



## **SAFEGUARDING ADULTS REVIEW (SAR): Adult F: Helen**

**22 Aug 2018**

### **A summary response by the Luton Safeguarding Adult Board**

The family members were consulted at length in the preparation of this Safeguarding Adult Review (SAR) report and have expressed a wish for this published summary to be entitled: Helen. The Safeguarding Adults Board would like to thank the family for their co-operation and contributions to this learning process.

#### **Introduction**

This SAR was commissioned by Luton Safeguarding Adults Board in July 2016. It describes the events leading up to Helen's death and in view of these events, looks at the key learning points for the Board and related organisations. The review was undertaken by an independent author, Sue Gregory, a senior leader in social care.

#### **Helen's story**

Helen passed away on the 1 October 2015 aged 39 years, from pneumonia and respiratory failure. The Coroner recorded a verdict of "Natural Causes". Helen had complex lung, renal and vascular problems. She left behind her mother, brother, sister, her brother-in-law, and her son who was 14 years old at the time. Her son has autism and was well supported by the local Education and Child Health and Social Care services. She initially became acutely ill in her mid-twenties and over the subsequent 14 years her health continued to fluctuate and deteriorate, requiring a number of hospital admissions and medical treatment. She gained a significant amount of weight and developed diabetes.

Helen remained a strong and independent minded woman with the mental capacity to make her own decisions which she often did. She had worked and lived independently with her son in her own flat for a while, before she moved back home to be with her mother. In December 2014, while she was living at home, she was rushed to A&E and was admitted to the Intensive Care Unit at Luton and Dunstable Hospital experiencing respiratory complications and later discharged to the Rehabilitation unit. During her stay there, it is reported that staff made "disparaging" comments about her which she found upsetting, and which was reported as safeguarding concern and addressed swiftly by management actions on the ward. A few weeks later it was reported that she was experiencing low moods and having suicidal thoughts and as a result, the level of supervision was increased and she was treated with medication. In March 2015 she was readmitted to the hospital. She continued to verbalise some negative thoughts, while she was receiving medical and nursing support and apparently improving.

A few weeks later her mood deteriorated and she became reluctant about accepting help on the ward. This coincided with her mother visiting less often because of her own ill-health. The Rehabilitation Unit where she was going to be discharged to could not accommodate her there because of her increased level of care needs. She found that upsetting. She was consequently admitted to a specialist hospital and discharged back Luton. These disruptions to her care plan appeared to make Helen very frustrated and she is reported to become more downhearted about her situation. She was referred for a psychiatric assessment, which concluded that she was not clinically depressed. She did not think much of that and insisted on being discharged home.

A discharge plan was hurriedly put in place based on an earlier assessment by the Discharge Team and a single home visit by the Rehabilitation Unit staff. This is not the usual complex discharge process whereby the Discharge Team would normally make a fresh assessment based on current home visits. In this case, this did not happen which proved to be a crucial missed step. The Discharge Team executed the discharge plan based on an assessment that was completed by speaking to Helen's mother on the telephone and arranging a care package comprising 3 visits per day by 2 carers. It is reported that Helen declined this and asked for a single daily visit. A further critical error in this process was that the assessment failed to

take account of the fact that Helen's mother who was her only informal carer in the house, had become less mobile and required an assessment of her own needs, aids and adaptations.

In early June 2015 Helen returned to her mother's home with a specialist bed installed in the living room. Her mother was reported to be sleeping on the sofa in the same room, as she was not able to walk upstairs and her son was the only person sleeping in his own bedroom. It is reported that Helen wanted to change the timing of the carers' visits, which did not happen promptly. Later she grew unhappy with the first two sets of carers and wished to change them because of their poor attitude to her, not staying for the full duration they were expected to and a lack of continuity to carers. Helen eventually did accept the third provider of care who continued with the planned visits, along with regular monitoring from Community and District Nurses.

In mid June 2015 Helen expressed further concerns about the new providers and requested an urgent review and this request was sent the Contact Centre of the Council, however, there was a long delay in allocating this request to a worker due to unprecedented staffing shortage in the adult social care service at the time.

Helen was also referred to the Community Rehabilitation team for a mobility assessment and support the day after she came home. However, it was reported that there had been delays in making contact with the family. The Community Rehabilitation team did visit 2 weeks later and recommended adaptations and a wet room to be installed. Two weeks later Helen's mother also had her mobility assessment and referred to the Council for major adaptations. During that time, District Nurses from the Cambridge Community Services continued to visit Helen at home.

