SAFER CORNWALL
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DOMESTIC HOMICIDE REVIEW DHR13

INTO THE DEATH OF ADULT A (PSEUDONYM) – 2021

OVERVIEW REPORT

Report Authors and Independent Chairs

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Report Completed – 15th December 2022

Foreword

A pseudonym has been used to protect the identity of the victim and her family.

Family Tribute

“It is extremely difficult to sum up 82 years of life, 61 years of being a wife, 60 years of being a mother, 35 years of being a grandmother and 6 years of being a great grandmother! You dedicated your life to being the best you could possibly be in each and every role.

You were a loving, caring person who is sadly missed by all your family. You were taken from us too suddenly and too soon, when we all still had so much more to enjoy together”.

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Preface

The Safer Cornwall Domestic Homicide Review Panel would like to express their sincere condolences to the family members affected by the sad events which have resulted in this Review. We hope this Domestic Homicide Review helps to answer some important questions relating to the events leading up to Adult A's (pseudonym) tragic death.

The independent chairs and authors of the review would also like to express their appreciation for the time, commitment and valuable contributions of the victim's daughter (referred to as C2), review panel members and the authors of the individual agency chronologies from which the foundation of the analysis of this overview report is formed.

The review has used the terms 'carer' and 'caregiver' interchangeably throughout the report in recognition of the different ways people who provide care to others denote to themselves when describing their own important role.

SECTION ONE - INTRODUCTION

Summary of circumstances leading to the Review

1. Police were called to the home address of husband (Adult B) and wife (Adult A) by ambulance control. A female at the address had called 999 to report that she had been stabbed in the back in the bathroom by her husband and that he was still in the property. First Responders arrived at the address but could not enter as a result of Adult B being present and being assessed as posing a danger.

2. Further updates were received by Police stating Adult A had stopped engaging with the ambulance control room, suggesting a possible loss of consciousness.

3. Upon Police arrival, Adult B was still in possession of a knife and refused to drop it. Whilst in the living room, Adult B began to superficially cut himself to the stomach which resulted in officers deploying a taser to control him.

4. Adult A was located deceased inside the property and was pronounced life extinct on the same day by attending paramedics. Adult B was detained by officers on suspicion of murder.

5. Whilst in custody, Adult B was seen by medical professionals and deemed unfit to be interviewed due to suspected vascular dementia. The investigation team approached the Crown Prosecution Service with a view to securing one charge of murder which was duly authorised. Adult B was charged and remanded into custody.

6. A forensic post-mortem identified four stab wounds to Adult A’s back and concluded that these alone were responsible for her death.

7. Adult B was deemed unfit to stand trial due to advancing dementia. He was sentenced to an indefinite hospital order.

Reasons for conducting the Review

8. Domestic Homicide Reviews (DHRs) came into force on 13th April 2011. They were established on a statutory basis under Section 9 of the Domestic Violence, Crime and Adults Act (2004). The act states that a DHR should be a review *'of the circumstances in which the death of a person aged 16 or over has, or appears to have, resulted from violence, abuse or neglect by:*
   - *(a) a person to whom he was related or with whom he was or had been in an intimate personal relationship, or;*
   - *(b) a member of the same household as himself, held with a view to identifying the lessons to be learnt from the death'.*

9. Adult A and Adult B were married and had recently celebrated their 60th wedding anniversary. There are no professional records pertaining to domestic abuse between them and their children describe their parents as 'caring, loyal, and devoted to each other'[1]. Despite Adult A's homicide being linked to Adult B's neurodegenerative disease, the criteria of a Domestic Homicide Review (above) was met and Safer Cornwall was obligated to commission a DHR in line with Multi Agency Statutory Guidance for the conduct of Domestic Homicide Reviews (2016).

10. The key purpose for undertaking this Domestic Homicide Review is to enable learning from deaths associated to, or as a consequence of domestic violence and abuse, even if the only known incident of domestic abuse was the final, fatal occurrence. In order for the learning to be as wide and thorough as possible, professionals need to be able to understand fully what happened, and most importantly, what needs to change to reduce the risk of such tragedies happening in the future. By taking this holistic approach and examining the accessibility and barriers to support within our own community, the review panel aims to identify appropriate solutions to make the future safer for the residents of Cornwall.

Timescales and Process

11. The Cornwall Community Safety Partnership were notified of the homicide of Adult A on the 01 June 2021. The decision to undertake a DHR was made in July 2021 by the Community Safety Partnership Chair and independent co-chairs were appointed on the 29th July 2021. The Home

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[1] Statement provided to court October 2021

Office was notified of the decision to carry out a DHR On 08 July 2021. The family were notified of the intention to hold a review by letter which included the Home Office leaflet and AAFDA leaflet on 29th July 2021. The Terms of Reference was shared with the family in December 2021 and accepted by the review panel and family on 1st February 2022.

12. Initial enquiries were made of statutory and voluntary agencies to ascertain which organisations had contact with Adult A and Adult B both in Cornwall and their existing area of residence (Bristol). Agencies were asked to secure their files via a formal written letter to the Chief Executive Officers. A chronology of contact was requested. Each agency was asked to describe what documents were accessed and whether interviews were undertaken with staff and/or volunteers. Electronic systems and paper records were examined. Consultations and interactions were recorded chronologically from letters, case notes, call logs, email communications and meeting minutes. This data capture was extremely limited for both Adult A and Adult B. After consultation, it was decided that the case did not meet the criteria for a Safeguarding Adults Review (SAR).

13. The first full panel meeting was held on 1st February 2022. This was attended in part by Adult A and Adult B's daughter who acted as the family representative. A second panel meeting was called on the 6th May 2022. A third panel meeting was held on the 11th October 2022. The following panel members were represented at these meetings:

- Jane Wonnacott and Martine Cotter - Independent Chairs
- Detective Sergeant - Criminal Case Review Team, Devon and Cornwall Police
- Detective Chief Inspector – Devon and Cornwall Police
- Consultant Nurse for Integrated Safeguarding Services for Cornwall Foundation Trust and Royal Cornwall Hospital Trust
- GP Lead for Dementia Care - Cornwall Foundation Trust
- Director of DA Services, First Light
- Domestic Abuse and Sexual Violence Strategic Commissioning Team, Cornwall Community Safety Partnership
- Head of Nursing NHS Cornwall and Isles of Scilly Integrated Care Board (formerly Kernow Clinical Commissioning Group)
- Quality and Information Manager, Cornwall Housing Limited
- Safeguarding Adult Reviews and Business Development Manager, CIOS Safeguarding Adult's Board

- Safeguarding Service Senior Manager (Adults), Adult Care and Wellbeing Directorate, Cornwall Council
- Carers and Wellbeing Manager, Cornwall Rural Community Charity
- Community Safety Partnership DHR Administrator, Cornwall Council

14. Chronologies revealed little involvement with agencies in Cornwall due to the couple moving to Cornwall in late 2020. Information was requested from Bristol agencies, who confirmed that no information relevant to the terms of reference was available. Subsequently, it was agreed by the review panel that there was insufficient information to necessitate Individual Management Reviews (IMRs). Instead, individual and specific questions were asked of -
    - Cornwall Foundation Trust
    - GP Services
    - Police

15. Individual conversations with practitioners and agencies took place virtually via Microsoft Teams to analyse and discuss strengths and limitations of engagement. These virtual meetings took place between February 2022 and March 2022.

16. A last full panel meeting was undertaken on 11th October 2022 via Microsoft Teams, whereby the final conclusions, recommendations and action plan were discussed. At this meeting it was decided that the report should be shared with the Cornwall Rural Carers Group (CRCG) to gain their lived experience knowledge and ideas to assist in forming meaningful recommendations. C2 was involved in this discussion and consented for the report to be shared.

17. The Cornwall Rural Carers Group and the Carers Service were consulted in October and November 2022 and a focus group discussion with the chairs took place on the on 7th December 2022. The feedback from this discussion was shared with a working group of panel members on the 8th December 2022. The reviewers took the decision to invite a representative from the Carers Service (with lived experience) to the working group as a full panel member. The valuable contribution of CRCG and the Carers Service was instrumental in forming the recommendations for this review and the chairs and panel wish to extend their sincere gratitude to Jayne and Wendy for their time and specialist knowledge.

18. The review was concluded in December 2022.

19. Completion of the review was affected by a number of factors, including:
    - The initial decision to consider whether the case met the criteria for a Safeguarding Adult Review (On the 9th December 2021, the SAR subgroup confirmed the incident did not meet Section 44 criteria)
    - Post COVID-19 staff capacity issues.
    - The decision to consult Carers with lived experience (with the support of C2)
    - Seasonal periods and panel availability

Confidentiality

20. The findings of this Review are confidential. Information is available only to participating professionals and their line managers until the overview report is approved by the Home Office Quality Assurance Panel for publication.

21. Statutory guidance requires that this report be anonymised to protect the identity of the victim, perpetrator, and their respective families. To fulfil this duty appropriate pseudonyms have been assigned and used throughout the report. Professionals are referred to by an appropriate designation.

22. Due regard has been paid to the balance of individual rights and the public interest. Any redaction within this report has sought to properly balance rights to privacy and confidentiality in a way which does not affect the thoroughness of each agency's individual analysis, actions, and learning.

Dissemination

23. Subsequent to permission being granted by the Home Office to publish, this report will be disseminated to members of the Safer Cornwall Partnership Board and all agencies represented on the review panel.

24. The report will be produced in a read-only format suitable for on-line publication with redactions finalised before publication. The final overview report and executive summary will be published on Safer Cornwall's dedicated DHR website page.

Epistemic Justice

25. The term epistemic *injustice* has been used to describe situations where someone's knowledge/information is given less credence than they deserve. As a source of testimony, they are treated unjustly. Research into serious case reviews nationally has identified that this imbalance of status between 'formal' professional and 'informal' family contributions, is too often present, leading to a hierarchy of testimony [2]. Rowlands and Cook (2021) propose a conceptual framework for family engagement to help capture (from the outset) different perceptions of purpose, process and outcome, and recognise conflict and the potential for alignment. Moreover, they propose that articulating the integral role of family in such a framework will increase transparency of family rights, aid knowledge about which forms of testimony are considered of epistemic value and increase the opportunity for systems/relational-repair and community safety solutions.

26. In the context of this DHR, where different sources of information were brought together, the independent chairs and review panel adopted the Rowlands and Cook (2021) conceptual framework and committed to the principles of equality by seeking, valuing, and counting family testimony. Reviewers valued all knowledge, including the lived experience of family members and treated all testimony with the same degree of credibility and worthiness. In order to achieve this, the family of Adult A and Adult B were invited as equal partners to share their experiences, discuss issues important to them, contribute to the scope of the review and have an equal stake in the prospect of prevention.

Terms of Reference

27. Home Office Multi-Agency Statutory Guidance for the Conduct of Domestic Homicide Reviews (December 2016) states that the purpose of the Review is to:

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[2] 'Navigating Family Involvement in Domestic Violence Fatality Reviews: Conceptualising Prospects for Systems and Relational Repair' (Rowlands and Cook, 2021).

- Establish what lessons are to be learned from the domestic homicide regarding the way in which local professionals and organisations work individually and together to safeguard victims
- Identify clearly what those lessons are, both within and between agencies, how and within what timescales they will be acted on, and what is expected to change as a result
- Apply these lessons to service responses including changes to policies and procedures as appropriate
- Prevent domestic violence homicide and improve service responses for all domestic violence victims and their children through improved intra and inter-agency working.

Specific Terms of Reference for this Review:

28. In the spirit of epistemic justice, Adult A and Adult B's daughter was invited to contribute on behalf of the family to the development of the Terms of Reference (ToR). The process of drafting a ToR started with them, and their priorities were considered in the following questions:

- What are the facts about events leading up to the death of Adult A in 2021?
    a) Did all important care plans and healthcare records transfer to Cornwall when Adult A and Adult B relocated and was there a seamless and timely transference of care?
    b) What was known and understood about Adult B' s dementia and any implications this may have had for the safety of Adult A as his primary carer?
    c) Were appropriate considerations afforded to protected equality and diversity characteristics e.g., age, disability, marriage, race, religion and belief, sex and sexual orientation?

