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Review
Overview Report
DHR 04

Report into the death of Margaret aged 85 years on 28th July 2016

Report produced by Malcolm Ross M.Sc.
Independent Chair and Author

A tribute to

Margaret and Angus Mayer

from their children

Our Mum and Dad

We loved and adored our parents.

We will always be thankful for the love they gave us, for the values they instilled in us and for making us the people that we are today. We thank them for giving us such a wonderful and happy family life.

For over 65 years they loved and adored each other.

We will never know the thoughts that were in our father's mind during the final days of our parent's lives but we will seek comfort in our belief that in his mind he was, as always, only doing what he believed to be the best for our mother and for their six children.

Our mother was beautiful in every way and our father, as our sister wrote in her eulogy to him, was 'a good man'.

Ann, Ian, Sheena, Stuart, Catherine and Andrew

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List of Abbreviations

C&VUHB	Cardiff & Vale University Health Board
CCC	Cardiff City Council
PSB	Public Services Board
CSP	Community Safety Partnership
CPET	Cardiff (& Vale University Health Board) Protected Education Time
DASH	Domestic Abuse Stalking and Harassment Risk Assessment
GP	General Practitioner
IMR	Individual Management Report
MARAC	Multi Agency Risk Assessment Conference
MAPPA	Multi Agency Public Protection Arrangements
SIO	Senior Investigating Officer (Police)
WAST NHS Trust	Welsh Ambulance Services NHS Trust

INTRODUCTION AND BACKGROUND

The members of this review panel offer their sincere condolences to the family of Margaret and Angus Mayer for the sad loss of their parents in such tragic circumstances.

1.1 Introduction

1.1.1 The family in this case consist of six children, now aged between 55 and 64, who have expressed their wish in writing that reference is made to their parents in this report by their names, Margaret and Angus. ***The family also request that this report contains the real names of the six children of Margaret and Angus.***

1.1.2 Margaret was an 85 year old lady who was killed by Angus, her husband of over 60 years. He was 86 years of age at the time of her death.

1.1.3 Margaret was diagnosed with Alzheimer's[1] disease in 2011, and by July 2016, the situation had become progressively more difficult for Angus to manage. He was disturbed most nights by the toileting arrangements for Margaret and he became frustrated and exhausted.

1.1.4 Social Services became involved with the couple and provided some household aids to assist Margaret in her day-to-day living, but Angus was a proud man who wanted to look after Margaret himself and politely declined more assistance from Social Services.

1.1.5 On 28th July 2016, there was a family gathering and breakfast with Angus and Margret and most of the children present. All of the children left the family home, leaving Angus and Margaret in the house. Later that morning Angus went to Cardiff Central Railway Station and jumped in front of a moving train, severely injuring his legs. Whilst being attended to by the emergency services, he disclosed that he had killed Margaret who was at the family home. Police and ambulance officers attended and found Margaret dead in her bedroom. She had suffered blunt trauma injuries to her head.

1.1.6 Angus was taken to hospital for emergency operations to his legs that involved amputation of one of his legs. He did not recover and died on 11th September 2016 of pneumonia, sepsis and complications arising from his injuries.

1.1.7 HM Coroner for Cardiff concluded that Margaret had been unlawfully killed and Angus had died of natural causes.

1.2 Purpose of the Review

1.2.1 The Domestic Violence, Crimes and Victims Act 2004, establishes at Section 9(3), a statutory basis for a Review, which was implemented with due guidance[2] on 13th April

[1] Alzheimer's disease, named after the doctor who first described it (Alois Alzheimer), is a physical disease that affects the brain. There are more than 520,000 people in the UK with Alzheimer's disease. During the course of the disease, proteins build up in the brain to form structures called 'plaques' and 'tangles'. This leads to the loss of connections between nerve cells, and eventually to the death of nerve cells and loss of brain tissue. People with Alzheimer's also have a shortage of some important chemicals in their brain. These chemical messengers help to transmit signals around the brain. When there is a shortage of them, the signals are not transmitted as effectively.

[2] Multi-Agency Statutory Guidance For The Conduct of Domestic Homicide Reviews - Home Office 2011 as amended by Home Office Guidance December 2016 *www.homeoffice.gov.uk/publications/crime/DHR-guidance*

2011 and reviewed in December 2016[3]. Under this section, a domestic homicide review means 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"

1.2.2 Where the definition set out in this paragraph has been met, then a Review must be undertaken.

1.2.3 It should be noted that an intimate personal relationship includes relationships between adults who are or have been intimate partners or family members, regardless of gender or sexuality.

1.2.4 In March 2013, the Government introduced a new cross-government definition of domestic violence and abuse[4], which is designed to ensure a common approach to tackling domestic violence and abuse by different agencies. The new definition states that domestic violence and abuse is:

"Any incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse between those aged 16 or over who are or have been intimate partners or family members regardless of gender or sexuality. This can encompass, but is not limited to, the following types of abuse:

- *psychological*
- *physical*
- *sexual*
- *financial*
- *emotional*

1.2.5 This Review is not an inquiry into how Margaret died or who is to blame. These are matters for Coroners and Criminal Courts. Neither are they part of any disciplinary process. The purpose of a DHR[5] is to:

- Establish what lessons are to be learned from the homicide regarding the way in which local professionals and organisations work individually and together to safeguard Margaret;
- 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 the policies and procedures as appropriate;
- Prevent domestic homicide and improve service responses for all victims and their children through improved intra and inter-agency working;
- Contribute to a better understanding of the nature of domestic violence and abuse; and highlight good practice

[3] Multi-Agency Statutory Guidance For The Conduct of Domestic Homicide Reviews - Home Office 2016
[4] Multi-Agency Statutory Guidance for the Conduct of Domestic Homicide Reviews Revised August 2013 Home Office revised again by 2016 guidance
[5] Multi-Agency Statutory Guidance for the Conduct of Domestic Homicide Reviews Home Office 2016

1.3 Process of the Review

1.3.1 South Wales Police notified Cardiff Public Services Board (CPSB) of the homicide on 15th September 2016, CPSB reviewed the circumstances of this case against the criteria set out in Government Guidance[6] and decided that a Domestic Homicide Review (DHR) should be undertaken.

1.3.2 The Home Office was notified of the intention to conduct a DHR on 24th October 2016. An independent company, Winston Ltd, was commissioned and appointed a chair for the DHR Panel and an author for the Overview Report. At the first review panel terms of reference were drafted. On 16th January 2018 the Executive Public Services Board approved the final version of the Overview Report and its recommendations.

1.3.3 Home Office Guidance[7] recommends that reviews should be completed within 6 months of the date of the decision to proceed with the review. However there have been a number of contributing factors that has meant this deadline has not been met in this case. Contributing factors include the necessity to:

- Establishing a new multi-agency process for conducting Domestic Homicide Reviews, that is distinct from Serious Case Reviews and which required approval from Cardiff's Public Services Board
- Developing a commissioning framework to recruit Independent Chairs/Authors to facilitate Domestic Homicide Reviews

In addition there has also been a delay between the completion of the Overview Report, Action Plans, and submission to the Home Office Quality Assurance Panel. This has been hampered by periods of long-term sickness of key members of staff contribution to Action Plans and the Local Authority Officer who co-ordinates Domestic Homicide Review on behalf of Cardiff Council. However, Cardiff Council have provided regular updates on progress to the Home Office.

1.4 Independent Chair and Author

1.4.1 Home Office Guidance[8] requires that;

"The Review Panel should appoint an independent Chair of the Panel who is responsible for managing and coordinating the review process and for producing the final Overview Report based on IMRs and any other evidence the Review Panel decides is relevant", and *"…The Review Panel Chair should, where possible, be an experienced individual who is not directly associated with any of the agencies involved in the review."*

1.4.2 The Public Services Board decided that in this case to appoint an independent chair and an independent author and commissioned Winston Ltd.

1.4.3 The Independent Author, Mr Malcolm Ross, was appointed at an early stage, to carry out this function. He is a former Senior Detective Officer with West Midlands Police and since retiring he has 18 years' experience in writing over 80 Serious Case Reviews and chairing that process and, more recently, performing both functions in relation to over 28 Domestic Homicide Reviews. Prior to this review process he had no

[6] Home Office Guidance 2016 Page 9
[7] Home Office Guidance 2016 pages 16 and 35
[8] Home Office Guidance 2016 page 12

involvement either directly or indirectly with the members of the family concerned or the delivery or management of services by any of the agencies. He has attended the meetings of the panel, the members of which have contributed to the process of the preparation of the Report and have helpfully commented upon it.