Since July 2015 Helen and her mother made a number of phone calls to the Contact Centre of the Council for number of reasons particularly for wanting to increase the care visits to twice daily. However, owing to missed communications between the Contact Centre and Adult Social Care service, these requests were not actioned. In August Helen made a formal complaint to the Council's Complaint Team for the lack of response from the Council, who requested urgent actions from various teams in the Council. However, without any further progress by early September, Helen escalated her complaints to Luton Health Watch, who are an independent health champion of people in Luton and a local Councillor.

In mid Sept 2015 the Wheelchair Service, a specialist health provision that meets assessed mobility needs by an Occupational Therapist, raised concerns about the living environment of the family to the GP who wrote the Council to request an urgent review of the case. Eventually, following a telephone review of Helen's needs a second visit was agreed. Unfortunately, on the day the second visit started, Helen was admitted to the hospital with further respiratory difficulties.

Helen died on the 1 Oct 2015

#### **Helen in her own words:**

***“what hope do I have to ever recover or feel better when this keeps happening. I encourage anyone who truly cares to come and spend a day with me to see what it's like to be helpless, when days feel like weeks, weeks feel like months.” My life is at risk day to day because I cannot get out of bed or out of the house. What if there's an emergency. I dread to think of it... And no one cares.... I have no fighting spirit left in me and why should I fight the system that helps so many people in need.”***

## Summary of the main findings of the Review

- One of the main lessons that the Luton Safeguarding Adults Board and partner organisations have learnt from this incident is that despite all efforts at multidisciplinary working, our services failed to evidence a “Think Family” approach that we are committed to as a partnership. “Think Family” means that services should have considered the needs of the whole family and the impact services have on each member rather than working in “silos”.
- All professionals in contact with the family with the exception of the Wheelchair service, failed to escalate or act on the inadequate living environment and condition that Helen her family endured since June 2015, due to their complex needs, which presented an immediate health and safety and fire risk.
- Given Helen’s dissatisfaction with successive external care providers, the concerns did not get escalated to the Council’s Quality Team for an urgent review.
- There did not appear to be a single point for co-ordinating the care and acting on the concerns that Helen was raising and the multi-agency approach to care co-ordination did not work in this case.
- At no point did any service engage with Helen’s brother as part of their assessment and support planning and the family felt let down by this. The assessment and care co-ordination should have taken a broader “Think Family” approach. These should have included consideration of the home environment and her mothers’ needs as she was the main informal carer and her son’s care and parenting needs.
- Although Helen had been receiving extensive levels of support from the GP, hospital and community health services for a long time, she was not referred to the Council until early 2015.
- While Helen made a number of decisions in her care arrangements, all on the basis of presumed capacity, the Review questioned if professionals could have exercised a greater level of objective, professional curiosity into the circumstances in which she was exercising her capacity to make these complex decisions about levels of care she was willing to accept, given her extensive physical health needs and their psychological impact on her.
- Family were not aware, nor consulted about the fact that Helen had a “Do Not Attempt Resuscitation” (DNAR) decision recorded in her hospital notes.
- The discharge process and handover between the hospital Discharge Team and the Community Team did not work for Helen, resulting in her not getting the right level of care which was based on an earlier assessment and without any home visit.
- Communications within and between organisations appeared to have broken down and were overly reliant on emails, which was unsafe.
- Despite multiple concerns and complaints these do not appear to have been consistently escalated to a senior level for a resolution.
- The service contingency / business continuity plan for dealing severe staff shortages was not effective.

## Recommendations

The Review identified 17 interrelated learning points that are listed below under different areas of practice:

### Mental Capacity and Patient Choice

1. All staff should exercise professional curiosity and seek to understand a patient’s motivation to act against medical and therapeutic advice.
2. Medical staff should consider whether there is anything that is impacting on a patient’s thinking ability ie. SAT’s (blood oxygen) levels.
3. Seeking Helen’s consent to engage family members, and in particular Helen’s brother may have supported greater understanding of needs and acceptance of services.

## **Assessments**

4. Assessments need to be timely and current and therefore need to be refreshed if the onset and delivery of plans are delayed.
5. Home visits should be made as part of the assessment of adults with complex needs. Where this is not achievable attention must be paid to the effectiveness of questions to elicit the most accurate picture possible of what life will be like for the adult and any other family members.
6. The resulting plan should be reviewed within the required timescales.
7. All staff working within adult and children services should use a 'Think Family' approach.
8. Consideration should be given to how the adult and significant family members, particularly if they are to have a caring or support role, participate in such meetings.
9. A lead professional should be identified for adults identified as having complex needs.