- What were the roles of the organisations involved in the case and the appropriateness of single agency and partnership/system responses? What factors were driving responses at an individual, organisational and systems level?
    d) What is the service response when a family relative refuses a formal needs assessment on behalf of another?
    e) What is the service response when a family member refuses a carer's needs assessment for themselves?
    f) How effective is the system at providing advice and support to friends and family who may have concerns about risks to an adult in their area?

g) How effective was supervision and training? Were there capacity or staffing issues at the time?

- What role did Covid-19 play in accessing and delivering expected levels of care during periods of national lock-down?
  h) How accessible and effective were health and adult social care referrals during lockdown and were the needs of older populations considered within virtual offerings?
  i) What consideration and support were offered to family carers, generally, and more specifically during periods of national lockdown, to improve coping potential and reduce burnout?
  j) Did the loss of face-to-face GP appointments during COVID compromise GP intuition meaning subtle signs (not necessarily linked to the presenting physical symptoms) observed during health consultations were missed, compromising professional curiosity (e.g., low mood, burn-out etc.)?
  k) Did the move to online systems, virtual meetings and automated telephone calls disadvantage elderly patients who were not 'tech-savvy' and was access to wider peripheral support systems compromised for elderly patients (who traditionally refer to their GP as their first port of call)?

- Establish whether there is learning from these circumstances which will include considering the way professionals from across the range of services worked together as a collective and review the whole system function.

Additional Questions

29. The family raised three questions specifically relating to the care of dementia patients post-arrest, which extended beyond the remit of a domestic homicide review. However, the reviewers felt these concerns were valid and important for future progress in dementia care. To ensure this learning was not lost, the specific post-homicide family questions have been allocated to a lead panel member who will take them forward with support from the Adult Safeguarding Board. The outcome of these discussions will be shared directly with C2 (Adult A and Adult B's daughter) – See recommendation 13.

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

30. The involvement of family and friends in any Domestic Homicide Review is integral. Their involvement provides an insight into the life of their loved ones from a perspective that is inaccessible to professionals. The family of Adult A and Adult B held mixed views about the commissioning of a Domestic Homicide Review. They experienced their parents to be devoted to each other, and believe the incident was directly attributable to their father's onset of dementia.

31. The chairs acknowledge this sensitive dynamic and have worked with the family to ensure learning is achieved and professional systems are effective at identifying, screening, and diagnosing dementia in a timely and consistent manner, ensuring carers are assessed and supported and families are assisted by a professional framework of care.

32. Adult B's views were not sought as part of this review. His dementia has significantly deteriorated since the incident, and he has no recollection of the homicide. Adult B believes his wife died of old age and this belief has not been challenged due to the vulnerable state of his health.

33. Adult A and B's family were invited to consider appropriate pseudonyms for their mother and father. After serious consideration, they asked the panel to use 'Adult A' for their mother and 'Adult B' for their father. This request was respected by the reviewers. They were also asked to write a tribute to their mother so that her life and her character are represented in this report. Adult A and B's middle child (C2) represented the family for the duration of the DHR. Two other siblings are too upset and traumatised to speak about the events. They have been updated by C2 throughout the process. Their loving words have been included as a foreword. They also assisted the reviewers by creating a 'pen picture' of their parents prior to the tragic event. These pen pictures have been included in section two.

34. The draft report was shared with Adult A and Adult B's family on 16th June 2022 as an electronic document with an invite for the family to contribute their feedback. Their suggestions and clarifications have been incorporated into this report.

35. The authors are very grateful to Adult A and Adult B's family for taking the time to write about their parents during such a difficult time.

Independent Chairs and Authors of the Overview Report

36. The Safer Cornwall Partnership commissioned Martine Cotter, a Home Office accredited DHR Chair, and Jane Wonnacott, an experienced independent reviewer as Independent Chairs to undertake this Domestic Homicide Review with the responsibility (in consultation with the Review Panel) to conduct the Review in accordance with the Terms of Reference and prepare this overview report and its executive summary.

37. Martine Cotter holds a Level 7 Post Graduate Diploma in Strategic Management and is a Fellow of the Chartered Institute of Management with over 17 years' experience working in the field of domestic abuse and sexual violence. She is currently studying a MSc in Neuroscience and Psychology of Mental Health at Kings College London and has a specialist interest in psychotraumatology and adverse childhood experiences (ACE). Martine has previously chaired and published four Domestic Homicide Reviews. She is currently chairing seven active DHRs.

38. Jane Wonnacott qualified as a social worker in 1979 and has significant experience in the field of safeguarding at a local and national level. Since 1994 Jane has completed well in excess of 200 Child Safeguarding Reviews, a Safeguarding Adult Review and two Domestic Homicide Reviews (DHRs). She is currently chairing seven active DHRs. Jane is a member of the National Child Safeguarding Practice Review Panel pool of reviewers and in this role has completed national thematic reviews. Jane is the author of 'Mastering Social Work Supervision', and 'Developing and Supporting Effective Staff Supervision' published by Jessica Kingsley Publishers and Pavilion.

39. The Independent Chairs are completely independent of the Safer Cornwall Partnership and any associated organisations in Cornwall. They have not had any contact, personally or professionally with Adult A, Adult B, or any other persons associated with the Domestic Homicide Review.

40. The Review Panel certified that they had no connections or ties of a personal or professional nature with the family. Where a connection with a participating organisation was unavoidable (i.e., they were employed by the organisation in a senior position) assurances were given to apply a fully independent judgement regarding the outcomes of the review. This was honoured and respected throughout the DHR process.

Parallel Reviews

41. In September 2021 Cornwall Partnership NHS Trust completed a Root Cause Analysis Investigation Report. This was carried out because Adult B was under the care of the Trust at the time of the incident. Involvement had included contact with the community nursing service, an assessment with the Memory Clinic and at the time of the homicide he had been referred for further tests. The full report has been made available to this Domestic Homicide Review and learning has been taken into account in the final analysis and recommendations.

42. A Coroner's inquest was adjourned pending the court case in October 2021. A letter was sent to the family from the coroner on the 22nd December 2021 asking their views as to whether the inquest should be resumed. The family did not feel that there would be any benefit to prolonging and extending the inquest. In June 2022 the coroner confirmed that the inquest would not be resumed.

43. At the Safeguarding Adult Review (SAR) subgroup meeting held on the 9th December 2021, it was decided that there was insufficient information and contact with Adult A and Adult B to consider assessable care support needs or to indicate meeting S44 criteria. The SAR subgroup agreed that any new evidence found during the DHR review should be reported back to the SAR subgroup for reconsideration of a SAR if appropriate. The learning from this review has been shared with the SAR subgroup and recommendations have been taken forward.

44. The reviewers have referenced an independent thematic review of seven cases involving unpaid caregivers as part of a commissioned report by the Safeguarding Adults Board (published June 22)[3]. This identified similar themes to the findings from this independent review. It is important that recommendations from the Safeguarding Adult Board Thematic Review are cross referenced

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[3] https://ciossafeguarding.org.uk/assets/2/cios_sab-thematic_carers_sar-2022.pdf

with the recommendations for this Domestic Homicide Review to ensure that efforts are not duplicated.

Equality and Diversity

45. Due consideration was given to The Equality Act 2010 which came into force on 1 October 2010 to legally protect people from discrimination based on the nine protected characteristics of people who use services e.g., disability, sex (gender), gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation, age, marriage or civil partnership.

46. Adult A was a white British national. She was 82 years old at the time of her death. Adult A was married to Adult B for 60 years, and they had three children together. Her records do not contain any information to suggest Adult A had a physical or learning disability or she was discriminated against based on any of the protected characteristics of the Equality Act 2010. Adult A's age was considered as an inequity issue in her struggle to access services through digital systems and the outcome of these findings have been included in this report.

47. Adult B is also a white British national, religion unknown. He is 85 (at the date of this report) and the father of 3 children with Adult A. Adult B had long-standing leg oedema and a chronic soft-tissue viability condition which greatly impacted his mobility. Oedema is not necessarily considered a disability; however, the severity of the condition, alongside soft-tissue wounds, can cause sufferers to require disability aids. By the time Adult B moved to Cornwall, his cognition and memory had started to deteriorate, and he was on the assessment pathway for a dementia diagnosis. Dementia is classed as a disability by the Equality Act 2010 as it causes "long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others".[4]

48. The reviewers considered Adult B's right under the Equality Act 2010 on the basis of his age and suspected neurological disability. The obligations of public services in relation to working with a person with a disability, and specifically, if these obligations were met by agencies working

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[4] https://www.dementiauk.org/get-support/living-with-dementia/dealing-with-stigma/

with Adult B were explored and the findings are contained within the analysis and learning of this report.

SECTION TWO – FAMILY BACKGROUND AND RELATIONSHIPS

Adult A

49. At the time of her death Adult A was 82 years old. She was living at a private rented residence in Cornwall having recently relocated from Bristol to be closer to family. Adult A was dedicated to Adult B and became his full-time carer when his health began to deteriorate in 2018.

Adult B

50. Adult B is 85 years old. He is currently detained under the Mental Health Act on an indefinite hospital order. He has advanced dementia and has no recollection of events. His family visit him frequently.

Their relationship and life together

51. The following pen portrait was provided by Adult A and Adult B's daughter, C2.

Mum and Dad met around 1955 when they both lived in Bristol. They were in their late teens and met at a local dance hall. They both enjoyed dancing to rock 'n' roll music. They married in 1960 and went on to have three children. Mum trained as a shorthand typist and worked in a variety of admin roles over the years. Dad did an apprenticeship in signwriting and then completed his National Service in the Royal Electrical and Mechanical Engineers R.E.M.E. This is something he still talks about now and obviously had an impact on him. After this he went on to become a painter & decorator, running his own small business. He did this for several years before going to work for the National Grid as part of the maintenance team.

They bought their first home together in Bristol. This was the first of many house moves, each time refurbishing and then moving on. They didn't have much time for hobbies but did share a love of going on holiday. This originally started as holidays to Devon & Cornwall, but when the weather kept proving inclement, they ventured further afield to Spain, Greece, Italy, USA etc. Dad used to spend a lot of his free time researching flights, accommodation etc.

When Mum took early retirement from British Telecom in 1996 and Dad took voluntary redundancy from National Grid, their love of travel prompted a move to Spain. They lived on the Costa Blanca for seven years.

In 2003, due to health concerns, they returned to live in the UK. They continued to holiday abroad, frequently staying for a month or more, especially during the winter months.

Mum was an avid fan of TV soaps and watched them all. Dad watched them as well, but I don't think he had the same level of enthusiasm. Mum also had a keen interest in clothes and Dad used to accompany her on her shopping trips, frequently ending up carrying her bags. They used to go everywhere together.

Over the years I did not see them that frequently as we lived hundreds of miles apart and with four children of my own, life was busy. Visits were often brief and because mum was very talkative and dad had always been quiet, nothing was significantly different. It was when they came to visit in 2018, that I noticed that they were both visibly frailer and dad was very quiet, indecisive, and tired. Mum believed he was depressed, as he did not like where they were living. Dementia was never mentioned or even thought of.

When they moved to Cornwall in December 2020, I saw them more frequently than before, but visits were limited, due to Covid. It did become noticeable however, that dad was very passive and only participated in basic tasks around the house and then only when it was instigated by mum. He frequently forgot things and although he would respond to questions this was always with a generic answer. He struggled to make decisions and did not like to talk to people as he took a long time to process the questions and then forgot or couldn't find the words to answer. In hindsight I think Mum covered for a lot of Dad's difficulties. She was a proud and independent woman and did not want to acknowledge that Dad had dementia and that they both needed support. Mum was of the generation that believed you just had to cope with life and what it threw at you. She was eventually persuaded to refer Dad for a memory assessment. This was completed and Dad was then referred for a CT scan.

Dad had multiple additional health issues and this, combined with his cognitive impairment finally made Mum admit that she wasn't coping and needed someone to look after her. A week later Mum was dead, and Dad was in prison.

Circumstances of Adult A's homicide

52. On the morning of the homicide, Adult A called 999 and reported that her husband had stabbed her in the back whilst she was in the bathroom. He was still in the property. Police were dispatched to the scene. The paramedic crew could see Adult A through the front window of the lounge leaning up against a wall. She was unresponsive, no respiratory effort, very pale, naked and with signs of blood loss. Police forced entry. Adult B was still in the lounge holding a knife, a taser was deployed and he was arrested on suspicion of murder. The ambulance crew entered the room and applied defibrillator pads to Adult A but she had received un-survivable stab wounds and was pronounced life extinct at 11:41am, approximately 30 minutes after making the 999 call.