1.5 Domestic Homicide Review Panel

1.5.1 In accordance with the statutory guidance, a Panel was established to oversee the process of the review. Mr Ross chaired the Panel and also attended as the author of the Overview Report. Other members of the panel and their professional responsibilities were:

Name	Designation
Sue Hurley	Independent Vulnerable Person Manager
Nikki Harvey	WAST NHS Trust Head of Safeguarding
Donna Newell	Safeguarding Nurse Advisor, Cardiff & Vale UHB
Alys Jones	Operations Manager Safeguarding, Cardiff Council
Stephanie Kendrick – Doyle	Community Safety Manager, Cardiff Council
Sue Phelps	Director for Wales, Alzheimer's Society Cymru
Linda Hughes-Jones	Senior Nurse Safeguarding Adults, Cardiff & Vale UHB
Bruce McLernon	Independent Consultant Social Services
Gail Weaver	Housing Policy Officer, Cardiff Council (Administrative Support)
Natalie Southgate	Policy and Development Manager, Cardiff Council
Nicola Jones	Domestic Abuse Co-ordinator, Cardiff Council
Martyn Jones	Independent Author, Winston
Malcolm Ross	Independent Author and Chair

1.6 Parallel proceedings

1.6.1 The Panel were aware that the following parallel proceedings were being undertaken:

- CPSB advised HM Coroner on 11th January 2016 that a DHR was being undertaken.
- A criminal investigation was commenced and a report has been submitted to HM Coroner. HM Coroner concluded that Margaret was unlawfully killed. Angus died from his injuries whilst in hospital so no inquest was held.

1.7 Time Period

1.7.1 It was decided that the review should focus on the period from 2011, when Margaret was first diagnosed with dementia, until the time of Angus' death, 11th September 2016. It is appreciated that the scope and timescales for the reviews is usually until the time of death of the victim, Margaret, however in this case Angus died 6 weeks later and it is thought that lessons learned may be identified during that period of time.

1.8 Scoping the Review

1.8.1 The process began with an initial scoping exercise prior to the first Panel meeting. The scoping exercise was completed by the Executive Public Services Board to identify agencies that had involvement with the Margaret and Angus prior to the homicide. Where there was no involvement or insignificant involvement, agencies were requested to inform the Review by a report.

1.9 Individual Management Reports

1.9.1 An Individual Management Report (IMR) and comprehensive chronology was received from the following organisations:

- Cardiff Council Adult Social Services
- Cardiff & Vale University Health Board

1.9.2 As agreed, reports for information were received from:

- South Wales Police
- WAST NHS Trust
- Cardiff Council Housing & Communities – Security and Alarms Monitoring Service

1.9.3 Guidance[9] was provided to IMR Authors through local and statutory guidance and through an author's briefing. Statutory guidance determines that the aim of an IMR is to:

- Allow agencies to look openly and critically at individual and organisational practice and the context within which people were working to see whether the homicide indicates that changes could and should be made.
- To identify how those changes will be brought about.
- To identify examples of good practice within agencies.

1.9.4 Agencies were encouraged to make recommendations within their IMRs and these were accepted and adopted by the agencies that commissioned the Reports. The recommendations are supported by the Overview Author and the Panel.

1.9.5 The IMR Reports were of a high standard providing a full and comprehensive review of the agencies' involvement and the lessons to be learnt.

1.10 The area

1.10.1 Cardiff is the capital city of Wales and a UK Core City. The city has a population of 350,000 and sits at the heart of the city-region of 1.4m, which is just under half the population of Wales. Cardiff was the fastest-growing of the Core Cities over the past decade and is projected to grow by a further 26% (or 91,500 people) over the next 20 years.

1.10.2 The city's economic strengths lie in the financial and business services sector, which employs over a quarter of the workforce, with a particular expertise in insurance, and has a fast-developing creative industries cluster, particularly related to film and TV production.

[9] Home Office Guidance 2016 Page 20

1.10.3 According to the 2011 Census, 15.3% of Cardiff's population is from a non-white ethnic group, equating to almost two-fifths (39.2%) of the total non-white ethnic population in Wales. The distribution of the non-white ethnic population across the six Neighbourhood Partnership areas ranges from 7.0% in Cardiff West to 36.2% in City & Cardiff South.

1.10.4 Cardiff's continued growth will not be evenly spread across the age groups. While there will be significantly more people of working age, there will also be more people over the age of 65.

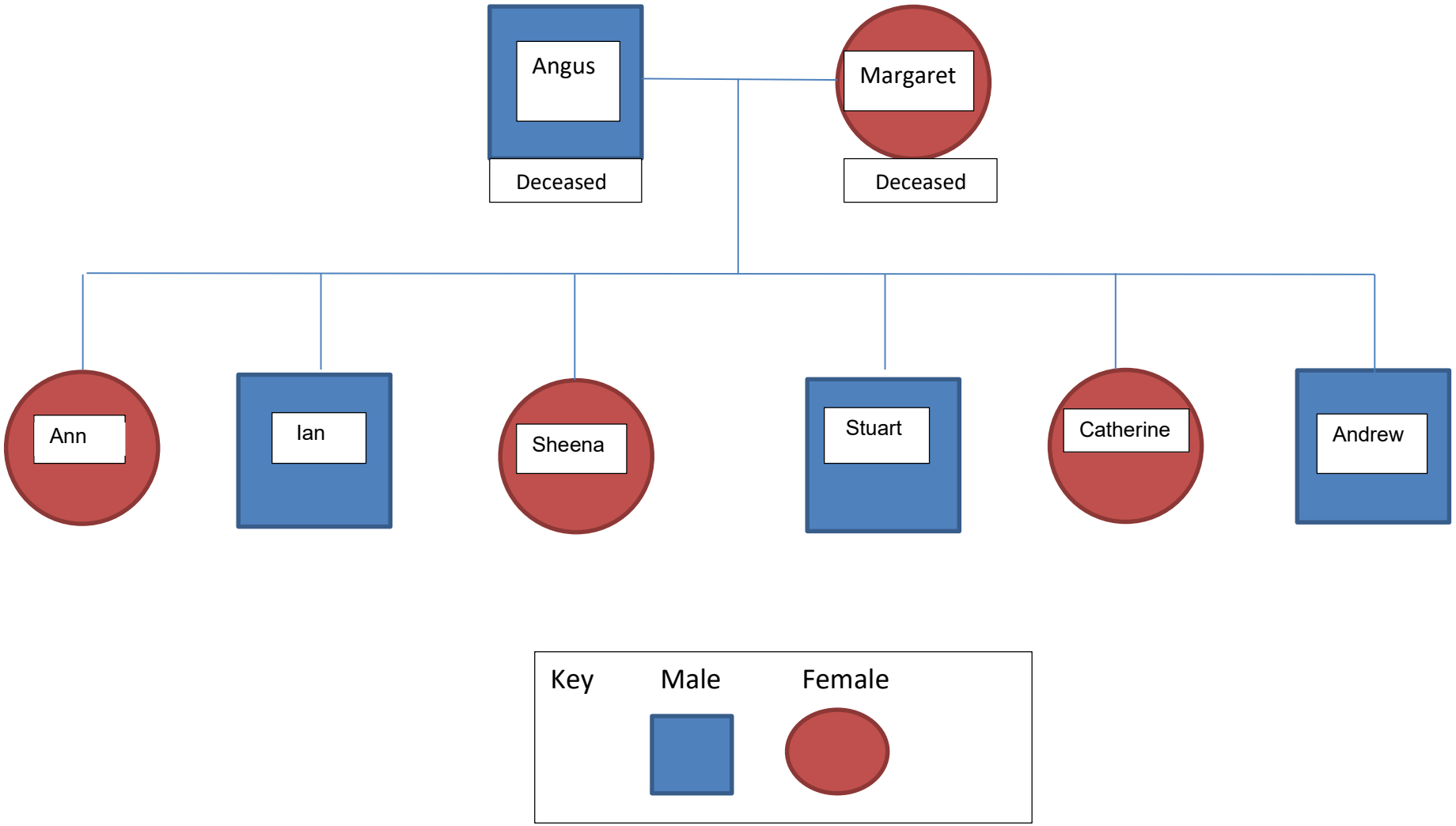
1.10.5 The majority of older people in Cardiff (68%) report that they are in good or excellent health; this is higher than the Welsh average. However, the risk of developing dementia is strongly age-related. As life expectancy increases, the total number of people with dementia will increase. It is estimated that 25% of women and nearly 20% of men over 85 in Wales currently have a form of dementia and by 2035 it is predicted that over 6,000 people in Cardiff will be living with dementia.

1.11 Family members concerned in this review

1.11.1 The following genogram identifies the family members in this case, as represented by the following key:

	Relationship
Margaret	Victim
Angus	Husband to Margaret and Father to Children
Ann	Eldest Adult Child
Ian	Second Adult Child
Sheena	Third Adult Child
Stuart	Fourth Adult Child
Catherine	Fifth Adult Child
Andrew	Sixth Adult Child

GENOGRAM


Angus
Deceased
Margaret
Deceased
Ann
Ian
Sheena
Stuart
Catherine
Andrew
Key
Male
Female

2. Summary

This review concerns an elderly couple who had been married for some 64 years. They married in 1952 and lived in the same house in Cardiff all of that time and brought up six children, Ann, Ian, Sheena, Stuart, Catherine and Andrew, all of whom are now adults, the youngest being in their 50s and the eldest being in their 60s. All of the siblings are close to each other emotionally, albeit there is quite a physical distance between some of them. They have made a specific request that they and their parents are referred to by their true names throughout this report.

2.1 Margaret and Angus had a large social group of friends. They were quite adept bridge players, more so Margaret, but as she became less able that group of friends naturally diminished. Margaret loved cooking and the couple often entertained friends and relatives at their home. She was an academic who had worked in a University Research Laboratory. It was here she met Angus who worked as a Laboratory Assistant. She was an active person all of her life until her illness restricted her mobility.

