risk of abuse or neglect and make it harder for them to protect themselves; they may not exhibit physical evidence of abuse; not eating (such as losing weight) and low self-esteem (such as not wanting to carry on living);
e) Awareness that there are particular dynamics and pressures for couples adjusting to cognitive disease that may produce behaviours not evident before in the relationship;
f) Awareness of domestic abuse in later life may be behaviour that has 'grown old' throughout the relationship; it may reflect behaviour that changes as a result of changing circumstances such as cognitive health and functioning or a new partnership in later life; a quarter of domestic homicides are women over 60 killed, most of whom have care and

[35] Wiglesworth A, Mosqueda L, Mulnard R, Liao S, Gibbs L, Fitzgerald W. Screening for abuse and neglect of people with dementia. J Am Geriatric Soc. 2010 Mar;58(3):493-500. doi: 10.1111/j.1532-5415.2010.02737. x. PMID: 20398118.

support needs with no history of recorded domestic abuse and are killed by their carer;

g) Being alert to factors that influence an absence of disclosure about domestic abuse can include embarrassment, lack of awareness about services and options, increasing dependency through ill health, loss of independent income, and isolation.

h) Not relying on one voice of authority about what is in a close relative's best interest or that LPA equates with always understanding the best interest; control of the narrative about the relationship and how professionals receive, process and make decisions about information can prevent effective protection from risk and abuse;

i) Understanding economic abuse; using the power of LPA to prevent care and support services is controlling behaviour that comes within the scope of economic abuse; economic abuse rarely happens in isolation; inquiring into the history of the relationship is an important part of assessment;

j) Cognitive disease (or brain injury or a disorder) robs victims of the ability to communicate or understand weigh up risks and make judgments about what is in their best interest; older spouses may also be experiencing adverse changes to their cognitive and physical health and need help to achieve best interest arrangements;

k) Completing good enough and updated assessments that are focussed on the best interest of the person, are informed about the particular vulnerabilities including abuse, exploitation and neglect and informed about the relevant legal options;

l) Ensuring the DoLS process is effective in ensuring the protection and safeguarding of vulnerable individuals in care and hospital settings, that it is based on consideration of the best interest of the person, it protects their human rights and is a crucial safeguard against potential abuse and is a mechanism for the voice of the person to be sought, supported and encouraged; the non-completion is a significant missing link in this case;

m) Ensuring clear communication and coordination of care plans for adults at risk that include explicit contingency arrangements for dealing with changes in circumstances including refusal of carers;

n) Recognising that less use of services is associated with elevated risk for abuse; refusing access to home carer support, and declining support from carer support services are examples of declining services that could have made a difference;

o) Legal literacy and confidence; seeking legal advice and using the Office of Public Protection and the Court of Protection where local best-interest decision-making is unable to resolve disputes;

p) Checking and understanding as early as possible who has particular legal responsibilities about an adult at risk such as LPA; this may need to be done through routine checking with the Office of Public Protection.

255. This DARDR was commissioned by the Stoke-on-Trent Safer City Partnership although the SSASPB are the appropriate body for overseeing the learning from the DARDR. A learning summary will be circulated to practitioners that draws attention to the particular vulnerability of older women with cognitive diseases who are victims of domestic abuse. The appendix at the rear of this report includes the recommended actions identified by agencies in their management reviews.

Recommendations

1. The SSASPB should ensure that the lessons learnt and recommendations from this DARDR are included in future learning events. Any additional professional development and learning opportunities that are identified should be reported back to the SSASPB.

2. The local authority in its role as the DoLS supervisory body should consider the findings of the DARDR alongside the corporate review of the DoLS service.

3. The Community Safety Partnership should seek assurances from the SSASPB that the relevant partners have produced guidance for practitioners to:

    a) Support their application of BIA and best interest decision-making.

    b) Understand the use of and differences between LPAs for health and welfare and property and financial affairs.

    c) Understand the role of the Office of Public Guardian.

4. The SSASPB should seek assurances from relevant partner agencies that they have reviewed the policy and practice guidance and included the need for a risk assessment following an adult's discharge from care and the adult (or carer) withdraws from the assessed need provision.

5. The SSASPB executive sub-group should consider the inclusion of learning from the DARDR as a case study in the annual report.

National policy

1. Although several approaches and techniques to screening for elder abuse among people with dementia are discussed in the literature, no validated screening instruments for use with older people with dementia have yet been reported.

Individual management review recommendations

Staffordshire and Stoke-on-Trent Integrated Care Board (ICB)

1. For the ICB to work with GP practice A to discuss recording the context of discussions relating to any advance decision to refuse treatment in patient records.

Stoke-on-Trent Adult Social Care

1. Stoke-on-Trent City Council Adult Social Care will deliver change and improvements concerning the Personalisation of Practice as part of the Adult Workforce Development plan for 2024.
2. Stoke-on-Trent City Council Adult Social Care will deliver change and improvements around carers as part of the Adult Workforce Development plan for 2024.
3. Stoke-on-Trent City Council Adult Social Care will deliver change and improvements concerning adults who transfer between practitioners or services as part of the Adult Workforce Development plan for 2024.