53. It has not been possible to establish the events that led to the fatal injuries suffered by Adult A. When Adult B was arrested and detained in custody he was disorientated to time and unable to give a coherent narrative around the incident. He was not able to retain information about the legal process or instruct a solicitor. Subsequently, Adult B was deemed unfit to be interviewed due to suspected vascular dementia. Adult B continues to believe that Adult A died of old age. He has no recollection of his actions.

54. Adult A and Adult B's family insist that there were no signs of domestic abuse or a previous history of disharmony within their relationship. They were a couple devoted to each other. The family did not see any signs of the relationship being under strain and were shocked and devastated by the events. The news of their mother's death was something they could never have imagined or foreseen. They still cannot relate the actions of the day with their father's usual disposition.

55. On sentencing of Adult B to an indefinite hospital order under the Mental Health Act, the Judge said on the day of the attack there was 'an explosion of violence utterly out of character and alien to [Adult B]', who had no previous convictions. He told the family in court, 'that their

father killed their mother is an almost impossible burden for them to bear' but said they could have done no more for their parents in what he called 'a sad case'. The Judge added, "[Adult B] had no idea of what he had done and believes his wife had died of old age". He hoped that would remain the case as Adult B is treated in hospital[5].

SECTION THREE – AGENCY INVOLVEMENT AND EVALUATION OF PRACTICE

56. The detailed chronology for this review started in December 2020 when Adult A and Adult B moved to Cornwall. Events prior to this were considered as part of the review particularly from their previous area of residence.

57. This section of the report outlines the facts of key contacts between Adult A, Adult B and agencies involved in their care and evaluates whether agency contacts were in line with national best practice guidance. Information about Adult B's involvement with Health Services is included insofar as this is relevant to an understanding of his cognitive state at the time of the homicide and the caring duties being undertaken by Adult A in the months preceding her death.

2020

58. On 11th December 2020 Adult A and Adult B registered at a GP surgery in Cornwall having relocated from Bristol.

Evaluation of practice

Health records from Bristol appear to have transferred to Cornwall in a timely manner.

2021

59. On 12th January 2021, Adult B attended his first appointment at his new GP surgery and was treated for a condition to his legs. No cognitive impairment or concerns were noted at this time.

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[5] Cornwall Live coverage of the court case.

60. Two weeks later on 26th January 2021, Adult B attended the GP surgery with his wife (Adult A) after she had made a call to the surgery the day before about the sudden onset of a large blister on his legs. She explained there was a background of long-standing issues with his swollen legs - but they had not sought help about them. Adult A also mentioned concerns with Adult B's memory since they moved to Cornwall at the end of 2020. Family had noticed his deterioration in his memory – a drop in cognitive function - which had remained constant since. Adult A explained that Adult B was forgetful, muddled, doing odd things, like putting odd things in the toilet. He had difficulty sleeping and was losing weight but was eating and drinking okay. His hearing had worsened since his onset of confusion. The GP noted that it was difficult to gain a clear history on previous level of cognitive function from Adult B.

Evaluation of practice

This was perhaps the first opportunity to enquire about a carers assessment and to establish the caring duties being undertaken by Adult A. Older adults with dementia may be at high risk for psychological and physical abuse[6], therefore it was also an opportunity for the GP to routinely enquire about domestic abuse.

People living with dementia are likely to have on average, an additional 4.6 chronic conditions[7], therefore they are subject to high rates of complications[8]. Adult B was suffering with long standing chronic leg oedema and a soft-tissue viability condition which developed into skin breaks and ulcerated areas, increasing his risk of infection. When the skin is broken and very wet, the risk of infection developing into sepsis is also high. [9] An altered mental state or delirium (acute confusion accompanied by a degree of cognitive impairment and/or perception) is a common feature of sepsis[10]. Therefore, when Adult A complained that Adult B was becoming muddled, confused and doing odd things, it would have been good practice to provide literature

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[6] https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2013.1261

[7] https://web.s.ebscohost.com/abstract?direct=true&profile=ehost&scope=site&authtype=crawler&jrnl=02634465&AN=149908009&h=c1eUVf5SWmrq17cSDzDWo4v2PoqMm0l9ldve9r%2fLF4cVw1YtX0caiCQXCxbMACcFLoaqtJLU%2f86HNrpQIglnGQ%3d%3d&crl=c&resultNs=AdminWebAuth&resultLocal=ErrCrlNotAuth&crlhashurl=login.aspx%3fdirect%3dtrue%26profile%3dehost%26scope%3dsite%26authtype%3dcrawler%26jrnl%3d02634465%26AN%3d149908009

[8] https://bmjopen.bmj.com/content/3/6/e002770.short

[9] Elwell and Craven, 2015

[10] https://www.medscape.com/answers/168402-27363/what-does-an-altered-mental-status-indicate-in-sepsisseptic-shock

to warn her of the risk of sepsis and delirium, and how to recognise symptoms and report them urgently.

Given that infection is one of the most important risk factors for delirium in elderly patients[11] there was also an opportunity for the GP to alert future professionals involved in Adult B's leg care to the risk of infection-related-delirium and a note to observe changes in Adult B's mental state alongside treatment for his physical health complaints.

61. Adult A was asked if she could facilitate Adult B getting to the surgery to receive regular leg dressings. Adult A became distressed and upset, explaining that it was difficult to get Adult B to the surgery because they were reliant on somebody bringing them. It also took two people to get him out of the car. She explained that undiagnosed dementia complicated things. A decision was made to contact the district nursing team. Adult B demonstrated poor cognition after scoring 3/10 on a mini mental health dementia screening assessment and it was recorded in notes that the provision of advice, assessment and treatment was limited due to coronavirus. The next day the GP made a referral to the district nursing team.

62. On 28th January 2021 a community nurse from the district nursing team undertook a home visit to treat Adult B's legs. The community nurse noted in their records 'I have been to see this lovely gentleman and his wife today'. The community nurse observed during their visit that Adult B's issues with mobility were as a consequence of painful toes and being unable to wear shoes. Due to problems with his toes a referral was made to a podiatrist. Adult A reported that Adult B was needing to use the toilet at least 6 times a night which was impacting his sleep. Full observations were taken.

Evaluation of Practice

This was the first opportunity for the community nurse to enquire about a carers assessment for Adult A and to undertake a routine enquiry about domestic abuse.

It was becoming apparent at this time that the caring responsibilities being placed on Adult A were not easy and she was distressed by the idea of leaving the property with Adult B due to his mobility issues. This would have been an ideal time to ascertain whether there was a support

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[11] https://journals.sagepub.com/doi/pdf/10.1177/2333721417739188

system in place and to establish the risk of isolation and loneliness. Adult A's family believe this would have been a good time to enquire about extended support within the family and an opportunity for the community nurses to ask Adult A if she wanted them to speak to or share information with another family member for additional support.

Similarly, C2 (Adult A and Adult B's daughter) was providing practical and emotional support to both of her parents at this time. As such, it would have been good practice to consider her role as an unpaid informal carer in her own right, which would negate the need for consent to share information with C2 (as she was already involved in her parent's care) and made her eligible for her own carers assessment.

Covid 19 restrictions to services were in place at this time and it is good to see that essential services like district nursing teams managed to operate and respond quickly to the needs of a vulnerable population.

63. A second home visit by the community nurse took place on 1st February 2021. Adult A reported that her husband's cognition was worsening, and he was becoming more forgetful. She had to prompt him to wash and get dressed in the mornings. Adult B was unable to tolerate a Doppler scan due to the pain and wounds were cleaned and dressed. A podiatry appointment was offered, but Adult A declined the appointment stating that Adult B could not leave the house. She would look to book an appointment later.

64. Further visits by the community nurse to clean and dress Adult B's legs took place on 2nd, 3rd and 4th February and on the 4th Adult A again mentioned Adult B's enlarged prostate meaning he had to get up a lot at night, disturbing his sleep. She was still of the view that they were unable to leave the house to take Adult B to a podiatry appointment and a private phone number for a foot health practitioner was offered but Adult A said she did not need it. During observations, it was noticed that Adult B's temperature was too low, and when the community nurse suggested solutions, Adult A appeared reluctant to take the advice given. Adult A was quite agitated throughout the home visit, complaining about being given insufficient information. Further explanation of what was happening and what was going to be arranged was given to Adult A but the community nurse noted that Adult A had forgotten this before she left the house. This raised concerns about the possibility that Adult A was cognitively impaired.

65. On 5th February 2021, the podiatrist and community nurse spoke to Adult A about a podiatry appointment for Adult B. Transport had been arranged for them, however, Adult A said they still could not attend any appointments at the moment. A telephone number was offered if Adult A changed her mind.

66. Eight home visits were completed between 6th and 26th February 2021 to clean and dress Adult B's wounds. No concerns were raised. Adult B seemed well.

Evaluation of Practice

Adult B needed to see a podiatrist, and professionals worked well together to facilitate appointments during COVID, even arranging transport to convey him to the hospital, however, Adult A declined the appointments on Adult B's behalf. Adult A's daughter (C2) explained to the reviewers that her mother was somebody who could only handle one task at a time. Adult A had explained to her daughter how important it was to heal Adult B's legs first, then she could think about his feet. Adult A could become easily overwhelmed with too many requests or tasks and liked to approach issues in a linear fashion.

This highlights the importance of speaking to carers and their support network to understand the context behind decision-making, particularly when a decision about an individual's care (that is in their best interest) is being made on their behalf. Listening to Adult A's concerns may have identified her increasing sense of overwhelm in her role as a full-time caregiver.

When Adult A became agitated during the home visit on 4th February 2021 this was another opportunity to try and understand the source of agitations and discuss a carers assessment for her or attempt to coordinate care for comorbid conditions. It is not known whether Adult A's agitation that day impacted her memory or ability to process what was being said to her, but the community nurse's concerns about possible cognitive impairment for Adult A was not shared with her GP, nor were the concerns for Adult B's care (low temperature and feet issues) shared with his GP. Given Adult A's agitation, it would also have been good practice at this point to consider the possibility of domestic abuse and see each individual separately to routinely enquire about whether this was a factor.

Adult B was living in a private rented bungalow; however, it is not known how many adaptions were already in situ for his needs. His mobility issues and decline in cognitive function would have created safety implications within his living environment. Support rails or walking aids may have assisted with mobility and washing, easing some pressure on Adult A. Consideration of day centres and luncheon clubs to foster companionship and reduce loneliness, and paid caring support to provide much needed respite may have helped Adult A feel less overwhelmed.

Adult A declined a social care needs assessment for Adult B, which the family state was due to the pressure she already felt and her desire to 'deal with one thing at a time'. This is not the first case in Cornwall whereby a carer refused intervention or treatment for a patient because of the additional pressure and overwhelm experienced by them as a fulltime, primary, informal caregiver. This should have raised concerns about Adult A's coping potential and the impact of such decisions on Adult B's health outcomes. A further discussion around a carer's needs assessment and a social care needs assessment should have been revisited by different professionals involved in Adult B's care or escalated to ensure that Adult B's safety was not compromised by his wife's decision. He could also have been consulted during more lucid moments.

Adult B's prostrate problems were causing him some sleep issues at night due to the number of times he needed to frequent the toilet. However, the CN did not inquire whether Adult A was assisting Adult B due to his mobility problems, therefore impacting her sleep too. Adult A's daughter confirmed that her mother's sleep was disturbed by Adult B's frequent bathroom visits. Adult A also got up earlier than Adult B, letting him sleep in, while she showered, dressed, and had breakfast, before helping him with his personal care. Adult A liked to be prepared for the day, allowing herself sufficient time to do things. Having multiple appointments impacted on this, meaning that tasks had to be hurried/rushed. This caused her anxiety, made her agitated and reluctant to take on too many appointments during the day. The psychological and physical wellbeing of caregivers must be considered alongside the person receiving care.

March 2021

67. Between 2nd and 28th March 2021 the community nurse completed six home visits to treat, clean and dress Adult B's leg wounds.