2.2 Ann and Sheena would care for their parents on a daily basis especially as the parents grew older. During recent years, Margaret, aged 85 years, became ill with early onset dementia[10] and together with other ailments was less able to cope with daily living and her mobility suffered as a result.

2.3 Angus, aged 86 years, was the main carer for Margaret, his wife. He had always been active, enjoying sea fishing and gardening in his allotment. He also enjoyed history and archaeology. He is described by the children as being a very proud man who preferred not to bother anyone if he could manage on his own. The couple were offered various forms of assistance from Social Services to aid Margaret with her physical activities, such as a walk-in shower/bath and securing her a place at a Day Centre two days per week. Angus is recorded as declining what he perceived to be more intrusive assistance from Social Services.

2.4 A few weeks before the death of Margaret, Angus told her he could not cope any longer. The children said he was exhausted by constant attention Margaret needed especially during the night, when he had to attend to her every two hours or so. He intimated that she would have to go into a care home.

2.5 Just before 28th July 2016, the whole family gathered at the parents' house in Cardiff. Plans had been made for a family holiday at the usual place in West Wales. On the morning of 28th July 2016, the children started to disperse, some on their way to the holiday destination. At 12.30 hours on that day, Angus was seen to jump in front of an incoming train at Cardiff Central Railway Station. He was not killed but suffered severe injuries to his legs. Whilst being tended to by emergency service personnel, he admitted that he had killed Margaret at their home address.

[10] The National Institute of Neurological Disorders and Stroke defines dementia as: a word for a group of symptoms caused by disorders that affect the brain. It is not a specific disease. People with dementia may not be able to think well enough to do normal activities, such as getting dressed or eating. They may lose their ability to solve problems or control their emotions. Their personalities may change. They may become agitated or see things that are not there

2.6 Officers attended at the home address and found the body of Margaret in an upstairs bedroom. She was declared deceased at the scene. She had suffered major injuries to her head.

2.7 Angus was taken to hospital where he repeated the admission to a number of people. He underwent surgery to amputate a leg but his condition deteriorated and he died of pneumonia, sepsis and complications arising from his injuries on 11th September 2016. HM Coroner for Cardiff had concluded that Margaret was unlawfully killed. As Angus died in hospital there was no formal inquest into his death.

2.8 **The aim of the Review**:

- 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 the policies and procedures as appropriate; and

- Prevent domestic homicide and improve service responses for all domestic violence victims and their children through improved intra- and inter-agency working.

2.9 **Terms of Reference**

The generic questions are as follows:

1. Were practitioners sensitive to the needs of Margaret and Angus, knowledgeable about potential indicators of domestic abuse and aware of what to do if they had concerns about them?

2. Was it reasonable to expect them, given their level of training and knowledge, to fulfil these expectations?

3. Did the agency have policies and procedures for risk assessment and risk management for domestic abuse victims or perpetrators (DASH) and were those assessments correctly used in the case of this victim/perpetrator?

4. Did the agency have policies and procedures in place for dealing with concerns about domestic abuse?

5. Were these assessments, tools, procedures and policies professionally accepted as being effective? Was Margaret subject to a MARAC?

6. Did the agency comply with domestic abuse protocols agreed with other agencies, including any information sharing protocols?

7. What were the key points or opportunities for assessment and decision making in this case?

8. Do assessments and decisions appear to have been reached in an informed and professional way?

9. Did actions or risk management plans fit with the assessment and the decisions made?

10. Were appropriate services offered or provided, or relevant enquiries made in the light of the assessments, given what was known or what should have been known at the time?

11. When, and in what way, were Margaret's wishes and feelings ascertained and considered?

12. Is it reasonable to assume that the wishes of Margaret should have been known?

13. Was Margaret informed of options/choices to make informed decisions?

14. Were they signposted to other agencies?

15. Was anything known about Angus? For example, were they being managed under MAPPA?

16. Had Margaret disclosed to anyone and if so, was the response appropriate?

17. Was this information recorded and shared, where appropriate?

18. Were procedures sensitive to the ethnic, cultural, linguistic and religious identities of Margaret, Angus and their family?

19. Was consideration for vulnerability and disability necessary?

20. Were Senior Managers or agencies and professionals involved at the appropriate points?

21. Are there other questions that may be appropriate and could add to the content of the case? For example, was the domestic homicide the only one that had been committed in this area for a number of years?

22. Are there ways of working effectively that could be passed onto other organisations or individuals?

23. Are there lessons to be learnt from this case relating to the way in which this agency works to safeguard Margaret and promote her welfare, or the way it identifies, assesses and manages the risks posed by perpetrators? Where could practice be improved? Are there implications for ways of working, training, management and supervision, working in partnership with other agencies and resources?

24. How accessible were the services for Margaret and Angus?

25. To what degree could the homicide have been accurately predicted and prevented?

2.10 In addition to the above, some agencies will asked to respond specifically to individual questions once they are identified following the submission of IMRs.

Individual Needs

2.11 Home Office Guidance[11] requires consideration of individual needs and specifically:

> "Were procedures sensitive to the ethnic, cultural, linguistic and religious identity of the victim, the perpetrator and their families? Was consideration for vulnerability and disability necessary?"

2.12 Section 149 of the Equality Act 2010 introduced a public sector duty which is incumbent upon all organisations participating in this review, namely to:

- Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;

- Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;

- Foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

2.13 The Review gave due consideration to all of the Protected Characteristics under the Act.

2.14 The Protected Characteristics are: age, disability, gender reassignment, marriage and civil partnerships, pregnancy and maternity, race, religion or belief, sex and sexual orientation

2.15 There was nothing to indicate that there was any discrimination in this case that was contrary to the Act.

2.16 In view of Margaret's dementia, the Panel requested the assistance of a dementia/Alzheimer's practitioner to attend a Panel meeting. On 10th July 2017, Mrs. Sue Phelps from the Alzheimer's Society, who has considerable experience with dealing with dementia patients, attended a Panel meeting and enlightened the Panel about the illness and the effects the disease would have on patients such as Margaret. She also explained the effects and consequences the illness could have had on Angus and his relationship with Margaret as her condition deteriorated. Mrs Phelps was able to help with details of support and assistance that would have been open to both Margaret and Angus. Mrs Phelps' contribution was extremely valuable and the panel are grateful for her time and opinions. Her views are contained within this report.

[11] Home Office Guidance 2016 page 36

Family Involvement

2.17 Home Office Guidance[12] requires that:

> "Members of informal support networks, such as friends, family members and colleagues may have detailed knowledge about the Victim's experiences. The Review Panel should carefully consider the potential benefits gained by including such individuals from both the Victim and Perpetrator's networks in the review process. Members of these support networks should be given every opportunity to contribute unless there are exceptional circumstances",
>
> and:
>
> "Consideration should also be given at an early stage to working with Family Liaison Officers and Senior Investigating Officers involved in any related Police investigation to identify any existing advocates and the position of the family in relation to coming to terms with the homicide."

2.18 The 2013 Guidance states[13]:

> 'The Review Panel should recognise that the quality and accuracy of the review is likely to be significantly enhanced by family, friends and community involvement. The Panel should therefore make every effort to include these parties and, to ensure that when approaching and interacting with these parties, the Review Panel follows best practice.'

2.19 In this case the Overview Report Author made contact with the Senior Investigating Officer (SIO) from South Wales Police at an early stage. Contact with the family was initially made by letters sent to all six children explaining the Review process and inviting them to contribute to the Review should they wish to do so. The eldest son was seen at his family home on 14th February 2017, and the two sisters who lived local to the deceased couple were seen on 7th and 8th March 2017. The remaining sister and two brothers were seen on 12th April 2017. All of their views are faithfully recorded in the section of this report 'Views of the Family' at Section 4.

2.20 On 7th September 2017, Ann and Stuart attended a panel meeting at Council Offices in Cardiff. Eight members of the panel were present and a discussion took place about the report and the findings of the review. Notes were made of the conversation and a record of the notes is attached to this report as an appendix. Andrew thanks the panel for their work and stated that the family were content with the report, the findings and recommendations.

3. Sequence of Events

3.1 The couple in this review had been married for some 65 years and had always lived in the same family home in Cardiff. Angus was one of four children and according to Ian, he was brought up by his older sisters. He completed his National Service in the Army. He was a Private in the Royal Norfolk Regiment. He met Margaret when they both worked in a University Research Laboratory. He was a Laboratory Assistant and she was an academic. They were also acquainted at a local golf club where Margaret and

[12] Home Office Guidance 2016 page 18
[13] Home Office Guidance 2013 page 16

Angus were members. Margaret brought up the children while Angus was a salesman for the textile industry and would fly all over the world in the course of his job. Ian described his mother as being soft and cuddly while his father was a deep thinker who could be charming. Once she was able to do so, the children's education permitting, Margaret returned to work as a Tax Inspector.

3.2 Both Margaret and Angus had an active social life with many good friends. Margaret played bridge to a high standard and was passionate about cooking and entertaining. Although Angus also played bridge, his passion was his allotment and sea fishing at Tenby, where the family had a caravan and a boat. He also enjoyed creating things from stained glass work.

