SERIOUS CASE REVIEW
OVERVIEW REPORT

SUBJECT: Peggy

SILP Reviewers
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Contents

1. Summary 3
2. Introduction to Significant Incident Process 3
3. Introduction to Case 4
4. Terms of Reference 4
5. Process 4
6. Background 5
7. Key Practice Episodes 5
8. Analysis by Themes 10
9. Conclusions 17
10. Recommendations 18

References 20

Appendix 21
1. Summary of findings

1.1 This review has concluded that although Peggy's death was not preventable, the tragic circumstances in which Peggy died could have been avoided. A number of actions or omissions within the professional systems involved in her care led to the circumstances in which Peggy died.

1.2 The window onto the system this review has allowed has identified some learning for the professionals involved, on both an individual and organisational level. It is pertinent to reflect on these aspects so that the learning can inform actions taken to ensure the continuous improvement of the multi-agency response to vulnerable adults in Gloucestershire.

2. Introduction to the Significant Incident Learning Process (SILP) for Serious Case Reviews

2.1 SILP is a learning model which engages frontline staff and their managers in reviewing cases, focussing on why those involved acted in a certain way at the time.

2.2 The SILP model of review adheres to the principles of

- proportionality
- learning from good practice
- the active engagement of practitioners
- engaging with families, and
- systems methodology

2.3 It has been generally accepted that in the past practitioners in the cases subject to the Serious Case Review (SCR) process in Children’s Services have sometimes been marginalised and their potentially valuable contribution to the learning under-valued and under-utilised. As Adult Services embrace the principle of undertaking SCRs where appropriate, it is recognised that the learning from Children’s Services’ experiences needs to be incorporated into their practice.

2.4 SILPs are characterised by a large number of practitioners, managers and Adult Safeguarding Leads coming together for a Learning Event. Agency reports are written and are shared in advance. At the Learning Event the perspectives and opinions of all those involved are discussed and valued. The same group then come together again to study and debate the first draft of the overview report, and to make an invaluable contribution to the learning and conclusions of the review.

2.5 Gloucestershire Safeguarding Adults Board (GSAB) has requested that the SILP model of review be used to consider the circumstances surrounding the death of Peggy in March 2014. This systems review is being undertaken in order to learn lessons about the way that local agencies work together to safeguard vulnerable adults.

2.6 GSAB has a SCR policy which identifies three purposes to be fulfilled by the review:

Overview Report 8.3.15
To establish whether there are lessons to be learned from the circumstances of the case about the way in which local professionals and agencies work together to safeguard adults at risk.

To establish what those lessons are, how they will be acted upon and what is expected to change as a result.

To improve inter-agency working and better safeguarding of adults at risk including the review of procedures where there may have been failures.

This serious case review has been undertaken using the SILP model, which ensures that these purposes have been met and provides a systems review of the case.

3. Introduction to the Case

3.1 Peggy was 88 years old when she died and had been a widow for many years. She had lived at The Home since June 2011 after a period as an inpatient in a Mental Health Assessment Unit. Prior to this she had spent six months living with her daughter after she became unable to live in her own home as she was becoming increasingly confused and suffered from extreme anxiety and panic attacks.

3.2 A review of her placement at The Home took place in September 2013 and concluded that The Home, which is a residential care home, was able to meet her needs appropriately. However over the next few months Peggy’s mental health deteriorated and she became more confused and her behaviour more bizarre. She was unsettled, especially in the evenings and at night, and on several occasions left the building and had to be persuaded to return by staff. In the early hours of the morning of 12th March 2014, unobserved by staff, Peggy left Home and, after being found collapsed in the road was taken to hospital by ambulance were she was found to have suffered a stroke. Palliative care was provided and Peggy died on 15th March, her family having been constantly with her since she was admitted.

4. Terms of Reference

4.1 The terms of reference are attached at appendix 1 and detail the agencies who participated in the review and also articulate the particular issues for consideration the agency authors were asked to consider in their reports.

5. Process

5.1 A meeting for authors of individual agency reports was held on 22nd October 2014 where the SILP process and expectations of the agency reports was discussed. A full day Learning Event took place on 11th December 2014. Most of the agencies involved were represented at the Learning Event by both the report author and staff, including managers, who had been involved during the period under review. Apart from a delay in receiving one report, all agency reports were available and circulated to attendees prior to the Learning Event.

5.2 Prior to a Recall Event held on 29th January 2014, the first draft of the overview report was circulated to those who had attended the Learning Event. The agencies that attended the Learning Event were again represented on 29th January and participants were able to provide feedback on the contents and clarify their role and perspective. All those involved...
contributed to the conclusions about the learning from this review.

5.3 Family engagement is an essential part of the SILP Process. The Overview Report Writer and a representative from GSAB met with Peggy’s adult children on 22nd October where the SCR process was explained and their views sought. A further meeting was held on 29th January before the Recall Event when the first draft report was shared with them. The family have welcomed the opportunity to give their views and where these contribute to learning, they have been integrated in to this report.

5.4 The overview report has been written by Jane Scannell. She is an independent social work manager and consultant and SILP accredited reviewer. The Reviewer is entirely independent of GSAB and its partner agencies.

5.6 The review has been written with an expectation that it will be published on the GSAB website, in order to ensure the learning is widely disseminated. The ultimate decision about publication will be taken by GSAB in consultation with the family.