68. On 2nd March 2021, the GP sent a request for an assessment to the Memory Clinic. It read – 'I would be grateful for your assessment of this eighty-three-year-old man who I have recently seen with his wife. She is quite concerned as he is having quite a number of memory issues which are progressively getting worse. It is actually quite difficult to get a clear history on his previous levels of cognitive function but there does seem to be quite a significant decline to the

point of actually trying to get him into the Surgery was very difficult. He is a poor sleeper and is losing weight, but he does eat and drink okay. His hearing does seem to be worse so that is tied in with his confusion. …[By] the time that I saw him he was also seen by one of our medical students who did a mini-mental and he scored 3/10. I would be grateful for your further assessment'.

69. On 3rd March 2021, the Memory Assessment Service attempted to call Adult A to undertake a triage assessment. There was no answer and no ability to leave a message.

Evaluation of Practice

It is not clear if the referral to the Memory Assessment Service made on the 2nd March 2021 was as a consequence of the consultation on the 26th January when Adult B was assessed by his GP and a medical student, or if it derived from a consultation regarding another health matter on the 1st March. Either way, Adult B's cognitive decline was recognised in January 2021, therefore, there was an opportunity to make an earlier referral to the Memory Assessment Service.

April 2021

70. The Memory Assessment Service called Adult A on 1st April 2021. She explained that the couple were unable to use a computer and unable to come to clinic due to Adult B's poor legs. The Memory Assessment Service agreed to arrange a home appointment "after lockdown". Later in the afternoon the community nurse completed a home visit to redress Adult B's legs. He reported feeling comfortable.

71. From 2nd to 22nd April 2021 the community nurse undertook four home visits to treat, cleanse, and dress wounds. And on 20th April Adult B attended the GP surgery for a medication review.

72. On 26th April 2021, during a phone call between the community nurse and Adult A to arrange a further home visit, Adult A became agitated and irate, complaining about the number of appointments Adult B had to attend and how inconvenient it was that she never knew what time the community nurses were coming. The community nurse suggested taking Adult B to the practice nurse for a planned visit time if this was more favourable for them, however Adult A replied that he was unable to go to the surgery unless he had a lift.

73. On 28th April 2021, two community nurses undertook a joint home visit. Adult A was very agitated throughout the visit and reassurance was given to her. They discussed reducing visits to twice weekly until Adult B's hosiery arrived. Both Adult A and Adult B were happy with this arrangement. Bloods were scheduled to be taken on the same date of the next visit to cause less confusion for Adult A as it was noted that 'unplanned visits seem to cause her to become anxious'.

Evaluation of Practice

It is mentioned that during lockdown Adult A informed the Memory Assessment Service that they did not use a computer, could not take part in a video conference assessment and could not attend the clinic. The decision not to undertake a home visit was based on an assessment of available information and this referral was not assessed as urgent and requiring a home visit. At this time a new assessor had been appointed but had a large backlog to manage and was allocated over 70 cases to work through. The assessment was therefore delayed. This raises concerns about the accessibility of vital health services for citizens who do not possess a computer or have internet access. Researchers have consistently found that the older population, lower socioeconomic classes, and minority groups are most likely to be disenfranchised from digital health information[12]. In the UK, nearly two million over-75s are still digitally excluded.[13] Services will need to ensure that accessibility to information, care, and support in a post-COVID-world does not disadvantage vulnerable populations.

Adult A was again reported to be agitated and angry about the communication of care and the irregularity of visits and timing. Her daughter told reviewers that it became difficult for her mother to make arrangements or implement a routine when she did not know when the community nurses would be arriving. Supposedly, it would have also been difficult to have found uninterrupted time in the day when Adult A could have rested and caught up on lost sleep. It was not unreasonable for Adult A to request a schedule of visits that she could plan for and work around, and it was good practice to see that her frustrations were acted upon with a plan to reduce visits, however, her frustration could have been a sign that Adult A was becoming overwhelmed by her caring responsibilities and the burden on her own cognition and health. At

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[12] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7790471/

[13] https://www.ageuk.org.uk/latest-press/articles/2021/nearly-two-million-over-75s-in-england-are-still-digitally-excluded--in-a-covid-19-world/

this stage, a carers assessment should have been a priority discussion together with an assessment for Adult B, to formalise his increasing levels of care and offer Adult A some respite.

If informal care arrangements are in place, professionals should be vigilant to the changing disposition of carers and the person being cared for. Caregivers are in some respects, hidden patients themselves, with physically and emotionally demanding work leading to a reduced capacity to attend to their own health and health care[14]. Family caregivers experience significant negative physical consequences as a patient's illness progresses and elderly spouses who experience stressful caregiving demands have a 63% higher mortality rate than their non-caregiver age-peers[15]. They are at high risk of fatigue and sleep disturbances, lower immune functioning, slower wound healing, increased insulin levels and blood pressure[16]. Their ability to exercise, recuperating from illness and tend to their own medical prescriptions are also compromised[17]. As such, there is a very high risk that a caregiver of Adult A's age, was unsafe and unsustainable in the long-term. Professionals should have been considering a 'Plan B' strategy for when informal care arrangements were no longer viable. This did not happen and there was an assumption that Adult A could cope with the scope, duration and intensity of caring support required.

May 21

74. A health practitioner from the Memory Assessment Service did complete a home visit on 4th May 2021. Adult A was present throughout. Adult B appeared receptive and engaging. His speech was slow, with muddled grammar, and sometimes incoherent. He would have to pause and re state his statement. His volume was low, but his tone was warm. Adult B had poor word finding and forming. Subjectively, his mood was "okay", he appeared apathetic, and his language seemed to be positive. The PHQ – 9 Depression scale was LOW. Both Adult B and his wife felt he was not depressed. No other abnormalities were noted in the mental state examination. The health practitioner recorded that the onset of memory loss was insidious; the progression was associated to fluctuations with his other comorbidities over a term of 3 years. Adult A recalled

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[14] https://www.ncbi.nlm.nih.gov/books/NBK2665/

[15] https://www.ncbi.nlm.nih.gov/books/NBK2665/

[16] https://pubmed.ncbi.nlm.nih.gov/1656478/

[17] https://pubmed.ncbi.nlm.nih.gov/9085384/

how they had a regular routine and social circle when they lived in social sheltered accommodation, but on arrival to Cornwall, to be closer to the family, they now felt more isolated and "out on a limb". Lockdown due to COVID19 also reduced opportunities to access social or community services. This is when Adult A really noticed a decline in Adult B's cognition. The cognitive result was 'low' on the Rowland Universal Dementia Assessment Scale (RUDAS) - a short cognitive screening instrument designed to minimise the effects of cultural learning and language diversity on the assessment of baseline cognitive performance. Adult B could not tolerate the Addenbrooke's Cognitive Examination-III (ACE-III) - a brief cognitive test that assesses five cognitive domains: attention, memory, verbal fluency, language, and visuospatial abilities. He scored 10 out of 30 with a functional impact on all Activities of Daily Living (ADLs). The health practitioner recommended a head CT scan. A consultant psychiatrist approved the request for a CT head scan and an appointment was made for 2nd June 2021.

75. During the assessment Adult A and B were asked about a home needs assessment and/or a carers assessment but Adult A said she felt it was her role to look after her husband and that that they were awaiting a placement in sheltered accommodation.

76. On 6th May 2021 the health practitioner discussed the assessment with the multi-disciplinary team and the psychiatrist agreed with the plan to refer for a CT scan. The risk assessment for Adult B was LOW in all categories (harm to self, harm to and from others, accidental, self-neglect, other risk behaviours, and issues).

Evaluation of practice

On 4th May 2021, the Memory Assessment Service recorded an insidious progression of memory loss over three years. By the time of the assessment, Adult A had been reporting a rapid deterioration in Adult B's memory since January 2021. Although COVID-19 was a contributing factor, it was still a period of 5 months before an appointment for a memory assessment was made.

When assessments are unintentionally delayed, the deferral of a dementia diagnosis can lead to lost opportunities for treatment and increase patient and caregiver burden.[18] The failure to evaluate memory or cognitive complaints in a timely manner is also likely to hinder treatment of underlying disease and comorbid conditions and may present safety issues for the patient and

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[18] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2787842/

others[19]. Since patients with early dementia are most likely to benefit from early intervention, future efforts to improve the timeliness of dementia diagnosis should especially focus on detection of more subtle and early manifestations of disease[20].

Adult A and Adult B were stuck midway in a pathway between referral, assessment and diagnosis. Once his diagnosis was confirmed, Adult B would have been assigned a dementia practitioner and Adult A would have access to Admiral Nurses (specialist dementia nurses specifically for carers). The Kernow Clinical Commissioning Group has just invested funding into Dementia UK and the Royal Cornwall Hospital Trust for a further two-years to expand the Admiral Nursing scheme for dementia patients and their families in Cornwall and this would have been an important resource for Adult A as Adult B's carer. However, support from these schemes is only available once a diagnosis has been confirmed. This leaves a gap in support for people who are symptomatic and, on the pathway, but not formally diagnosed. Commissioners have since confirmed that grants and a coordinator post has been allocated to memory cafes for people on the diagnostic pathway in Cornwall. Support for people living with dementia and their carers (without a formal diagnosis) is also available via the Carers Service (Cornwall), Age UK and the Alzheimer's Society (via advisors) which have all been given local dementia funding.

Adult A's description of feeling 'out on a limb' and missing her previous social circle should have raised some concerns about her risk of isolation and loneliness. Notably over two-thirds of approximately 700,000 caregivers of dementia sufferers in the UK report feeling lonely[21]. Adult A's life had changed considerably in a short space of time. Her husband's illness had limited their ability to leave the house and he slept for long periods of time during the day due to sleep disturbance at night. This would have had an impact on Adult A's own wellbeing and life satisfaction. Professional curiosity following her disclosure of perceived isolation (i.e., feeling 'out on a limb') may have identified Adult A's vulnerability to loneliness, and provided an opportunity to refer to interventions or voluntary organisations aimed at reducing stress and supporting meaningful social networks.

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[19] https://www.nia.nih.gov/health/assessing-cognitive-impairment-older-patients

[20] https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.930070809

[21] Full article: The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme (tandfonline.com)

77. Community Nurse home visits to wash and dress Adult B's legs took place on 12th and 21st May 2021. On the second of these visits Adult A had already removed his bandages and showered Adult B prior to their arrival. The community nurse agreed to leave visiting until the following week as family were due to visit on the Friday. The Community Nurse made a note in the records to take out information for carers "to take over weekly leg care if wife can't manage'.

78. On 27th May 2021 during a home visit from the Community Nurse, Adult A reported that she was unable to remove Adult B's hosiery as they were quite firm and Adult B found them uncomfortable. There was a small area at the top band where a little irritation had occurred, but no broken skin was observed. Adult A was given advice as to how to manage this and the Community Nurse explained that they do not undertake general leg care as a service and gave Adult A some telephone numbers for carers to contact. The nurse emphasised the need for leg care to be undertaken weekly and that they should not be left longer than this. Adult A was asked to contact the care agencies today and not to leave it until next week. If there were any concerns, Adult A was advised to contact the service. Adult A asked the Community Nurse to undertake some treatment to Adult B toes and nails but promised to contact a podiatrist this week to have full nail care undertaken.

79. On 29th May 2021, Adult A was killed by Adult B. Adult B was seen by a member of the Criminal Justice and Liaison Team. He appeared bewildered in manner, slow and hesitant in speech. He said he felt 'ok', and it had just been a 'normal' day. He recalled after some thought that he was in a police station, but he could not explain why. Adult B was referred to an Approved Mental Health Professional (AMHP) for request for Mental Health Act Assessment (MHAA).

Evaluation of Practice July 2018

Adult A's daughter (C2) explained to the reviewers that her mother was not comfortable taking over the general care of Adult B's legs. She became upset about the responsibility and told her daughter that she needed more support. This was a particularly demanding care task and was more than general leg care. Reduced leg care could have increased Adult B's risks of infection, and the side effects of infection, such as delirium. It is not known whether Adult B was suffering with an infection at the time of the homicide, but on the balance of probabilities, it was highly likely[22]. He was

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[22] https://www.nhs.uk/ipgmedia/national/Royal%20College%20of%20Psychiatrists/Assets/Delirium.pdf

admitted to an acute hospital within one week of the incident with life-threatening sepsis and clinical records of his admission state, 'Leg ulcers confirmed to be likely source of infection'[23]. This raises an important area of learning for this review. Without a delirium policy within the county, there is an inconsistent approach to workforce training to ensure frontline professionals are skilled and knowledgeable in identifying and screening for early signs of delirium. If professionals are untrained to spot the signs, there is no transfer of knowledge to informal caregivers, meaning carers like Adult A were not equipped to spot the serious signs of potential delirium. This type of education may help others to spot the early signs and seek treatment before it reaches a critical point of crisis. A simple leaflet on delirium, such as the one produced by the NHS and the Royal College of Psychiatrists may have helped[24].