## **Effectiveness of communication**

10. Email and electronic systems for routinely sharing information and allocating tasks should be used wisely. Such action should be supported by face to face or telephone contact particularly where a lack of response would be of concern.
11. Users of services should always be informed when a professional team or service cease working with them.

## **Effectiveness of Complaints Processes and Advocacy Services**

12. The inability to respond to service requests should be communicated to referrers.
13. The effectiveness of contingency plans, based on sound risk assessments should be reviewed when staff shortages lead to inability to allocate cases/tasks.
14. The process for managing complaints needs to identify a senior manager to take ownership, delegate the investigation and ensure an outcome. (It should be noted that these changes have been made). All staff and advocacy services should be encouraged to use escalation processes when unable to get a response or effect any change.

## **Systems Learning**

15. The organisation structures namely the MDT clusters around GP Practices and the role of the care-co-ordinators need to be firmly embedded to support the principles of effective multi-agency practice.
16. Staff working across adults and children services need to have sufficient awareness to use a 'Think Family' and systemic approach in order to both meet the needs of individuals and secure the most effective use of resource
17. The purpose and organisational structures, along with the operating systems and processes, of all agencies should be known by staff across partnership agencies. This would clarify expectations, support effective communication and, where necessary, inform appropriate escalation of concerns

## **Progress in service development and professional practice since 2015**

Following the completion of the SAR report, Luton Safeguarding Adults Board has taken time to engage all services and teams involved to understand the implications of the findings for their operations and practice. Staff from all agencies have been involved in two consultation events chaired by the independent author and other service specific learning events. All services were required to undertake key service improvements, in line with the recommendations. In preparation for the final SAR report, a further stocktake was undertaken involving all partner organisations to ascertain the durability and sustainability of those initial service improvements going forward. A summary of the main service improvements that have been progressed over the last two years are listed below:

- Multidisciplinary team working has now been well established and embedded as part of the GP clusters led locality approach. This had already been developed earlier to ensure that people living in their own homes, in receipt of adult health and social care continue to have their GP as the main point for co-ordinating their care to meet their additional needs.

- All complex discharges are discussed at multi-disciplinary discharge allocation and planning meeting to ensure that all relevant services are aware of their responsibilities.
- All services have reported that mental capacity consideration, assessment and overall practice have been stepped up, following training. The Safeguarding Board has established a multi-agency competency framework and requires all organisations to evidence the level of staff awareness and competence in relation to mental capacity practice: <http://area51wfs.co.uk/documents-2/>
- The Adult Social Care service has had a full and more stable complement of staff at all levels over the last 18 months, of which 26% are agency staff. An Initial Assessment Service has been established to ensure a prompt response to any new request. Both of these have helped improve the timeliness of assessments, service provision and reviews. Service performance in all respect is monitored monthly and team managers have access to individual staff performance in relation to service activities daily, in real time.
- Consistency of staff, while reducing reliance of agency, have also enabled the service to address complaints more proactively and helped reduce the number of complaints.
- The Council developed and embedded “Think Family” approach across all children and adults services and the Contact Centre by introducing Strengths Based model that focuses on including the whole family within a “Three Conversation” model.
- The Safeguarding Board has required all partner organisations to review their complaints procedures and ensure clarity of the escalation routes within each organisation.
- All services have emphasised to their staff teams the requirement to communicate to families and referrers if the service requested is not responded to or the response is delayed.
- Staff across organisations have also been made aware to follow up email communications with phone calls to ensure risk and support plans are communicated and instigated in a timely manner.
- The Discharge Team in the hospital now attend internal hospital discharge meetings and ward rounds in order to plan ahead and follow out complex discharges to the community in person. The Team has also established an operational protocol for completing home visits in such cases and all discharge planning and discussions now happen face to face rather via the electronic system.
- The Contact Centre has established an internal protocol to escalate any delay in response to a service request to senior managers.
- The Luton & Dunstable NHST Trust has now employed a full time palliative consultant to advise and support clinicians in decisions around palliative care. The Chief Medical Advisor has communicated with all medical staff reminding them of their decision making responsibility in relation to end of life care and DNAR.
- The Trust will be implementing a provision of information leaflets which can be left with a patient/relative following difficult conversations to ensure they have various methods of gaining information, which is currently in progress.
- Medical staff have been advised that there is training available on having ‘Difficult Conversations’ to increase confidence when these conversations are required. The Trust continues to encourage the use of Clinical Nurse Specialists to be involved (where appropriate) in these key conversations. Staff have been advised to ensure a clear record of conversations regarding DNAR are documented within the patients clinical record.

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