6. Background

6.1 The subject of this review is referred to as Peggy. Other people are referred to by their relationship to her. Other identifying details have been removed.

6.2 Peggy had lived in the village where The Home is for many years. As she had got older she found coping alone more and more stressful and, despite support going in to her home, her adult children noticed a deterioration in both her appearance and her confidence and eventually concluded she could no longer manage to live independently. She spent some time living with her daughter and received mental health services from 2010. In April 2011 she was admitted to a hospital which provides specialist assessment, treatment and care for older people with functional mental health problems and people with dementia and on 10th May 2011 she was diagnosed with dementia. Her family identified The Home as the best option for her after researching other care provision. Peggy moved in during June 2011 after she and the multi-disciplinary team caring for her agreed it was an appropriate placement. A Care Programme Approach (CPA) review was held by the Mental Health Trust in October 2011 and Peggy was discharged from their care.

6.3 The Home is a 36 bedded residential home in which all the residents have their own rooms with en-suite facilities. There are three lounges and spacious grounds. It is in a Village and lot of the residents are local people. This means that there is mixed client group with quite a broad range of needs. Staff from The Home reflected that Peggy's needs fell about midway the range of needs they had to accommodate. Residents are allocated a key worker and Peggy's Key Worker was able to attend the Learning Event.

7. Key Practice Events

7.1 The period under review has been divided into three key practice episodes. Key practice episodes are episodes that are judged to be significant to understanding the way that the case developed and was handled. The term ‘key’ emphasises that they do not form a complete history of the case but are a selection of the activity that occurred, and include key information to inform the review. The first key practice episode covers September and October 2013 during which the annual review of Peggy’s placement at The Home took place.
and when some changes in Peggy's behaviours were noticed. The time between this and the final two months of Peggy's life is considered as key practice episode 2. Key Practice Episode 3 covers February and March 2014 when the concerns for Peggy's physical and mental health increased and mental health professionals became involved. At this time plans were being made to assess whether Home was still an appropriate place for Peggy to live and to ensure her changing needs were met.

Key Practice Episode 1 – September and October 2014

7.2 On 12th September 2013 a routine annual review of Peggy's placement at The Home took place. The purpose of the review was to reassess Peggy's needs and confirm that the placement at The Home continued to meet them. The review was undertaken by a Social Worker (who hadn't met Peggy before) and besides Peggy, her daughter and one of her sons also attended. The Social Worker also spoke to some of the Home staff including the Home Manager. Peggy was not able to contribute meaningfully to the review and the Social Worker subsequently confirmed with Daughter that Peggy had a diagnosis of dementia. The staff from The Home that the Social Worker spoke with seemed unaware of this diagnosis and it was not included in any of the residents' notes held by The Home. The diagnosis had been made in May 2011 when she was in hospital. She had been discharged from hospital straight to The Home.

7.3 The review concluded that although Peggy's needs had increased as her dementia had progressed and that she needed more support with personal care (particularly around dressing), The Home continued to be an appropriate placement for her.

7.4 The Social Worker was told that Peggy had been experiencing fewer episodes of agitation despite a reduction in her prescription for risperidone1 from daily to 'as needed'. There is lack of clarity about exactly when this change occurred. The Home's report shows that Peggy's medication chart at the time of the annual review listed both risperidone 0.5mgs daily and risperdal (the same drug) 0.5mgs to be used when needed. Both The Home and GP time lines/reports show the prescription change taking place following a GP review on 24th September, sometime after the review meeting. Additionally, the family disagree that Peggy's episodes of agitation had decreased. It has not proved possible to clarify the reasons for these anomalies but the author hypothesises that the date the medication was reduced was 24th September and that conversations to finalise the review took place between the social worker, the family and The Home in the intervening period which led to people being confused about timings. The fact that the medication was listed twice on Peggy's chart has not been explained. A Care Quality Commission inspection in April 2012 identified that The Home's management of medications was not up to standard and it is possible that this was an example of the issues they found. At the Learning Event mental health professionals explained that, as there are significant risks to the long term use of risperidone, including an increased risk of stroke, there was a national public health drive to reduce its use. Although the drug alleviates anxiety – which Peggy had experienced for a long time – it also can have the effect of making people more confused which is particularly unhelpful in someone who has dementia.

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1 Risperidone (also called risperdal) is an anti-psychotic medication which is prescribed for behavioural and psychological symptoms in dementia. In some people with dementia, anti-psychotic drugs can eliminate or reduce the intensity of psychotic symptoms, such as delusions and hallucinations, and can have a calming and sedative effect.

Overview Report 8.3.15
7.5 During the remainder of September and October Peggy's life at The Home continued. She was visited weekly by a befriender and her family saw her very regularly, with one or other of them visiting most days. Following the review the family had raised some concerns with the Home Manager about missing clothing, Peggy's personal hygiene and the cleanliness of her room. They also thought she was losing weight. The outcome of the discussion was not recorded by The Home although The Manager stated that the issues would have been raised at staff hand overs. However, Peggy's weight was not checked until 12th November (when it was found she had lost a significant amount of weight).

7.6 The befriender is an employee of a not for profit organisation that provides help to people in their own homes. In November 2012 Peggy’s family had arranged for her to visit weekly because they were concerned that Peggy was becoming isolated and did not have enough social interaction and mental stimulation.