The request for Adult A to take over Adult B's general leg care, together with the withdrawal of the district nursing team was likely due to commissioning restrictions as Adult B was not officially considered housebound and therefore his continued leg care should have taken place at the GP surgery. However, Adult A insisted that she was unable to get Adult B to the surgery, which resulted in her being given telephone numbers for private carers. The reviewers explored this decision in accordance with disability rights and determined that dementia is a cognitive disability characterised by a decline in mental ability[25]. As with many neurological conditions, dementia is often considered a 'hidden disability' as symptoms are specific to the individual. [26] However, dementia is a recognised disability and the rights of people living with dementia are enshrined under both the Equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities (CRPD)[27]. This means that professional services need to uphold the relevant entitlements of people with the condition and make reasonable adjustments to prevent them from being disadvantaged or marginalised if they should become housebound. As Adult B was only on the memory pathway, his disability had not yet been formally recognised, therefore allowances were not continued, placing significant strain on Adult A as his primary caregiver. As an 82-year-old lady, it was optimistic (at

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[23] Royal Devon and Exeter Hospital Trust Chronology

[24] https://www.nhs.uk/ipgmedia/national/Royal%20College%20of%20Psychiatrists/Assets/Delirium.pdf

[25] https://pmj.bmj.com/content/97/1151/598

[26] https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf

[27] https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf

best) to assume she would have the physical and mental strength to galvanise Adult B and facilitate his transportation to the surgery several times a week. Commissioners need to consider whether this arrangement was fair and justified, or whether symptomatic people on the pathway should be entitled to the same rights as those who have received a formal diagnosis.

Caregiving is complex and can lead to psychological, physical, social, and financial stress for informal caregivers. Caregivers also report considerably higher levels of stress and depression, as well as a poorer quality of life than adults who did not care for a family member[28]. Community Nurses involved in the care of people with suspected or diagnosed dementia should also consider family caregivers, including understanding their needs and signposting them to relevant groups for support and guidance, particularly when they feel burdened by the level of responsibility. It was good practice for the community nurse to consider literature about support services and sharing the contact details of carers, however, there was no evidence of Adult A being asked if she felt ok with the arrangements or if she understood what was being asked of her (within the context of previous concerns about cognitive impairments). In light of the information shared by family (below), the request to seek carers for Adult B was another task (in addition to taking him for a podiatry appointment) that overwhelmed Adult A and she did not know how to engage appropriate help.

Family contribution to the chronology of events

80. Adult A and B's middle child (C2) explained that there was never any suggestion of domestic abuse or any unhappiness in the marriage. C2 described the last occasion she saw them during a family get-together as 'just normal, it was good'. There were no signs of unease, tension, or stress.

81. C2 explained that this made the event even more shocking, adding, 'it came completely out of the blue, there was nothing to suggest it might happen'. C2 cried when she said it was 'absolutely shocking' to get the call to say what had happened.

82. Prior to the homicide, C2 explained that Adult A and Adult B moved from a warden assisted block of flats in Bristol to a private rented bungalow in Cornwall in late 2020. They did not

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[28] The psychological effects of caring for a family member with dementia (rcni.com)

receive a lot of support whilst in Bristol and became rather depressed by their surroundings. They had a call button in their flat that they would inform the warden they were ok, and to request help if they needed it, but the warden did not provide any care. He seemed to disappear somewhat during Covid.

83. When the couple moved to Cornwall, C2 tried to arrange a piper alarm for her mum and dad, but her mum told her that she could only cope with one thing at a time, suggesting that settling in was a priority. C2 intended to continue the conversation at a later date. She described her mum as liking to do things herself in her own time.

84. Adult A and Adult B did register with a local GP, but they did not contact Adult Social Care. In fact, C2 had collected all the forms to request an assessment with Adult Social Care and was due to complete them with Adult A on the afternoon of the homicide. C2 explained that she had to download the forms online and this was not within her mother's capacity. Without her support, C2 doubted Adult A would ever have considered asking for help for Adult B. She saw it as her duty as his wife to care for him and this was underpinned by her traditional values of marriage.

85. Adult B's increasing health problems had started to overwhelm Adult A culminating a few days before the homicide, when Adult A became upset and told C2 that she needed some more support. They had interrupted sleep due to Adult B's prostrate problems, which meant that he needed to use the toilet frequently at night and she was not keen to take over the care of his leg dressings as suggested by the community nurse.

86. In addition, Adult A was aware that Adult B was experiencing memory problems. The family observed some confusion, describing one event whereby Adult B became slightly agitated by a man who passed their window. He mistakenly believed it was the same man he had had an altercation some years before in Bristol. Other than this incident, the family did not see Adult B behave in an aggressive or agitated manner again. C2 warmly added, 'he was more likely to doze-off in a chair'.

87. C2 feels that the loss of face-to-face GP appointments during COVID meant that the signs GPs instinctively picked up on during health consultations were not explored on telephone calls. For example, some less obvious emotional symptoms not necessarily linked to the presenting physical symptoms, such as feeling low or mildly depressed, or of carers becoming overwhelmed

or tired, could not be sensed or observed. C2 queried whether Covid was responsible for a loss of GP intuition which often leads to further exploration.

88. C2 also expressed concerns that the move to online systems, virtual meetings or automated telephone calls were difficult for elderly patients to navigate, particularly, for people like her parents, who were not 'tech-savvy'. C2 explained that her parents were in their 80's and did not use the internet, however the forms they required for an assessment with Adult Social Care were all online. C2 was concerned that without her help, her parents may have struggled to navigate online process to access essential services.

89. C2 expressed concern that the system for reaching GPs through the 111 systems reduced the opportunity for elderly patients to access wider services as they generally use their GP as the first port of call for access to peripheral support services. In this respect, C2 expressed concern that some elderly patients, like Adult A and Adult B, may not have the capacity or knowledge to overcome a different (mostly online) system.

90. When asked directly about the learning for the DHR, C2 stated that there was nothing any agency or professional could have done to foresee or interrupt the chain of events that lead to the homicide. C2 insisted that it was totally 'out of the blue'.

91. C2 did express some valid concerns about her father's treatment post-homicide, specifically linked to the appropriate detention of dementia patients. Adult B was 84 at the time of the homicide, very frail, disorientated, and with multiple medical issues. He became seriously unwell after his arrest and spent some time in hospital. Whilst Adult B's post-homicide care sits outside of the remit of a DHR, the reviewers support the need for more suitable psychiatric care to support the medical needs of detained dementia patients, therefore, these concerns were shared formally through the Safer Cornwall Partnership and senior representatives from Adult Social Care, Cornwall Foundation Trust, and the Kernow Clinical Commissioning Group.

92. It should be noted, that unless dementia screening and diagnosis is improved, there is a risk of sufferers and their caregivers being vulnerable to greater safety threats. This is not the first dementia-related homicide in Cornwall. Delirium can predispose dementia sufferers to severe impulsive aggression and domestic abuse can become a risk factor for caregivers and the

individuals being cared for[29]. Early assessment of changed behaviours, alongside education and advice to carers (who may be targets of aggression) would go some way towards reducing the number of dementia related DHRs and prevent the need for discussion around suitable post-homicide support for dementia perpetrators. In this respect, the family concerns about post-homicide treatment do sit firmly within the remit of domestic homicide reviews.

Evaluation

The concerns raised by C2 are extremely important. The significance of accessible services for an aging 'non-technical' population must be considered within a growing world of digital health information. Professional services will need to make a concerted effort to ensure that certain groups are not disadvantaged or excluded from services due to age, digital poverty or location (remote rural areas).

COVID-19 did reduce face-to-face consultations and C2 correctly identified the loss of primary care intuition when caring for patients with ongoing medical complaints. It is possible that Adult A and B's GP would have made enquiries about Adult A's wellbeing as a full-time informal caregiver if they had seen Adult A in person and could observe her demeanour. However, the professional system currently heavily relies on informal care with significant costs and caring responsibilities falling to family caregivers without appropriate levels of professional support[30]. At a time when all services were stretched (during a global pandemic and numerous national lockdowns) it is possible that this reliance and expectation increased, leaving carers even more isolated and less supported. How long caregivers are left unsupported likely depends on how long they can cope without their responsibilities leading to negative mental and physical health outcomes (for themselves or the person receiving care). This is not satisfactory. If there is a heavy reliance on informal care to keep professional systems operating effectively and preventing them from becoming overburdened, informal care should be accompanied with enhanced caregiver support and professionals should proactively encourage caregivers to undertake a needs assessment under the Care Act 2014.

C2 made an observation that her mother liked to manage one thing at a time. Adult A needed to settle into her new home before thinking about a piper alarm. She needed to heal Adult B's legs

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[29] https://www.karger.com/Article/FullText/521878

[30] https://www.kingsfund.org.uk/sites/default/files/Securing_Good_Care_Chapter_8.pdf

before she could think about his feet. It is likely that Adult A could not contemplate completing forms or assessments for herself or her husband without feeling overwhelmed by the amount of focus it required. It should be acknowledged that Adult A was 82 when she was providing full-time care for Adult B. This was a considerable responsibility for someone who was also elderly and experiencing a significant change in her role as a wife and partner. The fact that Adult A coped alone for as long as she did is a remarkable indication of her character, however C2 also said that Adult A was a fiercely independent woman of her time who held traditional values of marriage and was raised during a generation when 'you just got on with whatever life threw at you'. This strength is not uncommon for this generation, but professionals must ensure that their stalwartness is not taken for granted. Just because someone is willing to care for another, does not necessarily mean they should do so unsupported. The professional system should not be waiting for an 82-year-old caregiver to ask for help. Assistance needs to be offered before reaching crisis point, and professionals should not be deterred by initial steely refusals. Often, independent people of this generation need to build trusting relationships before they accept offers of help. Many will require help to understand their rights under the Care Act 2014 and will need encouragement to complete an assessment.

SECTION FOUR- ANALYSIS – WHAT CAN WE LEARN?

93. Reflecting on the detail of events and responses by professionals *at the time*, this section of the report aims to identify and explore key themes that have relevance for today's practice. These themes are:

- Support of informal caregivers in Cornwall
- Routine enquiry of domestic abuse
- Proactive facilitation of social care needs assessments
- Accessibility of services in a post-COVID world
- Diagnosing dementia and the importance of early intervention
- Comorbidities and delirium education
- Commissioning services and thresholds

Support of informal caregivers in Cornwall

94. Adult A and Adult B first came to the attention of health services in December 2020. By January 2021 it became apparent that Adult B was experiencing chronic leg problems prohibiting his movement, causing pain and requiring daily care. Adult A also reported an observed cognitive demise in Adult B. Adult A was recognised by the GP and the community nursing team as Adult B's primary carer. This was the first opportunity to discuss a carer's assessment for Adult A.

95. The Local Authority has an obligation to offer accessible advice and information about their support, to everyone in their area. This includes advice and information about a carer's right to an assessment. The Local Authority must carry out an assessment for any carer who they think may need support now, or in the future, regardless of their level of need, or their financial circumstances. The assessment should look at what the caregiver wants to achieve in their day-to-day life, and what is important to them. Although an assessment is optional, specialist advocacy around the process can help carer's make informed decisions[31].

96. Adult A declined a referral for a carers assessment. Where a carer refuses a carer's assessment the Local Authority is not required to carry out the assessment under section 10(1) of the Care Act 2014. However, if a professional thinks that the needs or circumstances of the carer or the adult needing care have changed, the carer should be asked again, and if they continue to refuse, they should be made aware that they can change their minds at any time. If there are welfare concerns or risks of neglect/abuse, a referral should be made utilising the powers to share information under Caldicott Principle 7.

97. Records do not suggest that Adult A received advocacy to understand the purpose of a carer's assessment, nor was she encouraged to speak to her family about the process. No enquiry was made to contact nearest relatives to extend Adult A's support network. A referral was not made by the GP or community nursing team and Adult A's decline to self-refer was accepted without revisiting the discussion again. No consideration was given to concerns about her own (suspected) cognitive decline (and thus, her own capacity) and the potential for impulsive aggression and domestic abuse associated to dementia-related delirium was overlooked as a

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[31] file:///L:/User/Downloads/carers-assessments-factsheet.pdf

possible risk factor[32].