3.3 Both were physically fit for the majority of their marriage, but Margaret had a hip operation after which she seemed to decline in her fitness. In her younger days she would play tennis and cricket.

3.4 The family say that it is without doubt that Margaret and Angus were a happy loving couple but Margaret's onset of Alzheimer's disease affected their relationship and put a great deal of strain on Angus as he continued to care for his wife.

3.5 The first relevant contact Margaret had with the Cardiff & Vale University Health Board was in March 2013, when she was seen with Angus in the Memory Clinic and she described how her memory was letting her down. Margaret was unable to expand on that but Angus described a range of symptoms, such as how she would leave toast to burn, how she had become confused and muddled with accounts and how she was not able to follow her well-known recipes. She was also having problems recalling words. An initial assessment was made and concluded that she was probably developing an Alzheimer's-type of illness. Further investigations were arranged.

3.6 In July 2013, Margaret was seen again in the Memory Clinic where it was noticed that her mobility was becoming worse, not due to her hip but due to her age (82 at that time).

3.7 In August 2013, Ann and Sheena took their mother to the Memory Clinic concerned about her increasing dependency on Angus for household tasks and she appeared to be losing her initiative. Ann and Sheena were worried about the effect that this was having on their father. Margaret was diagnosed with mild dementia and probable Alzheimer's disease. Arrangements were made for a Specialist Nurse to see Margaret. Communication was made with her GP.

3.8 Six days later, on 8th August 2013, a Specialist Nurse made a home visit where advice was given to Margaret and Angus about Alzheimer's disease and the support that may be available. The family advised the Specialist Nurse that there was no need for support at this time. Advice was also given about Lasting Power of Attorney, but Angus did not think that was necessary at that time. Angus described himself as being 'as fit as a flea', albeit his GP had been concerned about the risk of him having a stroke.

3.9 Between April and December 2013, Margaret saw her GP on 14 occasions for routine appointments for diabetic monitoring and blood monitoring.

3.10 Between 1st January 2014 and 31st December 2014, Margaret attended her GP's surgery 14 times for unrelated issues but also for her annual dementia review. As there is no record of a discussion with the GP at the annual dementia review around the

social context associated with dementia, it is assumed that there were no identified difficulties at home during this period of time.

3.11 During the same period of time, Angus attended his GP on 19 occasions for a range of routine issues.

3.12 During 2015, Margaret saw her GP on 9 occasions. It was noted that her physical health was deteriorating which would have been putting extra stress on her independence and the support needed from her husband. She was referred for an urgent incontinency consultation. In August 2015, Margaret fell and suffered a compression fracture to her lower back. She was given analgesics. In December there was another annual dementia review where it was noted that despite being offered the advice in August 2013 regarding Lasting Power of Attorney, the family had not followed this through.

3.13 During 2015, Angus made 28 visits to his GP for routine appointments, but in November it was noted that he appeared stressed due to looking after Margaret. He was also losing weight. There is nothing noted as to what support, if any, was offered to him or whether the reasons for his weight loss were explored.

3.14 On 8th January 2016, the family contacted Social Services requesting information about the provision of a walk-in shower for Margaret.

3.15 On 11th January 2016, the family again contacted Social Services asking for a bathing assessment for Margaret and requested an urgent response to discuss the situation. The case was opened for an Occupational Therapy Assessment.

3.16 On 25th January 2016, Andrew contacted Social Services advising that his mother was suffering from dementia and that his father was caring for her. He said that his father was a very proud man but he was totally exhausted. The services that might have been available were discussed but Andrew was told that it would require his father's consent before a visit could be undertaken.

3.17 On 5th February 2016, Andrew again contacted Social Services requesting an assessment for respite or sitting services and information about the activities that would be suitable for his mother in her condition. He stated that his parents' situation was becoming volatile and his father was, on occasions losing his temper and 'flies into a rage' with his mother. He also requested that this information was not passed back to his father as it would make the situation worse.

3.18 A home visit was planned by Social Services on 22nd February 2016, and on being told this, Andrew asked that it be done within the next week 'before it was too late and Dad had a crisis'.

3.19 The assessment took place on 22nd February 2016, with Angus, Catherine and Andrew being present. The outcome was that Margaret would attend a Day Centre twice a week and Telecare Sensors[14] were provided. It is noted that it was obvious that Angus wished to continue to care for Margaret but that both he and his wife required respite.

3.20 Further contact was made with Angus on 23rd March 2016, when it was suggested that a referral could be made to Mental Health Services for Older People Team as a result

[14] The Telecare UK Alarm is easy to understand and simple to use. If the user of the alarm suffers a fall, or if they feel unwell or need reassurance, then they simply need to push the red button on their pendant to ask for help. Alternatively, the user can push the red help button on the base unit of our Telecare alarms

of Angus stating that he was trying to manage his wife's illness. Angus declined the offer of a referral at that time.

3.21 Margaret commenced her visits to the Day Centre, initially once per week. Angus reported that she enjoyed her time there.

3.22 The case was transferred to a Review Team and although Margaret did not have a named case manager, the contact details were made available to Angus and the rest of the family.

3.23 In June 2016, Margaret was seen by her GP. It was apparent that she was increasingly dependent on her family and they were advised to contact the Memory Clinic and Adult Social Services. (There is nothing to suggest that referrals were made in addition to the advice.)

3.24 On 13th July 2016, the Day Centre contacted Adult Social Services stating that Margaret could not settle after lunch and wanted to be with Angus. The Day Centre was advised to contact family members.

3.25 Nothing more was heard until 25th July 2016, when Catherine contacted the Review Team expressing concern that her father was struggling to cope with caring for Margaret. She stated that her father was looking frail and he was exhausted. She had also seen him lose his composure. She was told to get agreement from her parents for a visit to take place.

3.26 On 26th July 2016, Catherine rang again to speak to the Review Team. She stated that her father's consent for a visit had not been given. He had stated that 'we're fine'. However the family felt better as her mother and father intended to go to West Wales to visit family. Catherine explained that her and her brothers were composing a letter for Angus as they thought he would more readily accept this form of communication.

3.27 On 27th July 2016, Andrew shared the email he and his siblings intended to send to Angus and the Social Work Assistant, stating that the letter accurately described the concerns and if their father continued to refuse intervention the annual review could be brought forward. The email was never sent.

3.28 According to the children, in discussion with the Overview Report Author, on 27th July 2016, most of the family had gathered together at the family home in Cardiff. It was intended that the family would go to West Wales to the caravan for a few days together. Ian had travelled from Norway where he lives and works. The gathering was described as being pleasant although the siblings were aware that their mother's condition had deteriorated. Catherine was at her home in the east of England and was not present.

3.29 On the morning of 28th July 2016, after a family breakfast the siblings dispersed either to their Cardiff homes or to West Wales. During breakfast Angus had generally asked those present about train times from Cardiff. This did not raise any suspicion other than Ian thought that his father was enquiring about trains to visit Catherine, who Angus had recently seen.

3.30 The family left leaving Margaret and Angus at home.

3.31 At 12.30pm British Transport Police responded to a platform at Cardiff Central Railway Station where Angus had jumped in front of a moving train severely injuring his legs. Whilst being treated at the scene he disclosed that he had killed his wife at their family home. Police Officers and Paramedics found Margaret deceased in her bedroom.

Angus had written notes apologising to the train driver and the emergency staff who would to have to deal with him. He told one of the officers, 'My wife suffers dementia and incontinence. She told me that if I put her in a home she would kill herself. I told her it would be quick then I'd throw myself under a train. But I couldn't even do that right.'

3.32 A forensic post mortem examination of Margaret revealed she had died from blunt trauma to her head.

3.33 Angus was treated in hospital and subsequently died in Intensive Care on 11th September 2016.

4. Views of the Family

4.1 The Overview Report Author has seen all six of the siblings in this family at their respective homes, with the exception of Ian who lives abroad and who was seen during a visit to his sister Catherine.

4.2 All of them describe their childhood years with their parents as being a very close family with their father being a traditional and somewhat strict parent with old- fashioned values. These values seemed to have shaped his views on caring for his wife during her dementia illness.

4.3 Stuart was seen by the Author on 14th February 2017. He described seeing a change in his mother during her late 70s, where she appeared confused with a loss of memory. He described how Ann would go and visit the parents every day and that she was the main carer for them. He was aware that his father had mentioned to Ann that he and Margaret should move in with her but Ann was not to tell the other siblings. Stuart saw this as a cry for help from his father.

4.4. Stuart described how his father was embarrassed by his mother being incontinent and how his father struggled with that side of her illness. He described his father as being physically exhausted due to lack of sleep getting his mother out of bed every few hours during the night to prevent her wetting the bed. She did, however, have a rubber sheet fitted to her bed and she wore pads to prevent accidents of this nature. Stuart described how his mother would not want to get up in the night and would become aggressive towards his father and how his father in turn would become frustrated.