7.7 During these months Peggy also saw a GP on a number of occasions including because of a concern that she may have had a Transient Ischaemic Attack (a 'mini' stroke) although the GP and The Home time lines are inconsistent about when this occurred.

7.8 This is a key practice episode because:

- Although there was an increasing awareness of Peggy’s dementia, it was assessed that The Home continued to be an appropriate place for her to live.
- Peggy was seen regularly by her family who raised some concerns about her physical well-being but these did not give rise to significant concern about the appropriateness of the placement.

**Key Practice Episode 2 – November 2013 – January 2014**

7.9 From the beginning of November staff at The Home started to notice more significant changes in Peggy's behaviours. She appeared to be unwell at the beginning of the month and at times refused to go to the dining room for her meals. By the end of the month she was regularly refusing to allow staff to help her with daily living activities such as bathing and preparing for bed. These were all activities that she had accepted help with before. Peggy's appetite remained poor and when she was weighed on 12th November (for the first time since August) it was found she had lost a significant amount of weight. The Home records show that the GP reviewed her medication because of this and also prescribed fortified drinks to address the poor appetite/weight issues. These seemed to have the desired effect and by December she had regained some of the weight she had lost. Peggy was not a slight woman, when she was admitted to The Home her weight was recorded as being 83.4 kgs (about 13 stone) and this may have accounted for the fact that even though it had been noticed she had lost weight in the summer of 2013, there was no particular anxiety about it.

7.10 In November the GP undertook an annual dementia care review and recorded that there were “no concerns, needs met”. The fact that Peggy had an annual review implies that there was knowledge within The Home that Peggy did have dementia. In addition the GP asked The Home Manager to discuss end of life wishes with Peggy’s family. The family were consulted and were clear when they met the Reviewer that they felt a DNAR (Do Not Attempt Resuscitation) approach was the right thing for their mother. The agency author for the GP report noted that it was the GP’s professional view that Peggy did not have the mental capacity to contribute to this discussion in a significant way. Specifically, he did not
feel that she was able “to understand, retain and weigh-up information relating to decisions about resuscitation or end of life care. Therefore the family and carers were involved in formulating decisions in her best interests”. The agency author notes that best practice in this situation would have been to undertake a mental capacity assessment.

7.11 During January 2014 Peggy’s disturbed behaviours increased. It was apparent that these were more noticeable in the evening and at night and mental health professionals at the Learning Event explained the phenomenon of “sundowning” (sometimes called late-day confusion) which is a symptom of Alzheimer’s disease and other forms of dementia.

7.12 During January Peggy was reported to be frequently agitated overnight, often having very little sleep. She was sometimes given risperidone - when needed - as prescribed, but staff at the Learning Event also described that efforts would be made to calm her with a cup of tea and a quiet chat before resorting to medication. It was noted in the Agency report that at times the risperidone did not appear to have any effect. In light of Peggy's ongoing disturbed behaviour the GP was consulted on 28th January. He wanted to rule out any physical reason for her agitation and confusion and asked the home to obtain a urine sample to test for infection. On January 11th Peggy tried to leave The Home for the first time although staff were able to dissuade her.

7.13 This was a key practice episode because:

- Peggy's mental health deteriorated during this time,
- her appetite and eating habits changed,
- she was seen by a GP at least four times but no referral to specialist services was made.

**Key Practice Episode 3 – February and March 2014**

7.14 From the beginning of February Peggy’s level of confusion increased and she displayed more bizarre and worrying behaviours that potentially put her at risk and she lost weight again. GPs from the practice that provided primary care via the GP Enhanced Care service to The Home reviewed Peggy weekly, with one, (not the Home’s regular GP) recording on 4th February that her symptoms meant that she was “possibly nearing end of life” (this opinion was not shared with Peggy's family). Her own GP re-prescribed risperidone and Peggy started taking it daily in the mornings. At the Learning Event practitioners reflected that as Peggy's behaviours were clearly more disturbed late in the day and at night, it may have been more appropriate to change the timing of the dose to evenings.

7.15 The Home continued to record incidents of confused and bizarre behaviour and Peggy's family became increasingly concerned. Her symptoms included loss of speech and, as the month went on, episodes of aggression. Her behaviour was generally worse at night, when often she barely slept, and sometimes caused alarm or distress to other residents. On 21st February Home recorded two incidents of Peggy leaving the building and GP subsequently requested the Care Home Support Team to become involved.

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2 The Care Home Support Team is jointly funded by Health and Social Care and is a multi-disciplinary team which provides education, training and hands on support to care home staff in Gloucestershire to enable staff to provide the best possible care and quality of life to individual residents.

Overview Report 8.3.15
7.16 The Team's Community Psychiatric Nurse (CPN) visited very promptly and initiated investigations into possible physical causes for Peggy's deteriorating mental health. The urine test requested by GP on 28th January had proved very difficult to obtain due to Peggy's lack of understanding and inherent need for privacy. The potential delay in treatment was discussed by practitioners at the Learning Event. The National Prescribing Guidelines suggest that GPs should not prescribe without first testing that an anti-biotic is needed but in this case, treatment was delayed for over a week while staff struggled to obtain a urine sample, and the time delay could have added to the degree of confusion Peggy was experiencing.