98. Adult A's daughter asked why it is not standard practice to ask elderly patients if they have a member of their family who could be contacted with regard to health concerns/issues, who can support them. C2 mentioned that any information regarding her father's health came via her mother, who did not remember all of it or understand the severity of it. C2 was not aware that her mother had been asked about a carer's assessment or that she had refused it.

99. The issue of carer's assessments not being fully explored was identified as a theme within seven cases involving unpaid family carers in an independent thematic review commissioned by the Cornwall Safeguarding Adult Board (published June 2022)[33]. The author suggested that unpaid carers should be considered as **an adult at risk** in their own right, and a carer's assessment should be considered at an early stage to ensure the well-being of both the caregiver and the person receiving care is maintained and supported. This conclusion is supported by paragraph 14.46 of the Care and Support Statutory Guidance, which states –

- *"Assessment of **both** the carer and the adult they care for must include consideration of the wellbeing of both people. Section 1 of the Care Act includes protection from abuse and neglect as part of the definition of wellbeing. As such, a needs or carer's assessment is an important opportunity to explore the individuals' circumstances and consider whether it would be possible to provide information, or support that prevents abuse or neglect from occurring, for example, by providing training to the carer about the condition that the adult they care for has or to support them to care more safely. Where that is necessary the local authority should make arrangements for providing it".*

Paragraph 14.44 of the Care and Support Statutory Guidance also states -

- *"Local authorities may choose to undertake safeguarding enquiries for people where there is not a section 42 enquiry duty, if the local authority believes it is proportionate to do so and will enable the local authority to promote the person's wellbeing and support a preventative agenda."*

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[32] https://www.karger.com/Article/FullText/521878

[33] https://ciossafeguarding.org.uk/assets/2/cios_sab-thematic_carers_sar-2022.pdf - Common Themes

100. Therefore, **unpaid carers can be considered, supported, and protected under the Local Authority's powers in exercising a non-statutory enquiry to promote a person's wellbeing and support a preventative agenda. All organisations need to be reminded of this ability and the referral route to the Local Authority.**

101. In summary, professionals were dissuaded from making a referral for a carer's needs assessment by Adult A's stalwartness and traditional values, even when there were clear signs of distress and burden. This was an issue raised within the Safeguarding Adult Board Thematic Review (2022) whereby a professional at a practitioner's event acknowledged they are often working with *'clearly vulnerable but fiercely independent people'.* This was coupled with the continuous concern of people who have capacity, making unwise decisions. Professionals identified that these issues required high levels of skill, knowledge, and training to overcome but there was a lack of multi-agency training in this essential area of practice. The recommendations from the Safeguarding Adult Board Thematic Review can be viewed here: https://ciossafeguarding.org.uk/assets/2/cios_sab-thematic_carers_sar-2022.pdf

102. Adult A would have benefited from a carers assessment and a personal budget may have helped engage private carers to offer Adult A much needed respite. At aged 82, this was a missed opportunity to look out for her wellbeing. Had it taken place, Adult A may not have reached the agitated and distressed state a week before the homicide, where she contacted her daughter in distress admitting she needed help. **All professionals involved in the care of dementia patients should actively enquire about informal caregiving arrangements and evidence in their records that the needs, risks, sustainability, and impact of the caregiver have been proactively explored, reviewed, and escalated (where risks are identified) in line with the Care Act 2014 and Caldicott Principle 7. This has been addressed in Finding One.**

103. As the number of people with dementia increases, more families will be affected by the daily challenges of providing effective support, given its current incurable status[34]. The professional system relies heavily on informal caregiving, a term used to describe people who provide care without payment[35]. Currently, there are around 700,000 informal caregivers of people with

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[34] What is the relationship between people with dementia and their caregiver's illness perceptions post-diagnosis and the impact on help-seeking behaviour? A systematic review - PubMed (nih.gov)

[35] https://bmjopen.bmj.com/content/7/11/e017236

dementia in the UK[36]. Research shows informal carers of people with dementia are saving the NHS an estimated £11 billion per year[37]. However, Informal family caregivers of people living with dementia are often older people, with their own mental or physical health issues, shouldering significant costs of providing care out of their own pocket[38]. They can have significant unmet needs of their own, and we must not take their role for granted[39]. Strain and negative emotions experienced by informal caregivers are often associated with symptom severity of the person with dementia[40], thus, as the disease progresses, so can caregiver burden. Moreover, in-home dementia caregiving is associated with greater psychological burden and poorer mental health[41] and almost half (43.7%) of caregiver's report loneliness[42].

104. We have a responsibility as a society to recognise that the state has a role to play in providing extra support to caregivers of dementia patients to ensure they can continue to fulfil these vital roles and maintain their own wellbeing, and to ensure there are appropriate safeguards in place to transfer the responsibility if their circumstances change. There were no 'Plan B' discussions with Adult A to implement back-up measures should she become too frail, ill, or unable to physically tend to Adult B's needs. Subsequently, *'everything was okay until it wasn't',* by which time, a rapid onset of symptoms created a critical situation where help was needed quickly, and agencies were required to respond in haste.

105. The issue of contingency planning was identified as a common theme within seven cases involving unpaid family carers in an independent thematic review commissioned by the Cornwall Safeguarding Adult Board (published June 2022)[43]. The report identified that "unpaid carers were managing complex, risky situations on an ongoing basis that resulted in the person

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[36] Lewis et al. (2014) The Trajectory of Dementia in the UK – Making a Difference. Office for Health Economics Consulting.

[37] Prince, M. et al. (2014) Dementia UK

[38] as_new_the-fog-of-support_carers-report_final-compressed.pdf (alzheimers.org.uk)

[39] "There isn't an easy way of finding the help that's available." Barriers and facilitators of service use among dementia family caregivers: a qualitative study | International Psychogeriatrics | Cambridge Core

[40] Perceived Help-Seeking Difficulty, Barriers, Delay, and Burden in Carers of People with Suspected Dementia - PubMed (nih.gov)

[41] Full article: In-home dementia caregiving is associated with greater psychological burden and poorer mental health than out-of-home caregiving: a cross-sectional study (tandfonline.com)

[42] Full article: The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme (tandfonline.com)

[43] https://ciossafeguarding.org.uk/assets/2/cios_sab-thematic_carers_sar-2022.pdf

receiving care becoming "invisible" and not being known to health and social care services until there was a breakdown of the situation, a crisis, or a serious incident". The author stated that "assessments should consider the impact of carers arrangements breaking down and what contingency planning would be required. In recognising the invaluable role that family carers provide to their loved ones; professionals need to ensure that services support family members to provide care in a safe way to meet the needs of the individual". **'Plan B' contingency strategies should be discussed as soon as informal caregivers are identified. The professional system should not wait until a crisis to have back-up measures in place. This has been addressed in Finding One**

106. Historically, informal caregivers have been reluctant to utilise services to reduce their burden. The support pathway can be challenging to navigate and often the onus is on carers to identify appropriate support services. This is particularly challenging given the responsibilities carers face and the pressures they are under. The need for carers to identify themselves and actively seek support is a barrier to local areas fully supporting their carer populations[44]. This was relevant for Adult A who communicated that she did not know how to access help and felt overwhelmed with too many responsibilities at once. C2 believes, without her help, Adult A would never have considered completing a needs assessment and requesting support for herself or her husband. **The professional system should have a robust method for identifying informal caregivers in Cornwall and a system of proactive engagement to encourage them to access support in their local communities, providing relevant and accessible literature and events that are not reliant on a formal diagnosis (of the person they care for), but exist to improve the wellbeing of the caregiver and acknowledge their vital contribution. This has been addressed in Finding One**

107. Research has identified barriers and facilitators to accessing support for caregivers and reducing carers burden across many types of services and supports. These barriers are –
    a) the inability to find information about relevant services or support
    b) poor quality or mistrust of services
    c) inflexibility of services
    d) a lack of clarity around affordability
    e) self-criticism
    f) caregivers' beliefs about their obligations to the caregiving role

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[44] as_new_the-fog-of-support_carers-report_final-compressed.pdf (alzheimers.org.uk)

g) resistance by the care recipient.

108. Key facilitators of accessing support are –
    a) having good communication with the care recipient
    b) having an 'expert' point of contact
    c) having beliefs about the caregiving role that enabled the use of services[45].

If the professional system wishes to rely on informal caregivers to provide care to people living with dementia, thus preventing professional services from becoming overburdened, **there must be a commitment to proactively address the barriers to help-seeking (para 107) through a well-defined caregivers strategy that addresses cultural beliefs, builds trust, self-care, and helps caregivers stay informed, safe, well, connected and appreciated. This has been addressed in** Finding One

Routine Enquiry of Domestic Abuse

109. At no point did any professional routinely enquire about domestic abuse with either Adult A or Adult B despite elder domestic abuse being amplified during the pandemic[46], and research into dementia reporting that 52% of carers admit to having carried out some form of abuse[47].

110. On at least one occasion, Adult A was showing signs of agitation. There were also concerns about Adult B's feet being neglected and his temperature being too low. Whilst this does not infer that Adult A was in any way abusive towards Adult B, it is important for future learning for professionals to be alert to potential signs that require further exploration. This should have triggered professional curiosity and led to Adult B being asked about abuse on his own. Similarly, due to Adult B's cognitive demise, Adult A should have been asked about her own safety, abuse, or perceived fears. **Routine Enquiry must be a priority and further training is required to ensure professionals supporting older populations feel confident to ask and engage in challenging conversations. This has been addressed in** Finding Two.

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[45] "There isn't an easy way of finding the help that's available." Barriers and facilitators of service use among dementia family caregivers: a qualitative study | International Psychogeriatrics | Cambridge Core

[46] https://www.cambridge.org/core/journals/bjpsych-advances/article/abs/domestic-abuse-and-mental-health-the-amplified-risks-created-during-the-pandemic/9F854B704B6ED995738028BB87D3615E

[47] https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.1525

Proactive facilitation of Adult Social Care Needs Assessments

111. Anyone with dementia is entitled to an assessment of their needs by the local authority. Even if a person lacks mental capacity, a carer or professional can request a needs assessment as long as it is in the person's best interests[48]. If Adult A declined a needs assessment on behalf of Adult B when he did have mental capacity, professionals should have sought Adult B's consent. If professionals did not believe Adult B had mental capacity to make the decision for himself, they may have listened to Adult A's concerns as his caregiver and wife, however, if they thought it was still in Adult B's best interests, a referral should have been made.

112. There are three criteria (conditions) that someone must meet for the local authority to consider funding care and support (after an assessment). The person will have eligible needs if:

a) They have care and support needs because they have a physical or mental condition (this includes dementia).

b) The person's needs mean they are unable to do at least two of the following:

- Manage and maintain nutrition – for example, buying and preparing food and eating and drinking.
- Maintain personal hygiene – for example, washing themselves and their clothes.
- Manage toilet needs – for example, getting to and using the toilet or changing incontinence pads.
- Be appropriately clothed – for example, dressing themselves in clothes suitable for the weather and their needs.
- Be able to make use of their home safely – for example, moving around the home safely (including going up and down stairs), using the kitchen, getting to and using the bathroom and being able to enter and leave the house safely.
- Maintain a habitable home environment – for example, keeping the home clean and safe and being able to manage and pay the bills.
- Develop and maintain family or other personal relationships – for example, staying in touch with others so they don't become lonely or isolated.
- Make use of necessary facilities or services in the local community including public transport – for example, getting to doctors or other healthcare appointments, using public transport and local services or shops.

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[48] https://www.alzheimers.org.uk/get-support/legal-financial/dementia-care-needs-assessment

c) The person is considered unable to do these things if they cannot do them without help, if they can do them without help, but it causes them pain, distress, anxiety or puts them (or someone else) in danger, or if it takes them much longer to do them than would be expected.

113. Due to Adult B's poor mobility and cognitive impairment, he was unable to meet many of the criteria outlined above, and therefore he would have benefited from a social care needs assessment. Not only could this have improved his safety in the home, but it may also have assisted Adult A in her caring duties and eased some strain on undertaking physical tasks.