4.5 During the Author's interview, Stuart raised concerns about what triggered procedures for care services to act in these circumstances and what would set 'the bell ringing', especially when there were identified flash points such as in the early hours of the morning when patience was running low between his mother and father. He compared this situation with that of child protection, in that if a parent is concerned about a child, something is done, whereas if an adult is concerned about an aged parent, services have to listen to the aged parent and obtain permission to visit their home. He is of the opinion that GPs especially need to recognise trigger points for action when family members call for help.

4.6 Ann was seen on 7th March 2017. She said that she would see her parents every day and do the washing, cleaning, shopping, ironing and cooking for them. She described how her parents would partake in a sherry and crisps every evening whilst watching 'Pointless' on the television. They were both fans of watching snooker and rugby. Her father would go to rugby matches regularly, especially to watch Wales play.

4.7 Ann described how an alarm was fitted to the door of her mother's bedroom in case she got out of bed in the night, but her mother removed it. She said that her mother had lost a significant amount of weight due to a urinary infection. Ann told how her father had had an allotment for 20 years and was a very proud gardener. She would help him in his allotment but in recent times he lost interest in gardening as Margaret became ill with her dementia. Ann put this down to his exhaustion.

4.8 Ann described how her mother increasingly found it difficult to take food and her medication and no matter what food was prepared by either her or her father, her mother would reject it, adding to the frustration of her father. Ann tried to get her parents a cleaner as cleaning was too much for Ann, but that idea was put to one side by her father.

4.9 Ann described how her father had said that he would never let his wife go into a home of any kind. Ann described how her mother started to fall over in the house and how it was difficult to pick her up again. She said that her father had said that he had lost his wife a long time ago due to her dementia. He would shout and become verbally aggressive with his wife when he was tired but she never saw him be physical towards her. Ann said that her father knew his wife was not going to get better and she had good days and bad days. She said that she thought that her father had tried with her mother; he had done his best and did a wonderful job.

4.10 Sheena and her partner were seen on 8th March 2017. Sheena also cared for her parents; she lived close by as did Ann. However Sheena is disabled and cannot do as much as Ann due to her restricted mobility. However she can drive and would provide transport that Ann could not. Sheena and her partner could see that her father was struggling with caring for their mother. Sheena is of the opinion that her father's cries for help ought to have been recognised and if services had insisted on helping and offering support, she is convinced that her father would have accepted in the end.

4.11 Sheena describes how she saw her father go 'downhill' in the last few months of his life. He became reliant on Ann for everything. Sheena said that her father would try to get her mother washed and dressed in the morning which would take hours and by lunchtime he was exhausted having been up all night due to her incontinency. Sheena and her partner would go to the family home during the afternoon so her father could catch up on his sleep.

4.12 Sheena said that her father would get irritated that her mother would not wear her hearing aid so the television would have to be turned up loud. Sheena stated that her father would say that 'if he took his eyes off his wife, she would be gone'. This constant attention to her movements added to his anxiety and frustration. Sheena stated that on the Saturday prior to the fatal incident, she heard her father tell her mother, 'I love you but I've got to put you in a home – it will be nice though'. Sheena said her father was serious and this was the first time to her knowledge that he had mentioned a home for her. He was tired and drained. He said that he would sell the family home, build a 'granny flat' onto Ann's house and move in with her. Sheena said that her mother refused to consider a home and her father said, 'I can't cope any more. I've had enough'.

4.13 Sheena is of the opinion that Social Services needed to be more helpful and ought to have had more contact with her parents. She said, 'The only time we got anything from them is when we phoned them'.

4.14 Ian and Catherine were seen on 12th April 2017 at Catherine's house, Ian having come to the UK. They said that they thought that Social Services were very good to their mother after her hip operation, in that a walk-in shower, hand rails, sofa raisers[15] etc. were provided for her. They said that her hip operation had left their mother confused which they put down to the medication she had been given post- operation.

4.15 They said that their mother had lost many of her circle of friends as they had passed away and this had affected her. They described their father as being regimented, putting their mother to bed at the same time whether she was tired or not. The last time they were at Catherine's house their parents had a 'spat' and their mother was in a mood for some time afterwards. They said that their father had no patience and would lose his temper. This would send their mother into "her shell". His threshold got lower as their mother's condition got worse and they considered it got to a crisis point. However, Catherine said that her father would say that every day was a blessing and that he wanted to live to be 100 years old. She added that her father found it hard that his vivacious, brilliant, active wife had become confused and disorientated and that shared history of 64 years was slowly being deleted from her memory. In an interview with a local newspaper, Catherine said,

> 'There's a sense of guilt at not being able to prevent it and frustration that Social Services could not act on our fears. They [Social Services] needed the consent of a carer who wasn't functioning or able to accept he needed help. The system needs to change so that children can override that consent. Society needs to look at how we deal with dementia. And we all need to build a place in our lives for elderly relatives'.

4.16 Ian and Catherine are of the view that there needs to be stronger communication between the family, Social Services and the GP, especially in cases where there is stubborn and difficult behaviour to manage. Their view is that the GP needs to identify the first signs of Alzheimer's disease or dementia and communicate with Social Services and to consider both the patient and the carer.

4.17 Andrew was seen on the same day. He had witnessed his father losing his temper in January and February 2016. Andrew made a telephone call to Social Services that resulted in a Social Worker visiting his parents' home. This was the occasion when the Day Centre was arranged. He described how his father banged his fist on the table in frustration and Andrew thinks that this was his father's way of letting everyone know his situation. Andrew also said that his father was in denial about Alzheimer's disease and would not even use the word Alzheimer's.

4.18 Andrew is of the opinion that there is a vacuum in communication between families and Social Services regarding the elderly. He questioned if allowing the family members to care for their parents was the best option and whether alternative care ought to have been considered. He mentioned that Ann did her best but she was not in good health, neither was Sheena able to fully care for their parents. He described his father as seeing Ann as his respite carer and that his father was the traditional 'father figure' of the family and would not accept what other people were saying especially regarding the care of his wife.

4.19 Andrew is of the opinion that his mother was the stronger of his two parents and offered support to his father. His mother was always emotionally strong and when she lost her cognitive ability, his father lost his support. His father did not want their mother to go

[15] Sofa Raisers – equipment to assist people getting up off sofas.

into a home but Andrew thinks that there were plenty of warning signs present, which if Social Services had been involved at that stage, the warning signs and the desperation would have been identified and positive action taken and support provided.

4.20 Andrew described how once Margaret had become ill, the daily clothes for his mother were decided by his father and she had to do what he said. He would maintain a routine on a daily basis. Andrew was telling Social Services that his father was not coping and that he was losing his temper with his mother but he was told that if his father needed help, he should ask for help. He said his mother was a vulnerable person but treated differently to vulnerable children, which, he thought, was not right. Andrew's views are that Social Services did not accept the information the family were giving to them and they did not assess that information against what his father was saying to them. He said that his mother needed to be cared for professionally; she was losing weight, she was 85 and her carer was 86 years of age, she had dementia and the family were saying that he was not coping. They were both vulnerable and at risk. He also pointed out that his father was assessed in the Emergency Department of the hospital for the criminal investigation after his mother's death. He said that he considered his father to have been 'in a dark place emotionally'. His view is that his mother still had some good times to look forward to.

5. Analysis and Recommendations.

5.1 On 10th July 2017, a representative from the Alzheimer's Society was invited to attend a Panel Meeting. She gave advice and important information about both dementia and Alzheimer's illnesses. She described the stigma, embarrassment and isolation carers and family experience when a family member is diagnosed with such illness. They often lose their social circle of friends as the dementia worsens. In the circumstances of incontinency, especially if the patient is of the opposite gender to the carer, the carer experiences significant embarrassment when dealing with the consequences of the patient's needs. This often causes additional stress and sometimes conflict, aggression and frustration between the carer and patient. She explained that patients often see the world differently to others, indicating that eating may be affected by the patient not being able to recognise food on a plate so not appreciating that the food is there. These examples of symptoms and behaviour should be triggers for escalation of referrals for additional care and support for both patient and carer.

Recommendation No 1

Where a person with dementia who is being cared for at home displays additional or increased needs that may lead to an increase in the carer's stress, then Social Services should consider if a review is required.

5.2 The Adult Social Services IMR sets out in detail the contact Social Services had with Margaret and Angus in two phases. The first phase deals with contact between January 2016 to May 2016 when the case was reviewed, closed and transferred to the Review Team. The second phase deals with the period between 13th July 2016 (when the Day Centre raised concerns regarding Margaret not settling) to the 28th July 2016.

5.3 The first contact in phase 1 was by an Occupational Therapist (OT) who made a home visit where an assessment was undertaken and appropriate services arranged, that consisted of sofa raisers and advice about the conversion of the bathroom to include

a walk-in shower unit. During this visit, Angus did mention difficulties in managing Margaret's behaviour and the OT suggested a referral to Mental Health Services for Older People but Angus declined that offer of a referral.