7.17 The CPN thought that Peggy was likely to need more specialist care than could be provided by a residential home. As she was aware that it could take some time for Adult Social Care Services (ASCS) to allocate a social worker to undertake an assessment and arrange the necessary placement, she spoke with a colleague at the Referral Centre to give them advance warning that an assessment may be needed. The CPN and ASCS representatives said this parallel planning – addressing possible physical causes while also allocating a social worker was the “normal course of action”. From a systemic perspective it does have the potential to overwhelm the ASCS system by allowing the over-estimating the number of service users who may need ASCS involvement. However, at the Learning Event it was clear that the professionals involved had a respectful and trusting relationship with each other which made the practice of doing these early referrals work for them. The Home Manager also contacted the Helpdesk at the Referral Centre to reiterate the difficulties the home was having in managing Peggy's behaviours.

7.18 The CPN confirmed the outcome of her involvement to date in a letter to the GP received on 6th March. In it she requested:

"1. Screening for Urinary tract infection (UTI)
2. To 'please consider' prescribing antibiotics in case a UTI is the cause of her behaviour change
3. To monitor bowel activity as constipation was noted 'on initial visit'
4. Request an increase in risperidone to see if this would help. The risk of the use of anti-psychotic medication was discussed with the family members and all agreed it was in her best interests."(Agency Report)

On 11th March GP prescribed both an anti-biotic and an increase in the risperidone which Peggy started taking straight away.

7.19 During the first weeks of March Peggy was described in the Home's records as having several "lovely days" when she appeared more settled and calm and, although she remained up and about at night, her behaviours were not as extreme as they had been. However there were also two incidents when she tried to leave the building but staff were able to dissuade her.

7.20 During the evening of 11th March Peggy left the building and was seen trying to get into a car in the car park before she was persuaded indoors. Two of her sons visited that evening and noted that she was more agitated than usual. When they left she could not be persuaded to stay in her room (they noted that one son was usually better able to
convince their mother to do this, but he left first). Her other son left her in the lounge and went to find some staff to tell them that Peggy was particularly agitated that evening. Peggy fell asleep in the lounge and when she woke at about midnight the two staff on duty made her a cup of tea. Later, at about 2am she was settled by them in a chair in the lobby with another cup of tea and one member of staff stayed with her. Peggy then went to the dining room, again accompanied by the staff member who left her there at about 2.40 am and went to help her colleague in the laundry room. When she returned to check on Peggy, she had gone. The staff initiated a search of the home and its immediate grounds and when they could not locate her they called the Police.

7.21 At 2.52 am the Police received a telephone call from a taxi driver reporting someone lying in the road and a minute later they got the call from the staff from The Home. The Police quickly realised the possible connection and by 2.58 had found Peggy and requested an ambulance for her. Peggy was conscious at this time and told the Police officer that “I fell over”. She had an obvious head injury. When a paramedic arrived ahead of the ambulance at just after 3.00 am she “was observed to be alert” but, whilst she was being assessed before being taken to hospital, her level of consciousness decreased and, by the time she arrived at Hospital, Peggy was unconscious.

7.22 Tests undertaken when she arrived diagnosed a cerebral bleed and doctors noted that the “large brain stem bleed” was “not likely due to a fall and more likely due to a stroke”. After discussion with the family and an assessment of the prognosis for Peggy, she was transferred to a ward and was given end of life care by a specialist palliative care team.

7.23 Peggy died on 15th March 2014. Her family had been with her since her admission to hospital. The Senior Pathologist was made aware of the events around Peggy’s death. The death certificate recorded that her death was due to natural causes.

7.24 This was a key practice event because:

- the impact of Peggy’s changing behaviour meant that it was questionable whether The Home would continue to be a suitable place for her to live. This needed to be considered, however, alongside the potential harm of a move could cause. Actions were taken to start the assessment to progress this but the situation was not considered urgent.

- Despite Peggy having left the home on several occasions no risk assessment was undertaken by The Home and Peggy was able to do so again without staff noticing.

- No safeguarding referrals were made – either by the home (when Peggy had to be “returned” by a member of the public who had met her walking down the road) or by the Hospital or the Police following her accident.

8. Analysis by Themes

8.1 From the information extrapolated from the agency reports, from the discussions at the Learning Event and from the meeting with family members, several key themes emerged. These can be summarised as:

- Safeguarding adults and the recognition of risk
Information sharing, communication and recording
Management of dementia
The complexity of the Home environment
Family involvement

Viewed from a systemic perspective it is apparent how these themes influenced and impacted on each other and led to the circumstances which are the reason for this review. This is illustrated by how the complexity of the Home environment meant that information, such as Peggy’s dementia diagnosis, which was known to one part of the system, was not effectively shared.

Safeguarding adults and the recognition of risk

8.2 It is apparent from Home's report that Peggy's behaviours posed a safeguarding issue, not only to herself but also to other residents in Home, but there was no consideration of the need to make a safeguarding referral and no internal risk assessment was undertaken by The Home. The safeguarding of adults needs to be seen in the widest sense – it is not only about protecting vulnerable people from abuse from others but is also about how those who care for vulnerable people, prevent and manage the risk of harm stemming from an individual's behaviour.