114. C2 told the review that her mother did request help in the week before her homicide, but she did not know how to ask for an assessment and did not have access to a computer. Consequently, C2 downloaded the appropriate forms on her behalf and printed them ready for completion. C2 had arranged to visit Adult A on the afternoon of her death to complete the questions together. Tragically, C2 received the call to say that her mother had been killed, and her father had been arrested, therefore overriding arrangements. C2 told the reviewers that, without her, her mother would not have known how to ask for help.

115. It is not known even with the benefit of hindsight if completing an assessment would have prevented Adult A's death, however, the thoroughness of the questions may have unveiled the scale of Adult B's support needs and reassured Adult A that help was available. It may have highlighted dangers and risks and exposed behaviours not previously known to family or professionals due to Adult A's pride and independence. This may not have interrupted the sequence of events, but it is important learning for domestic homicide reviews, nationally.

116. Research has consistently shown that people living with dementia and their caregivers seek help when symptoms become severe. Final help-seeking usually follows a pivotal triggering event[49]. Lack of knowledge, cultural beliefs, complexity of the healthcare system, threat to independence and acceptance of the illness are identified as major factors for delaying help seeking[50]. **Therefore, professionals need to be proactive in exploring perceptions, overcoming perceived barriers, and ensuring people living with dementia and their caregivers are aware of**

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[49] How people come to recognise a problem and seek medical help for a person showing early signs of dementia: A systematic review and meta-ethnography - PubMed (nih.gov)

[50] What is the relationship between people with dementia and their caregiver's illness perceptions post-diagnosis and the impact on help-seeking behaviour? A systematic review - PubMed (nih.gov)

their rights and supported to access a social care needs assessment at the earliest opportunity, before it reaches crisis-point or a pivotal triggering event, to achieve more effective outcomes. This has been addressed in Finding Three

Accessibility of services in a post COVID world

117. Many carers of people living with dementia spent many months in lockdown with the person they cared for. During that time many received no assessment of their needs, no respite care and limited outside contact[51]. Adult A and Adult B were fortunate to receive support from the District Nursing Team during lockdown, however, they encountered a delay in receiving a memory assessment and struggled to see their GP face-to-face. C2 believes this did impact professional understanding of the full extent of Adult B's cognitive impairment and the affect his decline may have had on Adult A as his fulltime carer.

118. Many local agencies rushed to implement alternative ways to access support during lockdown, some of which were temporary initiatives via online systems. GP consultations were diverted to e-consult systems or 111 systems. Face-to-face appointments changed to virtual meetings or telephone calls and forms were mostly downloaded and submitted online. Whilst many residents were able to adjust to the new ways of working, many people became more isolated as a result, with the older population and people from lower socioeconomic classes (without access to digital technology) most disadvantaged. In 2018 there were still 5.3 million adults in the UK, or 10.0% of the adult UK population who had never used the internet[52]. The government acknowledges that this has led to a digital divide between those who have access to information and communications technology and those who do not, giving rise to inequalities in access to opportunities, knowledge, services, and goods[53]. **In Cornwall, agencies are less clear about which populations or individuals are disadvantaged by digital technology or how to reach them. It is important to establish this demographic information in Cornwall to avoid making assumptions. This is addressed in Finding Four.**

119. The reviewers are involved in four other Domestic Homicide Reviews in the Southwest at present whereby the family or the victim did not use or have access to the internet. This is not

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[51] as_new_the-fog-of-support_carers-report_final-compressed.pdf (alzheimers.org.uk)

[52] https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04

[53] Office for National Statistics - Exploring the UK's digital divide 2021.

an uncommon phenomenon. As the world returns to some form of normality after the global pandemic, many changes are slow to return to previous ways of working. Some changes have resulted in more productivity, less costs and more efficiency, and many professional agencies are reviewing which working patterns and systems will stay and which ones will revert to pre-COVID times. For example, virtual meetings have become the norm and many busy professionals feel that it is a good alternative to wasted commute times. However, other systems, such as e-consult for access to GP's and digital health information has disadvantaged vulnerable populations and these will require reviewing to ensure that people are not excluded from vital healthcare information. **Professional agencies in Cornwall will need to review its services to ensure that alternative access is available for non-digital service users. This will need to be considered in line with the Equality Act, 2010 particularly under the category of age as older people's adoption of digital technologies remains below other age groups**[54]. **This has been addressed in** Finding Four

Diagnosing dementia and the importance of early intervention

120. Health professionals can be reluctant to speak openly and honestly with patients and their families about dementia.[55] In the absence of a cure, a professional belief that nothing can be done has contributed to delays in diagnosis[56]. However, increasing evidence showing that dementia may be preventable has led to an international focus on earlier diagnosis and intervention[57].

121. There are many advantages to early diagnosis and evidence suggests that people prefer to know if they have dementia in order to access appropriate support and treatment and to plan for the future[58]. Early diagnosis also increases early access to medication, non-medication-based therapies, information, access to support networks, the ability to make life plans, arrange power of attorneys and discuss end of life wishes and preferences[59].

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[54] https://journals.sagepub.com/doi/full/10.1177/0038038520975587

[55] https://pubmed.ncbi.nlm.nih.gov/20650401/

[56] https://pubmed.ncbi.nlm.nih.gov/19226529/

[57] Prince M, Albanese E, Guerchet M, et al. World Alzheimer report 2014. Dementia and risk reduction: an analysis of protective and modifiable risk factors. Alzheimer's Disease International, 2014.

[58] https://pubmed.ncbi.nlm.nih.gov/21281553/

[59] https://www.bmj.com/content/350/bmj.h3029.full

122. Adult B was known by Cornwall agencies to have been experiencing cognitive decline for 6 months prior to his arrest for the homicide of Adult A – although he had been showing signs of an insidious onset for 3 years. The first visit to the GP to discuss cognitive impairment was the 26/1/21. The referral to the memory assessment was 02/03/21. The memory assessment took place on the 4/05/21 - 9 weeks after the referral and 14 weeks after the first complaint of cognitive demise. Adult B was still on the diagnosis pathway at the time of the incident. This is beyond the national average of a 6 week wait for an initial assessment[60]. Subsequently, Adult B only received a formal diagnosis of dementia post-homicide and after his impairment was so severe, he lacked mental capacity to take advantage of the benefits that an early diagnosis can bring. The delay in identifying the early signs of cognitive impairment and receiving a memory assessment played a part in this. **Healthcare agencies in Cornwall need to bring the waiting times for initial dementia assessments in line with national averages.** This has been addressed in Finding Five

Comorbidities and Delirium Education

123. Adult B had a range of co-morbidities, as is the case for many people living with dementia[61]. Studies show on average 77% of people living with dementia have an additional 4.6 chronic conditions[62] [63], therefore they are subject to high rates of complications[64]. The way that the healthcare system is arranged (typically responding to single conditions) meant that Adult B's multiple conditions received an uncoordinated care approach adding to Adult A's frustration as she could not establish a routine for Adult B or plan her day. Rejecting support on the basis of it being unsuitable at the time can increase carers guilt and negatively affect coping potential. Healthcare records for Adult B clearly show that his wife was becoming agitated by unannounced visits and requests to access additional support for other health conditions.

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[60] https://www.england.nhs.uk/mental-health/dementia/#:~:text=people%20with%20dementia.-,Our%20work,initial%20assessment%20at%20six%20weeks.

[61] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3994526/

[62] https://web.s.ebscohost.com/abstract?direct=true&profile=ehost&scope=site&authtype=crawler&jrnl=02634465&AN=149908009&h=c1eUVf5SWmrq17cSDzDWo4v2PoqMm0l9ldve9r%2fLF4cVw1YtX0caiCQXCxbMACcFLoaqtJLU%2f86HNrpQIglnGQ%3d%3d&crl=c&resultNs=AdminWebAuth&resultLocal=ErrCrlNotAuth&crlhashurl=login.aspx%3fdirect%3dtrue%26profile%3dehost%26scope%3dsite%26authtype%3dcrawler%26jrnl%3d02634465%26AN%3d149908009

[63] https://www.gov.uk/government/publications/dementia-comorbidities-in-patients/dementia-comorbidities-in-patients-data-briefing

[64] https://bmjopen.bmj.com/content/3/6/e002770.short

Dementia care is not just about supporting the person living with dementia – it is about supporting the carers to coordinate treatments for dementia alongside other comorbid health conditions. **It is important that professionals recognise the important role of informal carers when making a new diagnosis of dementia and acknowledging the significant change in their life, the strain of older caregivers and the level of responsibility placed on them. Their frustrations and worries should be heard and where possible, attempts should be made to coordinate care for comorbid conditions and put prearranged schedules in place to reduce stress and anxiety on the whole family – wherever they are on the diagnostic pathway. This has been addressed in Finding Six**

124. Adult B was suffering with long standing chronic leg oedema and a tissue viability condition which developed into skin breaks and ulcerated areas, increasing his risk of infection. Infection is one of the most important risk factors for delirium in elderly patients[65] causing acute confusion accompanied by cognitive impairment and/or perception. Adult A complained that Adult B was becoming muddled, confused, and doing odd things, yet infection-related delirium was not considered by community nurses. **Professionals involved in dementia care should be vigilant to the risks of delirium and impart this knowledge with informal caregivers through a simple screening tool. A county-wide delirium policy would help set training standards and evaluation methods for measuring the effectiveness of early intervention on health outcomes for high-risk patients. Public Health should consider the benefits of delirium education to accompany public awareness of other serious conditions such as sepsis. This has been addressed in Finding Six**

Commissioning services and thresholds

125. Adult B was on the diagnostic pathway for dementia, but he did not have a diagnosis at the time of Adult A's homicide. He has received a diagnosis of severe Alzheimer's since his conviction. His diagnosis was delayed in Cornwall due to capacity issues and COVID. Subsequently, neither Adult B or his wife were eligible for a dementia practitioner or Admiral nurse, who could have provided invaluable support for the family. This midway status, especially if delayed, increases the risk of carer burden, poorer health outcomes for both patient and carer, and lack of access to appropriate dementia support. **Commissioners should consider whether commissioned services such as dementia practitioners and Admiral nurses**

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[65] https://journals.sagepub.com/doi/pdf/10.1177/2333721417739188

should be made available to patients and carers on the pathway, not just post-diagnosis. This has been addressed in Finding Seven

126. Adult B's leg care was transferred to Adult A and the district team advised that this care could take place at the GP surgery if required, however, Adult A advised that she could not get Adult B to the surgery. This decision was made whilst Adult B was on the diagnostic pathway, however, he was symptomatic of dementia, which is a recognised disability. **Commissioners will need to review whether the policy that restricted the district nurses from continuing care was considerate of his rights under the Equality Act 2010. Is there merit is extending the remit of commissioned services to people on the diagnostic pathway? This has been addressed in** Finding Seven

SECTION FIVE – SUMMARY AND CONCLUSION

127. This has been a very sad case to review. At first glance, the suddenness of Adult B's decline on the morning of the homicide seemed misaligned from the usual progression of vascular dementia. However, psychological fears, embarrassment, stigma, and pride can all deter help-seeking until symptoms become severe[66] and it is possible that Adult B's cognitive impairment had been declining significantly for some time. There is also a strong possibility that Adult B could have developed an infection, which led to delirium, although this cannot be proved retrospectively. However, his admission to hospital a week later with life threatening sepsis caused by the same leg ulcers may justify the hypothesis being included in this review.

128. C2's pen picture of her mother describes a proud, independent, and strong woman who was loyal and devoted to her husband. Her traditional views of marriage and her commitment to her vow of 'in sickness and in health' may well have motivated her to cope independently for as long as she possibly could. There is no way of knowing if a previous pivotal event triggered her final plea for support.

129. Help was forthcoming in the form of her daughter C2 and her efforts to download forms for her and her mother to complete together. It is a tragedy that the arrangements to complete the forms were made for the afternoon of Adult A's death. We hope C2 will take some comfort

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[66] https://www.tandfonline.com/doi/abs/10.1300/J018v27n04_03?journalCode=wcli20

in knowing she did everything she could to help her parents, however, dementia care is complex, and she could not have foreseen what would happen.

130. Learning from this review is crucial to future dementia care in Cornwall. The way in which the professional system identifies, diagnoses, supports and cares for people living with dementia must improve. Similarly, the recognition and proactive support of caregivers must align with dementia care to achieve effective outcomes.