5.4 The second contact was with the Assessment Team at a home visit with other members of the family present, conducted by a Social Work Assistant. The Social Services IMR states that staff that have completed an NVQ Level 4 should carry out assessments. The Social Work Assistant in this case was qualified to NVQ Level 3 and was completing an NVQ Level 4. The referral was screened by a Team Manager/Senior Practitioner who deemed it suitable to be allocated to a Social Work Assistant with the option of referring it to more senior manager if it was identified that there were any concerns during the assessment. This was a new case to the Assessment Team with no prior involvement with either Margaret or Angus. Prior to the assessment, the Social Work Assistant was aware of recorded comments on file that Angus was under stress, losing his temper. She was also aware that Andrew did not want these comments fed back to his father. (See Social Services IMR Recommendations page 29/30)

5.5 It was clear to the Social Work Assistant that Angus was finding it stressful caring for Margaret, hence the request for support, but the Social Work Assistant did not identify any safeguarding concerns or domestic abuse concerns. She found the family very caring and that Angus was very independent and wanted to continue to care for Margaret. The conversation focused on how support could be provided to Angus to reduce the stress. He admitted losing his temper and stated that he was exhausted. A conversation took place regarding the provision of the Day Centre with regard to which the Social Work Assistant was satisfied that Margaret understood the content of the discussion and arrangements. The result of the visit was both a Care and Support Assessment and a Care and Support Plan were completed together with a formal referral for a place at the Day Centre.

5.6 The Assessment of Need assessed Margaret as critical under the eligibility criteria on account of her inability to carry out vital personal care, domestic or other routines that could result in significant health problems, possibly life threatening. Safety, protection from abuse or neglect was not identified as an issue. A Carer's Assessment had been offered to Angus but he had declined. It is the family's view that despite their father's refusal for a carer's assessment, this should have been carried out and it may have identified that he was unable to cope, despite his insistence that he could. A Carer's Assessment could have been offered to another member of the family and not confined to Angus. The advice from the Alzheimer's Society representative was that both Angus and Margaret could have been allocated a 'Key Worker' to support them and also to listen to the voice of Margaret, which is an important feature missing in this case. An advocate could have been offered to Margaret and again her views, thoughts and wishes may well have been considered. There were opportunities for Margaret to be spoken to on her own to obtain her views throughout the numerous medical appointments she attended but the difficulty was that she was usually accompanied by Angus or one of her daughters and may have felt restricted to what she could say. There were also opportunities at the Day Centre when she was there on her own to have a one-to-one conversation with Margaret and determine what was important to her, but again the Day Centre staff may have assumed that such conversations were taking place elsewhere and Margaret was there as respite for Angus.

Recommendation No 2

Where a Carer's Assessment is refused by a husband or wife deemed to be the main care giver, the assessment should be routinely be offered to additional family members who are also undertaking care giving tasks.

Recommendation No 3

All social care staff should ensure that the voice of the individual at the heart of the assessment should be heard. This should ensure that they are interviewed in their own right, and also alone if felt to be appropriate or necessary.

5.7 Phase 2 commences in July 2016, when the Senior Carer from the Day Centre contacted the Review Team by email stating that Margaret was not settled at the Centre and after lunch was distressed and wanted to go home to Angus. The Senior Carer asked for advice which was given by the Social Work Assistant. She told the Senior Carer that the Day Centre ought to communicate with the family and have a meeting about Margaret's distress. There was no suggestion that the Social Work Assistant would be part of that discussion. In any event that meeting never materialised as the Senior Carer went on annual leave. There was also an extended period of sickness for staff members at the Day Centre, which may have added to the missed opportunities to engage with Margaret.

5.8 Once at the Day Centre the usual 'getting to know you form' was left for Margaret and Angus to complete, but it was not returned. This was not followed up by Day Centre staff, although the Social Services IMR notes that this is not unusual. (See Social Services MIR Recommendations page 29/30)

5.9 A routine six-week review was conducted in May 2016, over the telephone between the Social Work Assistant and Angus, which is normal practice. She was told by Angus that Margaret was enjoying her time at the Day Centre and there were no issues of concerns raised.

5.10 The Social Work Assistant was interviewed as part of this review process and stated that she considered that this was a very caring and supportive family with a very proud husband, independent and determined to continue to care for Margaret but who wanted some respite and time to himself, which Margaret's Day Centre placement provided.

5.11 Regarding the Telecare equipment, after being installed for only two weeks Angus removed it all saying that he found it intrusive. There is no record of Angus returning the alarm to the company, so it appears that they were not aware that the alarm had been removed. Enquiries with the alarm company indicate that if they become aware that an alarm has been removed, they would routinely inform Social Services so as financial arrangements could be cancelled or amending.

5.12 With regard to the six-week review there is nothing to indicate that the Day Centre was contacted or that Margaret was seen during the review. (See Social Services MIR Recommendations page 29/30)

5.13 On 25th July 2016, Catherine contacted the Review Team and spoke to the Social Work Assistant saying that she was concerned about her father and how he was struggling to cope with her mother and that she had seen him lose his temper with her mother on a number of occasions. The IMR recognises that in these circumstances Margaret

could have been deemed a vulnerable adult and a potential safeguarding concern should have been raised, but it was left to Catherine to seek consent from her father for a home visit. Catherine returned the call the following day saying that Angus had again refused engagement and declined the assessment saying 'he was fine'. Catherine explained that the family intended to go to West Wales and that she felt that her parents were in better spirits. However she stressed that the family remained concerned and felt that extra support was needed albeit she appreciated the consent problem. Catherine said that she and her siblings had agreed to write a letter to her father thinking that he would communicate better with them in that way.

Recommendation No 4

Adult Social Care Services to ensure that concerns expressed by family members, and/or others, regarding any potential safeguarding concerns as regards an adult, when the adult in question is deemed and assessed to be an Adult at Risk, are acted upon in accordance with the guidance in Part 7 (Vols. 1 and 6) of the Social Services and Well-being (Wales) Act 2014.

5.14 The letter was read to the Social Work Assistant by Andrew and it was agreed that once the letter had been delivered to their father, if the situation had not changed the review could be brought forward.

5.15 In conducting the IMR, the IMR author interviewed the Operations Manager of Social Services with responsibility for Review Teams and also the Team Manager for the Review Team. Both stated that in the circumstances there was nothing to trigger a different intervention and the service delivered was appropriate given the information received from the family and the home visits. The family would disagree with this statement.

5.16 The Operations Manager does however consider that there could have been more proactive action taken regarding Angus' refusal to undergo a Carer's Assessment to attempt to persuade him to engage more. In addition the IMR author is of the view that a more in-depth analysis of potential risks in these circumstances and the case could have gone to the Care Management Team for ongoing support rather than the Review Team. (These issues are dealt with in the Social Services IMR Recommendations)

5.17 The Cardiff & Vale University Health Board IMR indicates that the care and treatment for Margaret during the decline in her health was appropriate and the referrals made by the GP were considered necessary to deal with her dementia. The GP recognised that Margaret was supported well by her family. Although Angus accompanied her to several appointments in the early stages of her illness, during the latter stages of her illness, it was often her children that took her to the GP surgery

5.18 With regard to Angus, he had significant involvement with his GP between 2013 and 2016. He was treated for his weight loss but there was nothing to indicate that this weight loss could have been attributed to his anxiety over caring for Margaret. His appointments in 2016 focused more on his medical needs and there were no documented references to his caring responsibilities. During this time, Angus presented at his GP surgery, anxious, exhausted and losing weight. It appears that the connection between his symptoms and the fact that he was a carer for Margaret, whose condition was deteriorating, was not made. Their symptoms should have been a trigger for a referral to Adult Social Care in relation to both of them. In June 2016 the GP told the family to contact the Memory Clinic when Margaret was increasingly

becoming dependent on her family for support. The GP should have made a referral to Adult Social Serviced rather than expecting the family to do so. (This is dealt with in the Cardiff & Vale University Health Board IMR Recommendations.)

5.19 The Health IMR makes several very relevant observations which are:

- It should be recognised the provision of health care is complex; GPs are the lynchpin of health care provision and as such would appear to be the most appropriate health professional to collate information that builds a picture of a patient's life.
- The absence of some information such as GPs' capacity to consider the challenges of a caring role as a possible explanation for a patient's presentation; given that carer may suffer from stress, and the burden of responsibility; it is likely opportunities are lost for the GP to ask relevant questions.
- Some of what could be described as "soft" information such as appointments including the annual dementia review and home visits may also give GPs opportunities to open discussion with patients.
- GPs to consider the stress placed on relatives of being a carer and raise this as a discussion point at each contact
- A "flag" system on GP records would be helpful for GPs to make contacts count. Some of the stresses that patients disclose to their GPs could be moments to raise patients' awareness of what support is in place to build resilience.
- There is reliance on family members to self-initiate referral for further support and guidance. Direct referrals to support agencies from professionals with consent from the patient/ family may overcome the barrier and assist in connecting and maintaining support systems, so that carers feel more supported, informed and heard.
- No capacity assessment appears to have been undertaken when the patient attended alone despite identification of her cognitive function impairment.

(See Cardiff & University Health Board MIR Recommendations page 29/30)

5.20 The Alzheimer's Society[16] representative also made a helpful suggestion that all GP surgeries should be 'Dementia Friendly' and provide literature, awareness and guidance to patients and members of the public, and that dementia and Alzheimer's should be as prominent in GP surgeries as Domestic Violence is since the 2011 General Practice guidance on Domestic Abuse. Cardiff PSB has already committed to Cardiff being determined a 'dementia friendly' City.