8.3 When considering whether a safeguarding referral is needed, staff need to consider whether the concerning behaviours places the person at risk of harm. Staff at the Learning Event reflected that some of Peggy's behaviours, although bizarre and possibly frustrating to her carers, such as wearing multiple layers of underwear, did not constitute any risk. However leaving Home and having to be brought back by someone who had met her going down the road clearly did.

8.4 The system for making a safeguarding referral requires the concerns to be raised with the Adult Social Care Help Desk. The concerns are then passed to the Safeguarding Adults Team where a threshold decision is made by Specialist Practitioners, in consultation with other multi agency partners as necessary, to determine whether the threshold has been met. If the concern is judged to meet the threshold – it is passed to the relevant team with recommendations for further actions. Where the threshold is judged not to have been met the practitioner will signpost the referrer to other services/procedures as appropriate. The Safeguarding Adults service also operates an advice line for professionals which offers the opportunity to discuss and clarify whether a concern warrants a safeguarding referral. There is evidence that, generally, care homes make good use of this facility to discuss concerns on safeguarding issues and there does not appear to be any systemic problem with accessing advice and support. The reason for not doing so in Peggy’s case appears to be because there was not a recognition that her changing needs were putting her at risk of harm and so no risk assessment was done by The Home. Had they done a risk assessment or sought advice, steps that could have been taken to reduce the risk of Peggy leaving the building again such as a review of the policy regarding door alarms or requesting additional staffing could have been identified.

8.5 The Care Act 2014 once implemented will clarify the threshold for s42 (safeguarding)
assessment but it is clear that the Act's intention is to make safeguarding a personalised experience. The chapter on safeguarding in the statutory guidance to the Act draws heavily on the approach developed by the Making Safeguarding Personal (MSP) programme. At the Learning Event participants reflected on the need to provide person-centred care, seeing the person with dementia as an individual rather than focusing on their illness or on abilities they may have lost. There is no dichotomy between providing person-centred care and ensuring that a person's safeguarding needs are addressed.

8.6 Peggy's occasional efforts to leave The Home (the agency report recorded that she had succeeded in doing so three times and had twice been persuaded not to before 12th March 2014) did not prompt a consideration of whether a Deprivation of Liberty Safeguard (DoLS) application was needed. Had an application been made it would have triggered a Best Interest Assessment that would have reviewed all of Peggy's care. At the Learning Event staff reflected that this was just before the Cheshire West judgement3 which clarified the threshold for DoLS applications. The agency report author for the Mental Health Trust noted that the CPN had recorded that Peggy was “generally happy and content” to be at Home. This would have been taken into account when considering the restrictions in place to ensure her safety and did amount to a DoLS assessment (i.e. although she lacked the capacity to make a decision about receiving care at Home, she was content to be there, and her family were fully involved with her care).

8.7 Neither the Hospital, the Police or the Ambulance Service recognised that the circumstances of Peggy's hospital admission warranted a referral to the Adult Safeguarding Service. (Even though the incident occurred out of office hours the referral/alert could be made to the Emergency Duty Team (EDT)). Participants at the Learning Event speculated that each agency may have assumed the other was going to do so, although from the agency reports it appears more likely that there was no consideration of the need to make a safeguarding referral.

8.8 As Peggy's dementia increased, the likelihood that she was not able to exercise autonomy also increased which also put her potentially at risk. Everyone has the right to make decisions for themselves and the Mental Capacity Act (MCA) makes it clear that health and care professionals should always assume an individual has the capacity to make a decision themselves, unless it is proved otherwise through a capacity assessment. If a person lacks the mental capacity to make a certain decision it will be necessary for someone else to make a decision on behalf of that person. Every capacity assessment is decision and time specific. The MCA states that whoever is making that decision or taking any action on the person’s behalf must do this in the person’s best interests. The GP had, in effect, done a capacity assessment regarding Peggy's ability to make decisions about end of life care and concluded she did not have the capacity to make the decision but had not formally recorded it as such.

8.9 DoLS and capacity assessments and best interest decisions are all safeguards in the system to protect vulnerable people. The review has not identified that there were any systemic problems with them – although it was noted that the recording of the process of how a conclusion that Peggy lacked capacity to make a decision, for example about DNAR, needed to be documented. However, the review participants recognised that the risks to

3 Supreme Court ruling P v Cheshire West and Chester Council March 2014
Overview Report 8.3.15
Peggy’s could have responded to in more timely and less formal way had The Home undertaken a risk assessment, and also sought advice from the Care Home Support Team earlier.

8.10 Learning related to this theme

- homes need to undertake assessments in response a resident’s changing behaviour to see if there are steps they can take at a local level to minimise risk
- staff need to keep a broad definition of safeguarding in mind and raise safeguarding alerts to prevent and manage the risk of harm stemming from an individual’s behaviour.
- whilst accountability for meeting an individual’s needs, including the need for safeguarding, remains the responsibility of the professionals working directly with them, the Safeguarding Adults Service’s advice line can provide expert advice in complex cases.
- universal services such as the Police, Ambulance Service and hospitals need to refer to Safeguarding Service if they identify that there may have been a failure in the duty to care for a vulnerable person. No agency should assume that another has taken responsibility for doing this but make their own referral.
- Mental Capacity assessments, and where necessary best interest plans, need to be recorded as such.