131. There were missed opportunities to provide support for both Adult A and Adult B in this case. Carer's needs assessments and social care needs assessments were not proactively pursued or followed up even when the assessments would have been in their best interests. Routine enquiry of domestic abuse did not happen, indicating that professional curiosity around elder domestic abuse is not adequate. There was a missed opportunity to share information about Adult A's frustration, agitation, and possible cognitive decline with her GP or to make gentle enquiries about her own wellbeing and mental state. Adult A's expression of 'feeling out on a limb' did not raise concerns about loneliness or lead to discussions about support networks.

132. There were areas of good practice. The ability of community nurses to reach vulnerable patients during a global pandemic, putting their own welfare at risk, demonstrates an honourable commitment to vulnerable community members. Community nurses listened to Adult A's frustrations and made concerted efforts to coordinate care and make prearranged visits. There was active encouragement to support Adult B to see a podiatrist and efforts were made to arrange transport. Even with so many challenges to overcome, the district nursing team were able to provide continuous treatment to Adult B's legs and heal his painful blisters.

133. There remain a number of barriers to overcome in the state's response to dementia care. Early diagnosis is essential as it facilitates access to early intervention. Psychological and physical barriers need to be overcome to encourage early reporting of symptoms and help-seeking from individuals and families. Information needs to be accessible, and support needs to be proactive. Commissioning thresholds need to consider the needs of individuals transitioning through the diagnostic pathway. More effort needs to be made to reach vulnerable populations rather than waiting for them to identify themselves when their coping potential has reached crisis point. Agencies must be mindful of digital exclusion and ensure that health information is accessible to non-digital users.

SECTION SIX – FINDINGS AND RECOMMENDATIONS

134. The following specific findings and associated recommendations are designed to highlight key learning from this review and provide the basis for developing an action plan to improve services in the future.

135. To assist with the forming of the DHR recommendations, consent was obtained from C2 to share a copy of the draft report with the Cornwall Rural Carers Group and the Carer's Service (Cornwall) to obtain input from Cornish residents with lived experience. The group were asked to read the report, its findings and conclusions and feedback their views through a focus group discussion with the chairs on the 7th December 2022. Consequently, the reviewers asked if a representative from the Carers Service would join the panel as an expert to assist in the formulation of the recommendations and action plan at a working group meeting on the 8th December 2022. This representative also agreed to act as a lead conduit to continue communication with C2 (after the DHR) to update the family on the progress of actions.

Finding One

Support for informal caregivers on the diagnostic pathway is inadequate.

136. There were missed opportunities to identify Adult A as an informal caregiver and refer her for a carers assessment in line with the Care Act 2014. Professionals did not consider carer's burden or make plans in the event that Adult A could no longer care for Adult B. Psychological, social or respite support for Adult A, as an elderly caregiver, was not offered or considered.

137. Professionals observed behaviours that suggested Adult A was becoming distressed, agitated, and overwhelmed. This should have triggered sensitive and gentle encouragement to complete a carers assessment or to speak with nearby family members for extra support. There was an opportunity to explore her reservations and concerns and address them. There was also an opportunity to continue to a referral if they felt that it was in Adult A's and Adult B's best interests.

138. Adult A never received encouragement to access support in her own right. Her responsibilities were significant for a person of her age, and this was not acknowledged. Reminders were

provided to Adult A to access health support for Adult B, but her own wellbeing, loneliness and upset were not adequately explored. She was not provided with literature about support groups or befriending schemes. No emotional, social, or pastoral care was offered or provided.

139. An independent Thematic Review into the role of unpaid carers by the Safeguarding Adults Board (SAB), published in June 2022, also identified common themes that echo findings from this review. These include a) a reluctance by unpaid carers to access professional help, b) a lack of consideration as to the vulnerability/suitability of unpaid carers, c) disguised compliance and a lack of professional curiosity resulting in avoidable risk, d) unpaid carers not being subjected to adequate assessments resulting in a lack of support and interventions. The recommendations from the SAB Thematic Review should be considered in line with the following DHR recommendations -

Finding Two

Routine enquiry of domestic abuse did not happen

140. Despite daily and weekly interactions with Adult A and Adult B, they were never seen on their own and no professional ever routinely enquired about domestic abuse. Elder abuse is associated with Dementia and Dementia Care[67]. All professionals involved in the care of people living with dementia should be including routine enquiry into their professional functions. Professionals should feel confident to explore sensitive questions and know how to respond if a positive response is achieved.

Finding Three

A social care needs assessment was not adequately explored or followed up for Adult B in accordance with the Care Act 2014.

141. Adult B had obvious mobility issues, a number of comorbid health conditions and deteriorating cognitive function. He was 84 and his carer was 82. They needed help to make their environment safe and to improve his quality of life. Although it was in his best interests to receive a needs assessment, it did not happen. Professionals did not proactively pursue this even though it was in his best interests. They accepted Adult A's decline on Adult B's behalf.

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[67] https://psycnet.apa.org/record/1993-38909-001

Finding Four

There are people living in Cornwall who are disadvantaged from accessing health advice, support, and assessments due to digital exclusion.

142. Adult A and Adult B did not have a computer and did not access any information through digital technology. They were unable to navigate e-consult systems and found alternative phone systems convoluted. Adult A did not know how to access a needs assessment without going through her daughter. Adult A was becoming increasingly more isolated and housebound due to Adult B's mobility issues, therefore her access to alternative methods of information (such as leaflets and posters) were restricted.

Finding Five

It is taking too long to diagnose dementia in Cornwall and opportunities for early intervention are being missed.

143. Adult B's memory assessment was delayed due to capacity issues. He had been experiencing insidious onset for three years and a rapid onset of dementia symptoms for 6 months at the time of Adult A's death. This waiting time exceeded the 6-week target set by the government[68] and the 28-day target set by the local commissioning contract. Subsequently, Adult B only received a formal diagnosis of dementia post-homicide and after his impairment was so severe he lacked mental capacity to take advantage of the benefits that an early diagnosis can bring.

Finding Six

Uncoordinated care for comorbid conditions can increase carer's burden and delirium education needs to be improved for professionals and informal caregivers.

144. Adult B's multiple conditions received an uncoordinated care approach adding to Adult A's frustration as she could not establish a routine for Adult B or plan her day. If a referral had been made to Adult Social Care for a needs assessment, a care plan would have been developed in accordance with section 25 of the Care Act 2014.

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[68] https://www.alzheimers.org.uk/sites/default/files/2021-08/20210608-Alzheimer-s-Society-briefing-Lords-Oral-Question-Memory-Assessment-Services-Waiting-Times.pdf

145. Adult B was at higher risk of developing infection-related delirium due to his soft tissue viability condition. Delirium and dementia can commonly coexist, with dementia being a leading risk factor for delirium; and delirium being an independent risk factor for subsequent dementia[69]. Despite this, Adult A was unaware of the risks of delirium or the signs to be aware of. Professionals involved in his care did not consider his delirium risk before or after his immediate arrest.

Finding Seven

Commissioning arrangements need to be reviewed for people on the dementia diagnostic pathway

146. Neither Adult B nor his wife were eligible for a dementia practitioner or Admiral nurse, who could have provided invaluable support for the family. Their prolonged status on the diagnostic pathway increased the intensity of caring duties for Adult A who was left largely unsupported. Adult B's health outcomes were also compromised. No agency checked on Adult B's cognitive impairment whilst he was waiting for an assessment.

147. On the 27th May 2021 Adult A was told that the district nurses do not undertake general leg care as a service and provided telephone numbers for private carers for Adult A to contact. There was an assumption at this point that Adult A and Adult B could afford private carers. The community nurse emphasised that Adult B's hosiery and leg care needed to be done weekly and his legs should not be left longer than this. Adult A told C2 she was overwhelmed with the request but was unable to transport Adult B to the surgery for a professional to complete it, therefore the responsibility for preventing infection fell to her. Adult A did not discuss the provision of private carers with her daughter, C2, instead she admitted she did need help, which instigated C2's attempts to download forms for a social care needs assessment for Adult B. Unfortunately, they were due to complete the forms together on the afternoon of Adult A's death.

148. The reviewers were informed that there are a shortage of carers and carers working in rural areas throughout the county. Post-pandemic recovery is slow and workforce capacity remains

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[69] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4535349/#:~:text=Delirium%20is%20a%20known%20risk,abnormalities%2C%20stroke%2C%20or%20medications.

on the risk register for all statutory health services. The Chair of the Health and Social Care Committee welcomed a government decision to publish a standalone dementia strategy in 2022 but warned that extra investment in social care services will not be enough for local authorities to sustain services at the levels considered essential for dementia patients[70].

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[70] https://committees.parliament.uk/committee/81/health-and-social-care-committee/news/160901/dementia-strategy-welcomed-but-extra-government-investment-not-enough/

Recommendations

Recommendation 1 – Integrated Care Boards

149. The ICB to work with partner agencies to make system changes that overcome help-seeking barriers and improve the way people interact, engage, and access the specialist support available.

Recommendation 2 – All agencies

150. If an individual needs another person to help them function on a day-to-day basis, all professionals should routinely enquire about unpaid, informal caregiving arrangements. This should extend to family members and community members who may also be providing unpaid informal care.

Recommendation 3 – All agencies

151. Once an unpaid informal caregiver has been identified, all professionals should refer to the Carers' Service and discuss a carer's needs assessment, its purpose, the best placed agency to undertake the assessment. and the specialist support that can follow. If a caregiver declines support a sensitive one-to-one discussion should take place to understand and alleviate their reservations.

Recommendation 4 – All agencies

152. Identified unpaid informal caregivers should be encouraged to contact their GP to add themselves to the GP carers register. Or, if they are a member of the Carer's Service, the Carers Service should offer to contact their surgery on their behalf. GPs should code unpaid informal caregivers for their practice area accordingly on SNOWMED.

Recommendation 5 – Public Health Cornwall

153. Public health (Cornwall) should work with the Carer's Service to design a community campaign to raise awareness of the definition of unpaid informal caregiving and the support available to them in the county to encourage self-identification and help-seeking. Relevant and accessible literature and campaign events should not be reliant on a formal diagnosis but exist to improve the wellbeing of the caregiver and acknowledge their vital contribution.

Recommendation 6 – Commissioners

154. Commissioners should make dementia practitioners available to patients and carers on the pathway, not just post-diagnosis. At the very least, a system to check on the welfare of patients on the waiting list should be introduced.

Recommendation 7 – Public Health (Cornwall)

155. Cornwall should have a county-wide delirium policy with a strategy for professional and public health awareness training. A screening tool for delirium (similar to that of sepsis) should be made available to professionals involved in dementia care and shared with informal caregivers. Information leaflets, such as the one designed by the NHS and Royal College of Psychiatrists should be shared with families[71].

Recommendation 8 – Integrated Care Areas

156. Integrated care areas should work with caregivers to create a bespoke coordinated care plan that reflects the multi-disciplinary treatment needs for people living with dementia and those on the diagnostic pathway with comorbid conditions requiring regular treatment. Attempts should be made to listen to carer's concerns and coordinate treatment in a way that reduces the number of visits and appointments, enabling families to establish a routine and improve their quality of life.

Recommendation 9 – All agencies

157. All agencies should undertake an immediate review of their accessibility to services post-COVID to ensure vulnerable populations are not excluded due to restrictive digital access to information, assessments, forms, and appointments.

Recommendation 10 – Cornwall Foundation Trust

158. The Memory Assessment Service to develop a strategy to bring the waiting times for initial dementia assessments in line with commissioned timescales (28 days).

Recommendation 11 – All agencies

159. Routine Enquiry must be a priority and further training is required to ensure professionals supporting older populations feel confident to ask about domestic abuse, know the difference

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[71] https://www.nhs.uk/ipgmedia/national/Royal%20College%20of%20Psychiatrists/Assets/Delirium.pdf

between domestic abuse and behaviours deriving solely from cognitive impairment and know how to engage the correct specialist services when required.

Recommendation 12 – Safeguarding Adults Board

160. The family of Adult B raised three specific questions related to Adult B's treatment post-homicide which sits outside of the remit of this DHR but has significant importance for future work in this area. These issues will be followed up by a nominated lead panel member representing the Carers Service (Cornwall). This representative should be supported by the Safeguarding Adults Board in their ongoing communication with C2 to improve dementia care across Cornwall, using the learning from this review to support the wider aims of the family.