Recommendation No 5

In line with Cardiff & Vale Dementia Strategy, Cardiff & Vale University Health Board will encourage GP surgeries in Cardiff and the Vale of Glamorgan to become designated 'Dementia Friendly' and provide literature, awareness and guidance on dementia to patients and members of the public.

[16] www.alzheimers.org.uk

Recommendation No 6

Cardiff & Vale University Health Board to encourage GPs to undertake dementia training in Cardiff and the Vale of Glamorgan in line with the Cardiff & Vale Dementia Strategy. Dementia training should also be provided as part of the CPET programme for GP education.

6. Conclusions

6.1 Margaret and Angus were part of a close family unit. They had provided their children with a very happy fulfilled life. They both enjoyed their long marriage together. They had an active social life with many long-term friendships. They both had hobbies and interests. Angus had said that he wanted to live to be 100 years old. However Margaret was struck down with a progressive dementia illness that changed their life plans.

6.2 Angus was left caring for his wife whose memory was deteriorating. He found it frustrating and found it hard to cope with her worsening condition. He admitted losing his temper. Angus told his family that he could not cope. The Health Service and Adult Social Care did all they could do within due bounds of guidance. With Angus' dogged independence and strong will to look after and care for Margaret, it meant that he did not accept the offer of additional help. He refused to be assessed as a carer which may have made a difference. He admitted he told Margaret that he was going to put her in a home. He also admitted whilst he was terribly injured, that he had told her what he intended to do to himself.

6.3 Angus was desperate to prevent Margaret suffering and took a course of action that he thought was the best way for her and then himself.

6.4 The children have views about what could have been done better. So too have the IMR Authors of both the C&VUHB and Adult Social Services, and IMR recommendations are made by both agencies in an attempt to improve responses to similar situations in the future.

6.5 No one knew or could have suspected that the end of their lives would happen the way it did.

7. Recommendations

7.1 Overview Report Recommendations

Recommendation No 1

Where a person with dementia who is being cared for at home displays additional or increased needs that may lead to an increase in the carer's stress, then Social Services should consider if a review is required

Recommendation No 2

Where a Carer's Assessment is refused by a husband or wife deemed to be the main care giver, the assessment should be routinely be offered to additional family members who are also undertaking care giving tasks.

Recommendation No 3

All social care staff should ensure that the voice of the individual at the heart of the assessment should be heard. This should ensure that they are interviewed in their own right, and also alone if felt to be appropriate or necessary.

Recommendation No 4

Adult Social Care Services to ensure that concerns expressed by family members, and/or others, regarding any potential safeguarding concerns as regards an adult, when the adult in question is deemed and assessed to be an Adult at Risk, are acted upon in accordance with the guidance in Part 7 (Vols. 1 and 6) of the Social Services and Well-being (Wales) Act 2014.

Recommendation No 5

In line with Cardiff & Vale Dementia Strategy, Cardiff & Vale University Health Board will encourage GP surgeries in Cardiff and the Vale of Glamorgan to become designated 'Dementia Friendly' and provide literature, awareness and guidance on dementia to patients and members of the public

Recommendation No 6

Cardiff & Vale University Health Board to encourage GPs to undertake dementia training in Cardiff and the Vale of Glamorgan in line with the Cardiff & Vale Dementia Strategy. Dementia training should also be provided as part of the CPET programme for GP education.

This section of the report lists all recommendations made by Social Services and Cardiff & Vale University Health Board as detailed in their IMRs.

7.2 Recommendations from Adult Social Services IMR

Recommendation No 1
That an appropriately phased programme of training be developed to ensure that Social Work Assistants who will be required to undertake assessments and reviews have a relevant social care qualification at Level 4 or above.

Recommendation No 2
As an extension of the recent 'Better Conversations' training, all relevant staff undertake additional carer awareness training to further enhance a proactive approach in supporting carers and providing them with information

Recommendation No 3
Day Centres to ensure proportionate follow up and further consideration where the "Getting to know you" forms are not completed and returned by the family.

Recommendation No 4
That Adult Social Care Service revisit the overall Review-related risk assessment process to maximise safeguarding and escalation measures. In effect, this would aim to improve the capacity of the Reviewing role to recognise when it would be more appropriate to conduct Reviews in person and where service users should be interviewed on their own.

Recommendation No 5
That Adult Social Care Service considers how to assess the risks in a case prior to being transferred into Review.

7.3 **Recommendations from Cardiff & Vale University Health Board IMR**

Recommendation No 1
General Practitioners to be encouraged to develop systems to be able to identify when a patient has caring responsibilities associated with a relative who has a diagnosis of dementia.

Recommendation No 2
General Practitioners should make any referral onto appropriate services and should not expect family to make contact with services themselves.

Recommendation No 3
General Practitioners to consider signposting carers of a relative with dementia to third sector for support and advice when they are presenting with stress related symptoms associated with a caring role.

Recommendation No 4
Further strengthen partnership working between the memory team and third sector to further develop support that is provided to family members involved in a caring role.

Recommendation No 5
A capacity assessment should be considered at each contact following a diagnosis of cognitive impairment in relation to having the ability to accept care and support.

Bibliography

Multi-Agency Statutory Guidance For the Conduct of Domestic Homicide Reviews – Home Office 2011 as amended by Home Office Guidance December 2016 www.homeoffice.gov.uk/publications/crime/DHR-guidance

Multi-Agency Statutory Guidance for the Conduct of Domestic Homicide Reviews – **Revised August 2013** Home Office

Multi-Agency Statutory Guidance for the Conduct of Domestic Homicide Reviews – Home Office 2016 www.homeoffice.gov.uk/publications/crime/DHR-guidance

Appendix No 1

Record of notes taken during a Panel Meeting on 7th September 2017 at Willcox House, Cardiff where Stuart Mayer (SM) and Ann Clarke (AC), children of Angus and Margaret Mayer, attended.

Welcome to family members and introductions

Chair, Malcolm Ross (MR), welcomed AC and SM to the meeting and introductions were made.

MR briefly outlined the process followed in undertaking the Review, and producing the resulting Report and recommendations, with input received from Health and Social Services, Police, Ambulance and Housing Services. He also described the process that will be followed to gain final approval and publication of the Report, and implementation / monitoring of the Action Plan.

Family Input

SM described the ongoing devastating effect of their parents' death on the family. He described their happy family life and struggle with the way in which their parents' lives ended so tragically. He advised that the family had provided as much support to their parents as they could (given their own individual circumstances) and this was acknowledged by the Panel. The family feel that there are lessons to be learned in order to improve responses and help avoid future tragedies. These primarily relate to:

- **The issue of consent**: The family feel that the absence of consent from the main carer should not prevent family members being listened to. They believe that professionals involved should use their expertise to assess the situation and engage with the family. AP (Assistant Director Adult Social Services, Cardiff Council) expressed sympathy with this view and agreed that staff should be more assertive in engaging with family members and should explore if there are any potential safeguarding issues. She apologised for the fact that their mother's voice was not heard and that opportunities to engage with the family were not taken. She gave her full support to the recommendations set out in the Review Report and her intent to ensure that associated actions are implemented.
- **The role of GPs** in identifying potential issues, especially where patients are suffering with dementia. SM advised that his father had visited the surgery approximately 28 times in the period leading up to his death, giving the opportunity to identify a decline in his condition and ask relevant questions in the knowledge that he was the main carer for a spouse with dementia. The family feel that :
    - information and awareness-raising about the likely deterioration of the dementia sufferer would help families to plan for the future. SM advised that

the family had discussed their mother's deterioration over the 18 months leading up to her death and had provided all the support that they could to help with the situation. However, with limited knowledge about the condition, it had taken some time to make the decision to ask for help. AP advised that Cardiff is working towards being a 'dementia friendly' city with a great deal of work ongoing to increase awareness and train staff. NJ (Domestic Abuse Co-ordinator, Cardiff Council) advised that there is much work ongoing across Cardiff to engage citizens of all ages to become 'Dementia Friends'.

- as the potential for violence has been shown to increase where dementia is an issue, routine questions should be asked of carers/ family members to identify this potential and provide preventative support.

- **The identification of trigger points for a review of services**: SM advised that all family members had witnessed the fatigue experienced by their father and the increasing pressure and frustration within their home with the progression of their mother's dementia. This included their father's weight loss (that was never identified as an issue by health professionals), and the deterioration in their mother's language and continence, and her increasing lack of cooperation e.g. with using her hearing aid and toileting. These issues had been known to, or identifiable, to support services, but had not triggered any review of services or other action. AP acknowledged the value of identifying potential trigger points, and advised that these need to feed into the review. She assured AC and SM of her commitment to improve responses within Social Services and regularly review services.

SM advised that the family are happy with the Review Report and thanked Panel Members for their time.

MR thanked SM and AC for their input on behalf of the family and offered them the opportunity to include a personal tribute at the beginning of the Report. SM agreed to provide a short paragraph for inclusion.