Information sharing, communication and recording

8.11 Several of the agency reports identified shortcomings in recording. This was particularly apparent in Home’s report and was acknowledged as not being good enough. A Care Quality Commission (CQC) review of The Home in April 2014 identified that record keeping did not meet essential standards. The same inspection also found that the management of medications was not up to standard. This chimes with the identification through the review process of the anomaly involving Peggy’s medication identified in key practice episode 1. An unannounced inspection in August 2014 found that both record keeping and the management of medications now meet the required standard.

8.12 The timelines completed to inform this review identified significant differences between Home’s records of GP involvement and those of the GP. The Home’s timeline showed considerably more entries of contact with the GP (although it was not always clear if this was face to face contact or a telephone conversation). Additionally there was discrepancy in dates between the two agencies. For example, The Home recorded GP had visited and examined Peggy on 16th September as she was “chesty”. The GP timeline shows no visit on 16th September but that on 1st October there was a visit by the GP as Peggy was “a bit chesty this week”. The reason for these anomalies appears to be related to the Enhanced Care Service provided by the GP practice. This service, described as “fantastic” by The Home, provides a nominated GP who takes responsibility for the primary health care needs of all the residents in a home. The nominated GP visits the home regularly (either weekly or fortnightly) and meets with a manager and discusses the health needs of all the residents as well as personally seeing any resident whose health is giving

Overview Report 8.3.15
concern. The discrepancies would appear to be due to The Home recording the weekly discussions whereas the GP records only record substantive involvement.

8.13 Of particular significance was the lack of shared knowledge of Peggy’s diagnosis of dementia. She was admitted to The Home from a hospital which provides specialist assessment, treatment and care for older people with functional mental health problems and people with a diagnosis of dementia. It is therefore difficult to understand why staff appeared to be unaware of this when the social worker undertaking the annual review spoke with them. The GP undertook an annual dementia review in November 2013 (presumably the third one since she had started living at Home) and so it seems the lack of awareness of the diagnosis was not system-wide. Practitioners at the Learning Event spoke of the “nervousness” residential homes used to have about admitting people with “a written diagnosis of dementia” due to CQC requirements at the time to provide “specialist” services and how this had caused services to “mask” a dementia diagnosis with, potentially unintended consequences. Another possible systemic reason for The Home’s lack of a record of Peggy’s diagnosis is the fact that Hospital discharge letters are routinely sent to people’s GPs but not to care homes. In Peggy’s case, she changed GP practice when she moved into The Home, and staff speculated that this may have caused a delay in information about her diagnosis being received by The Home. It is not clear whether either of these facts were the reason why there was not common knowledge amongst the carers at The Home. It is just as likely that the unawareness was due to a changing staff group and poor information sharing.

8.14 The sharing of information is sometimes compromised by anxieties about confidentiality. However, this did not seem to be a significant issue in this case. There were some instances of poor communication – the fact that the befriender was not informed of the circumstances of Peggy’s death was an extreme example. In fact the befriender’s role and involvement appeared very peripheral to the care Peggy received and little attempt was made by either the Home or the befriender to include the befriender in a holistic care package to be provided to Peggy. The fact she was employed by Peggy’s family to visit may have contributed to staffs’ uncertainty about her role and what information it was appropriate to share with her.

8.15 Learning related to this theme

- all professionals involved in the care of an individual need to ensure that all relevant information is shared. When a person has a diagnosis of dementia it is essential that this information is shared with their care-givers so that they are able to tailor the care appropriately. When a person is discharged to a home from an acute mental health setting it is good practice for the home staff to visit the ward prior to discharge to inform themselves of the person’s needs and care regime.

- the need for accurate and timely documentation/record keeping of key activities needs to be reinforced

- the role of befriender/ advocates/ independent visitors needs to be defined on a case by case basis and there should be agreement with the resident and their family about the parameters of their involvement and what information will be shared with them. Their responsibilities in relation to safeguarding concerns should be stated.
Management of dementia

8.16 Both of the themes discussed above have the common thread of the management of dementia. Participants at the Learning Event reflected on how the word dementia is used as both a diagnosis and also as an informal description of changed behaviours in older people and how this imprecise use can affect understanding of the changing needs of the individual. As already discussed, a substantial proportion of residents of care homes generally, and of the Home specifically, live with a diagnosis of dementia and systems need to be responsive and flexible to their needs. At the Learning Event participants reflected on the need to provide person-centred care, seeing the person with dementia as an individual rather than focusing on their illness or on abilities they may have lost.

8.17 In Gloucestershire, the care home system is supported by the Care Home Support Team. The team’s remit is support care homes to help prevent a resident having to be admitted to hospital or to move home unnecessarily. They provide care home staff with support, education and training in the management of certain behaviours. If a resident is referred by a GP, the team will undertake an assessment of an individual resident’s needs, and offer to care home staff. Although, as identified in the key practice episodes, Peggy’s behaviours changed and became more disturbed, particularly from January onward, a referral to the Care Home Support Team was not made until 25th February. The effectiveness of the service provided by the Care Home Support Team is dependant on care homes making use of the service in a timely way when a resident's behaviours change (as well as acting on the recommendations made). Similarly, it is important that GPs refer for assessment to support the current placement as soon as the provider starts to struggle to manage a resident's behaviour rather than only when they feel a different placement is needed.