University Hospitals of North Midlands NHS Trust

1. UHNM will ensure that all staff groups receive information regarding carers (inclusive of unpaid, family, and friends), services and support which is available to signpost and refer to, and the associated risks and escalation process.
2. UHNM will ensure that specific outpatient information is available for staff regarding how to respond to safeguarding concerns, and care concerns.
3. UHNM to cascade a learning alert throughout the organisation regarding carers, associated risks, support services, and safeguarding considerations.
4. UHNM to ensure that staff have accessible information with regards to carers (inclusive of unpaid, family, and friends), services and support which is available to signpost and refer to, and the associated risks and escalation process.

Glossary

Advance decision to refuse treatment	An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT, or a living will) is a decision made in advance to refuse a specific type of treatment in the future.
BIA (best interest assessor)	The BIA is responsible for deciding whether a restrictive situation is authorised by Sections 5 and 6 of the Mental Capacity Act 2005 (MCA), or whether it amounts to a deprivation of the person's liberty. If they conclude, given all evidence and scrutiny of the situation of the person, and in the light of current case law, that the person is deprived of their liberty, they must assess holistically whether the restrictions are in the person's best interests, and proportionate to the risk and seriousness of harm to that person without the proposed restrictions. Their role is governed by regulation and statutory guidance.
Best interest decision	If a person has been assessed as lacking capacity, then any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests (principle 4 of the MCA).
Care Act assessment	An assessment under the Care Act 2014 is an assessment of needs for care and support, or an assessment of a carer's needs for support. It includes assessing any safeguarding concerns.
Carers assessment	Section 10 of the Care Act 2014 requires the local authority to complete an assessment where a carer may have support needs. This includes whether the carer is able or is likely to continue to be able to provide care for an adult requiring care.
Care Plan	A care and support plan states what type of support is needed, how the support will be provided, how much money the local authority will spend and what charges will be the responsibility of the person receiving the care and support.
Complaint process	By law, all health and social care services must have a formal written procedure for dealing efficiently with complaints which includes providing information about how to make a complaint, arrangements to have the complaint investigated and providing a full and prompt response that includes information about having the complaint looked at independently.
Court of Protection (COP)	The Court of Protection was established under the terms of the Mental Capacity Act 2005, which came into force on 1st October 2007. It is a specialist court which makes specific decisions or appoints other people known as deputies to make decisions on behalf of people who lack the capacity to do so for themselves
DNACPR, DNAR or DNR	DNACPR stands for Do not attempt cardiopulmonary resuscitation. It's sometimes called DNAR (do not attempt resuscitation) or DNR (do not resuscitate) but they all refer to the same thing. A DNACPR decision is usually recorded on a specific form that is easily recognised by health professionals.

	It is a decision made in advance (hence the term advance decision) when a person still has the legal mental capacity to say what they want to happen if they become ill.
DoLS (deprivation of liberty safeguarding)	The Deprivation of Liberty Safeguards (DoLS), which apply only in England and Wales, are an amendment to the Mental Capacity Act 2005. The DoLS under the MCA allows restraint and restrictions that amount to a deprivation of liberty to be used in hospitals and care homes – but only if they are in a person's best interests. To deprive a person of their liberty, care homes and hospitals must request standard authorisation from a local authority (the Supervisory Body).
Economic abuse	Economic abuse is a legally recognised form of domestic abuse and is defined in the Domestic Abuse Act 2021. It often occurs in the context of intimate partner violence and involves the control of a partner or ex-partner's money and finances, as well as the things that money can buy such as goods and services associated with care and support needs.
IMCA (independent metal capacity advocate)	Introduced by the MCA the role of IMCAs is to be a legal safeguard for people who lack the capacity to make specific important decisions: this includes making decisions about where they live and about serious medical treatment options. IMCAs are mainly instructed to represent people where there is no one independent of services, such as a family member or friend, who can represent the person's best interests or there is a conflict of opinion as occurred in this DARDR.
LPA (lasting power of attorney)	LPAs came into force in October 2007 and include two categories; a health and welfare LPA and a property and financial affairs LPA. A health and welfare LPA gives the attorney the power to make decisions about daily routines (washing, dressing, eating), medical care, moving into a care home and life-sustaining medical treatment. It can only be used if the person is unable to make their own decisions. A property and financial affairs LPA give the attorney the power to make decisions about a person's money and property. This includes managing any bank or building society accounts, paying bills, collecting a pension or benefits and, if necessary, selling a home. In this DARDR Duncan had LPA for health and welfare but not for property and finance although claimed he did.
Mental capacity	The MCA refers to a specific decision made at a specific time. The MCA sets out a two-stage test of capacity; Firstly, does the person have an impairment of their mind or brain, whether as a result of an illness, or external factors such as alcohol or drug use? Secondly, does the impairment mean the person is unable to make a specific decision when they need to? People can lack the capacity to make some decisions but have the capacity to make others. Mental capacity can also fluctuate with time – someone may lack capacity at one point in time but may be able to make the same decision at a later point in time.
SALT	Speech and language therapy services

Supervisory Body	The role of the local authority to act as a supervisory body for DoLS imposes upon it a more general duty to act as a human rights champion for those adults who might lack the capacity to agree to actions taken by others. When a local authority is carrying out its supervisory functions, its processes and practices must promote human rights, be open, transparent and helpful to the person at the centre of DoLS, the 'relevant person' (or person for whom detention is sought), and their relatives or friends. The 'positive obligation of the state' means that all its interventions must be accompanied by scrutiny within this essential framework. Oversight and management of the supervisory body functions relating to the Safeguards should be assessed against the standards laid down in the funding fact sheet produced by the DH in 2012.