Overview Report Recommendations

Agency	Recommendation/Action	Lead Officer	Target date for completion	Desired Outcome	Monitoring arrangements	How will success be measured?
Adult Social Services	**Recommendation No 1** Where a person with dementia who is being cared for at home displays additional or increased needs that may lead to an increase in the carer's stress, then Social Services should consider if a review is required.	S Schelewa	Ongoing	Mainstream into current and future operational systems Shared with all Adult Services Staff	Internal audit arrangements including file and case audits	Individuals with dementia will receive appropriate and timely support

Agency	Recommendation/Action	Lead Officer	Target date for completion	Desired Outcome	Monitoring arrangements	How will success be measured?
Adult Social Services	**Recommendation No 2** Where a Carer's Assessment is refused by a husband or wife deemed to be the main caregiver, the assessment should be routinely be offered to additional family members who are also undertaking care giving tasks.	S Schelewa	Ongoing	Assessments identify all potential carers Shared with all Adult Services Staff Carers assessments offered	Internal audit Performance indicator regarding carers assessments analysed	All carers offered assessment and supported accordingly
Adult Social Services	**Recommendation No 3** All social care staff should ensure that the voice of the individual at the heart of the assessment should be heard. This should ensure that they are interviewed in their own right, and also alone if felt to be appropriate or necessary.	A Jones	ongoing	Assessment process guides professionals to speak to individuals alone	Internal audit arrangements including file and case audits Professional supervision of staff	Individuals are able to express wishes and feelings
	Recommendation No 4	A Jones	Work plan completed by	Professionals have clear	Internal audit arrangements	Individuals will be safeguarded

Adult Social Services	Adult Social Care Services to ensure that concerns expressed by family members, and or others, regarding any potential safeguarding concerns as regards an adult, when the adult in question is deemed and assessed to be an Adult at Risk, are acted upon in accordance with the guidance in Part 7 (Vols. 1 and 6) of the Social Services and Well-being (Wales) Act 2014.		October 2018 then ongoing	understanding of adults at risk criteria Safeguarding measures applied appropriately	including file and case audits	
Cardiff & Vale University Health Board	**Recommendation No 5** In line with Cardiff & Vale Dementia Strategy, Cardiff & Vale University Health Board will encourage GP surgeries in Cardiff and the Vale of Glamorgan to become designated 'Dementia Friendly' and provide literature, awareness and guidance on dementia to patients	Head of Primary Care	Completed	All practices are "Dementia Friendly"	Through annual practice visiting programme Practice Development/Cluster Plans Report through Unity Quality & Safety Group	Outputs from practice development plans/cluster plans. Visibility of leaflets, posters within the practice

	and members of the public					
Cardiff & Vale University Health Board	**Recommendation No 6** Cardiff & Vale University Health Board to encourage GPs to undertake dementia training in Cardiff and the Vale of Glamorgan in line with the Cardiff and Vale Dementia Strategy. Dementia training should also be provided as part of the CPET programme for GP education.	Head of Primary Care	In progress	**Cardiff North** Cluster to become part of the Dementia Friendly Neighbourhood – all practices completed training **Cardiff South West** All practices to undertake Dementia Awareness Training **Cardiff West** Working to maintain Dementia Friendly status **Western Vale** Virtual Dementia Friendly Organisation	Participation in Mental Health DES/Dementia Training 9 practices have submitted reports for the MH DES to date and 3 of these were on topics related to dementia and the Mental Capacity Act Report through Primary Care Quality & Safety Group	Outputs from practice development plans/cluster plans Training registers Reports presented to Quality and Safety Group

				Working with Public Health Wales to create a Dementia Friendly Community in Western Vale **Eastern Vale** Completion of Dementia Management in Primary Care Toolkit		

ADULT SOCIAL SERVICES

Agency	Recommendation/Action	Lead Officer	Target date for completion	Desired Outcome	Monitoring arrangements	How will success be measured?
Adult Social Services	**Recommendation No 1** That an appropriately phased programme of training be developed to ensure that Social Work Assistants who will be required to undertake assessments and reviews have a relevant social care qualification at Level 4 or above.	Liz Begg Jackie Burns	31.03.2019 30.04.2019	Initially SW Assistants undertake a lower level qualification in preparation for the new level 4 Relevant staff will have enrolled or have enrolment planned (according to service area need) via their managers on the new qualification framework	Team managers will put forward relevant staff to the Training Unit and monitor their progress in supervision. Managers will keep a record of those undertaking the course and completions. The Training Unit will keep records of staff undertaking the qualifications and report to Team Managers as appropriate	Social Work Assistants will have an excellent underpinning knowledge and be able to apply this to their work. Better Outcomes will be evident and recorded for Service Users

Adult Social Services	**Recommendation No 2** As an extension of the recent 'Better Conversations' training, all relevant staff undertake additional carer awareness training to further enhance a proactive approach in supporting carers and providing them with information	Liz Begg	31.03.2019	All relevant staff have an enhanced understanding of the support that carers may require and be open to seeking advice from senior staff when unsure in any situation. They will have a good understanding of the Assessment process and information sources. Specific training be made available regarding carers Carer awareness is incorporated into all other relevant training courses	Team managers will put forward relevant staff to the Training Unit and monitor their progress in supervision. Managers will keep a record of those undertaking the course and completions. The Training Unit will keep records of staff undertaking the qualifications and report to Team Managers as appropriate	Staff will feel confident in conversations with carers and have a sound understanding of the principles and legislation relating to carers. Carer's assessments will increase Carers will feel supported in their roles.

Adult Social Services	**Recommendation No 3** Day Centres to ensure proportionate follow up and further consideration where the "Getting to know you" forms are not completed and returned by the family.	Sue Schelewa	31.03.2018	Service Users receive a more responsive service, taking into account their history and experiences	Day Service Manager to follow up on each referral to ensure completion of the form. Team Managers to raise as required with case managers.	A 'getting to know you' form completed for all service users attending OP day service. Staff will feel more assured in providing person centred care
Adult Social Services	**Recommendation No 4** That Adult Social Care Services revisit the overall Review related risk assessment process to maximise safeguarding and escalation measures. In effect, this would aim to improve the capacity of the Reviewing role to recognise when it would be more appropriate to conduct Reviews in person and where service users should be interviewed on their own.	Sue Schelewa	30.06.2018	Establish the principle that individuals should always be interviewed on their own where this is feasible. Team Managers to agree any rationale presented for not conducting a review in person. Same day visit to be conducted where carer breakdown may be indicated (see	Team Manager to monitor progress	All reviews carried out in person where feasible. Carers will feel supported in their role.

				recommendation 2)		
Adult Social Services	**Recommendation No 5** That Adult Social Care Services consider how to assess the risks in a case prior to being transferred into a Review.	Sue Schelewa	31.03.2018	Review of documentation so that prompts can be in place to assess the risks.	Review TMs develop clear criteria/checklist against which transfers are assessed	Review team staff can be assured that all people within the service are safe.

Cardiff and Vale University Health Board

Agency	Recommendation/Action	Lead Officer	Target date for completion	Desired Outcome	Monitoring arrangements	How will success be measured?
Cardiff & Vale University Health Board	**Recommendation No 1** General Practitioners to be encouraged to develop systems to be able to identify when a patient has caring responsibilities associated with a relative who has a diagnosis of dementia.	Head of Primary Care	December 2018	Confirmation that systems are in place **Cardiff North** Working towards providing better support for patients with dementia at any stage	Through annual Practice Visiting Programme Report through Primary Care Quality & Safety Group	Annual Practice Visiting undertaken Through scrutiny of report to ensure systems are in place to support patients who are living with a relative suffering from dementia.
Cardiff & Vale University Health Board	**Recommendation No 2**. General Practitioner's should make any referral on to appropriate services and should not expect	Head of Primary Care	March 2018	**Cardiff City & South** Practices are supported by Dementia support worker role	Through monitoring of cluster plans	Audit number of referrals made to Dementia Support Worker in a specific dementia friendly practice

	family to make contact with services themselves			Working towards supporting early diagnosis, access to support services for patient, carers and families	Report through Primary Care Quality & Safety Group	Reports received by Quality and Safety Group and progress demonstrated
Cardiff & Vale University Health Board	**Recommendation No 3** General Practitioner's to consider signposting carers of a relative with dementia to third sector for support and advice when they are presenting with stress related symptoms associated with a caring role.	Head of Primary Care	March 2018	**Cardiff East** Engagement with Alzheimer's Society	Through monitoring of cluster plans Report through Unity Quality & Safety Group	Audit compliance in a dementia friendly practice Consider family satisfaction questionnaire to determine service user approval
Cardiff & Vale University Health Board	**Recommendation No 4** Further, strengthen partnership working between the memory team and third sector to further develop support that is provided to family member s involved in a caring role.	Delyth Jones, Directorate Manager, Clinical Gerontology, Medicine CB	October 2018	Family member is acknowledged as carer with possibility of requiring support	Ensure strong links are in place with third sector agencies to support families.	Ensure that feedback from family members is obtained to ascertain their thoughts and feelings

Cardiff & Vale University Health Board	**Recommendation No 5** A capacity assessment should be considered at each contact following a diagnosis of cognitive impairment in relation to having the ability to accept care and support.	Head of Primary Care	Completed 2017	MCA Training has been undertaken through CPET (GP Training sessions	Regular sessions to be undertaken through planned education events through the clusters on an ongoing basis.	MCA Audit to be agreed