8.18 The need to provide person centred care was illustrated by the retrospective analysis at the Learning Event that Peggy’s behaviours could be attributable in some part to sundowning syndrome. People suffering from this syndrome get more confused and agitated in the late afternoon and evening - as the sun goes down. They may want to go home, check on their children or cook the tea - or other behaviours that were appropriate in the late afternoon in their past. Sundowning most often affects people who have mid-stage and advanced dementia. The representatives from the mental health services and ASC were obviously very aware of this phenomenon as it is a common problem for people with dementia, but staff from The Home were less so and did not have a specific strategy for dealing with residents that suffered from the symptoms. A person centred approach towards people affected by this syndrome could include strategies such as distraction, preventing day time napping, not eating heavy meals late in the day, limiting caffeine, special lighting in the rooms the person uses and having purposeful activities at key times. These strategies require care homes to be responsive and prepared to alter routines etc. to meet individual needs. Had the ABC (antecedents, behaviours and consequences) charts the CPN asked The Home been completed, they would have identified the timings of Peggy’s heightened agitated behaviours and assisted in the identification of appropriate strategies to defuse them.

8.19 It is evident that the relationship between the Care Home Support Team and ASCS is a respectful and trusting one. This may account for why ASCS staff did not identify either the need for an urgent response to the referrals (both the CPN and The Home Manager
contacted them to discuss Peggy's changing care needs) or, given the behaviours that she was exhibiting and which The Home were having difficulty in managing, did not advise that a safeguarding referral was needed. The ASC agency report identified that the team had subsequently reflected on their actions following these contacts and concluded that their decision not to treat the referral more urgently was because they felt the CPN was “following up the matter with the home”. This reflects the Referral Centre’s staff’s confidence in the CPN’s judgements and a failure to critically evaluate and cross check the information provided to form their own decision.

8.20 Learning from this theme

- Care homes need to take advantage of the Care Home Support Team support as part of an early intervention strategy when they identify a resident’s needs are changing and the associated risks need managing.

- Similarly, GPs should refer individuals to the Care Home Support Team in a timely way before situations become critical and there is a risk that the resident will have to move in an unplanned way.

- ASCS screening decisions should be based on a collated account of all the circumstances of a referred individual.

Complexity of The Home environment

8.21 At the Learning Event it was acknowledged that a care home can be a complex environment. The residents will include people with varying and complicated needs. The Home estimated about 70% of their residents have some degree of dementia. An older person with a diagnosis of dementia will inevitably have changing needs over the years. When someone makes their home somewhere like The Home then staff are reluctant to see them move out even if their needs have changed significantly. This may result in staff having to care for people whose needs, had they been at such a level when they first came in to residential care, may have been considered too significant for The Home to cope with. The issue of locking exterior doors and thus mitigating against a homely ambiance has, to some extent, been superseded by technology which allows for the alarming of exits which can alert staff quickly should someone leave. During the period under review The Home did not have such alarms on the doors, had they done so, staff would have been immediately alerted to Peggy’s absence. Since Peggy’s death The Home have installed alarms on all external doors which give outside access.

8.22 The review heard about a drug that may assist people with dementia-related symptoms such as “sundowning” but also heard that it could only be prescribed by secondary tier services and not by primary care practitioners such as GPs. A variety of systems have been developed to bridge the gap between primary care and secondary services and the Care Home Support Team is one of these. This is a way of making the best use of resources as more and more people live with dementia. However it does, in effect, limit the opportunity for access to some drug regimes.

8.23 In addition to the residents, the care home environment also includes a large number of staff. These people will bring with them a variety of skills, knowledge and experience which
will interact with each other, the needs of the residents and with the management of the home. The Home’s agency report noted that during the time under review some care staff made allegations of poor practice against colleagues which then resulted in counter- allegations. These were dealt with by The Home’s disciplinary process and no information has been given to the review to indicate any of these allegations directly involved Peggy. Nevertheless it illustrates the interaction of a number of different systems, all of which will impact on individuals’ behaviour and adds to the complexity of the environment.

8.24 Learning related to this theme

- There are dilemmas in the use of alarm systems on external doors but they can play a role in minimising risk.

Family involvement

8.25 Peggy had a very involved and committed family – one son lives in the same village as The Home is in. They were anxious to ensure their mother was not only well cared for but that she was able to maintain her quintessential attributes such as the way she dressed. The family felt they had made an informed choice of Home as a place where their mother would feel comfortable and have her needs met appropriately. They were aware of Peggy’s mental health needs which had started some time before she went to Home. In fact Daughter had cared for her at her home for six months and was aware how draining caring for her could be.

8.26 The Family feel that they were not informed of the reasons for the change in Peggy’s medication (when risperidone was reduced from a daily dose to “as needed”) until they questioned why it had been changed. They questioned it because they felt Peggy’s behaviours changed once the dose had been reduced. Although The Home staff explained the rationale it is not clear if this was as accurate as necessary. Arrangements were not made for family members to speak with the GP about their concerns.

8.27 It was clear from the agency report that although the family brought “concerns” up with staff, including with the manager, they did not at any point make a formal complaint. It is good practice to try and resolve issues in the least formal and bureaucratic manner as possible but The Home’s report identified failings in the recording of how these concerns were responded to.

8.28 At the Learning Event staff from the Mental Health Trust described how the family members of people with dementia were provided with services including information about the condition and confirmed that this would include families of people in care homes. The Home also confirmed that they have run a dementia information day for families. However this took place soon after Peggy’s death and, although the family were invited, they felt unable to attend.

8.29 Peggy’s family are now reflecting over the fact that they were resisting the proposal that Peggy should move to another home more designed to meet her needs. At the time they had felt that The Home was the best place for her, and despite some concerns about the care she received, they felt a move would be harmful.

8.30 Learning related to this theme

Overview Report 8.3.15

17
homes need to agree with residents what issues their families should be informed about and how this will be done. Where a resident’s capacity to make such decisions is impaired, this should be agreed with their families in line with the MCA guidance.

- Home's process for families and others to raise “matters of concern” needs to more widely disseminated

9. Conclusions

9.1 This review has sought to establish whether

- the circumstances in which Peggy died were preventable
- agencies worked together to safeguard Peggy from harm and to meet her needs
- a DoLS application had or should have been considered
- family concerns were handled appropriately

9.2 The review has attempted to avoid hindsight bias which “oversimplifies or trivialises the situation confronting the practitioner and masks the processes affecting practitioner behaviour” (Woods et al 2010). It has identified that, although Peggy’s death was not preventable there were a number of actions or omissions, which could have altered the circumstances in which Peggy died. Had a safeguarding referral been made or the Care Home Support Team involved sooner, the advice and support The Home would have received to manage Peggy’s behaviours may have meant that the distressing circumstances of Peggy’s death may have been prevented. The fact that these referrals were not made reflects some lack of joined up practice between agencies which was compounded by some examples of poor record keeping and communication between professionals.

9.3 Peggy’s needs, as evidenced in her attempts to leave The Home, meant that an application for a DoLS assessment should have been considered. However, like the issues referred to above, of itself, an application would not have altered the circumstances under which Peggy died – it would not have stopped her leaving the home. A DoLS would have prompted a best interests assessment which may have resulted in a different approach to managing Peggy’s risky behaviours but this could have been achieved by involving the Care Home Support Team earlier or by requesting the Local Authority to undertake a review which would have resulted in a reassessment and would have led to a Best Interest meeting.

9.4 The family remains traumatised by the circumstances of Peggy’s death and hope that their participation in this review will offer them some “closure”. The concerns they raised during the last few months of Peggy’s life at The Home with the home itself, with the social worker and with the CPN were not viewed by those professionals as significant and the recording of the responses was minimal. The family themselves have reflected that they felt, a not uncommon, reticence about “making a fuss” in case their mother suffered as a result and this is a possible reason for their concerns being seen as, and responded to, as minor complaints.

9.5 Some actions, such as The Home installing alarms on all external doors, the updating of Overview Report 8.3.15
referral forms for befrienders to include consideration of information sharing and ASCS implementing changes in the way screening decisions are made, have already been taken by agencies as a result of the lessons learned from this case. The Learning Event identified other lessons learnt from undertaking the review and which assumed significance from the inter-agency feedback the event allowed. For example, how a safeguarding referral can assist a person-centred approach to the management of risky behaviours. This reflects that some of the “best learning from serious case reviews may come from the process of carrying out the review” (Brandon et al 2012).

9.6 In addition to the learning identified above the review also identified aspects of strong professional practice. These included:

- Home staff using distraction techniques (such as a cup of tea in quiet place) to try to calm Peggy rather than resorting to medication straight away when she became agitated
- The Care Home Support Team's prompt involvement
- The very quick response by the Police and ambulance services following Peggy's fall
- Staff were supportive of the family following Peggy's fall and subsequent death. The Police Community Support Officer was “kind and caring” and the family especially appreciated the help provided by the Registrar when they went to register her death.

In addition the review participants expressed appreciation of the honesty and self-critique The Home’s report contained and commented on how The Home’s representatives’ openness contributed to the effectiveness of the review process.

10. Recommendations

10.1 It is recognised that actions have already been made in relation to some of the individual agency’s identified learning. In addition agency reports included some recommendations which this review endorses. The purpose of providing additional recommendations is to ensure that all professionals in the partner agencies of the GSAB are confident that the areas identified as of concern in this review are addressed.

Recommendation 1

The GSAB should ensure the use of safeguarding alerts to prevent and manage the risk of harm stemming from an individual's behaviour is emphasised with staff across all GSAB partners.

Recommendation 2

GSAB should assure itself that MCA training is part of the GPs’ annual safeguarding updating and that that training includes the guidance on the recording and documenting of capacity assessments and best interest plans.

Recommendation 3

GSAB should assure itself that the protocol about how the GP Enhance Care service records their involvement with residents in care homes is robust and is adhered to.
Recommendation 4

GSAB should promote the practice of care home residents’ care plans:

a) stating how families will be informed about incidents. The plan needs to include a description of the type of incidents it is agreed the family will be notified about.

b) recording details about individuals involved with the resident - such as a befriender/advocate/independent visitor

c) addressing the limitations (or not) of information that will shared with these individuals

Recommendation 5

The Home should share their learning from the review process with colleagues in the Gloucestershire Care Providers Association (GCPA).

Recommendation 6

The GSAB should satisfy itself that arrangements for care homes to receive relevant information following a resident's discharge from hospital are robust.
References


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