

Safeguarding Adult Review Mr. A1

Executive Summary

1.0 Background

- 1.1 Mr A1 a gentleman who lived with a severe learning disability and epilepsy died on 14th July 2013 in Croydon University Hospital.
- 1.2 A1 was born in 1953 a second son. His older brother and only sibling was born five years earlier. A1 lived at home until he was fifteen but when his mother could no longer cope he was admitted to St Lawrence's Hospital. He was much loved by his family. A1's brother visited him on a regular basis throughout A1's life.
- 1.3 A1 experienced an institutionalised lifestyle after spending many years living in a long stay hospital, St Lawrence's and then moving with some of the same staff to a care home, The Gables in 1990. The Gables was run and managed by the NHS Trust that eventually became Surrey and Borders Partnership NHS Trust. It was set up as part of the national movement to care for people with a learning disability in smaller community based homes rather than big institutions. The Gables was taken over by The Brandon Trust before a decision was taken a few years later for it to close. As part of the closure plan A1 was transferred to the Tree Tops, a residential home run by Totem Care on the 13th July 2013.
- 1.4 During the period of transition from The Gables to Tree Tops A1 became unwell. A1 was seen by a GP in the surgery and then again in an out of hours GP visit to The Gables. As a result of the out of hours assessment A1 was taken to Croydon University Hospital where he was given an abdominal x-ray, blood tests and catheterised, before being discharged home.
- 1.5 A1's condition deteriorated and by the time he moved to Tree Tops later that week staff at Tree Tops were very concerned. The day following his move a GP was called to Tree Tops. The GP arranged an emergency admission to hospital. When A1 was found to have a bowel obstruction that needed urgent surgery a best interests decision was made not to operate. A1 died in hospital the following day.
- 1.6 A safeguarding adult review (SAR) was carried out because this case met with the criteria outlined in the Care Act Statutory Guidance for carrying out a SAR. *'An adult at risk has died as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked together more effectively to protect the adult'*. (Care and Support Statutory Guidance, DH, 2014).

1.7 The SAR enabled professionals and organisations to work together to learn from this case. It has resulted in recommendations and actions plans to improve practice in safeguarding adults. The lessons learnt from this SAR will be disseminated to professionals and organisations working with vulnerable adults in Croydon.

2.0 Findings

2.1 A1 led an institutionalised life governed by changes in government policy and their local implementation, which focused on systems of care rather than individual people. Decisions were made about A1's life from the perspective of what worked best for the organisation, the NHS health trust where he was first admitted as a long stay patient, the care home providers Odyssey and the Brandon Trust and the joint commissioners of his care. Despite government policy changes intended to bring about personalised care, there is little evidence of this in the life experienced by A1.

2.2 When A1 was admitted to hospital on the 13th July and a best interests decision was made not to operate on his bowel, it was the final act in a series of events that started as early as 1992. This decision relied in part on his brother's perception around the deterioration in A1's quality of life since the loss of his sight.

2.3 From 1992 when A1 moved from St Lawrence's, a long stay hospital to The Gables, a care home his care was institutionalized to a significant extent. Care staff moved with A1 from the hospital to the care home meaning that practice did not change significantly. A1's environment changed but staff took with them deeply entrenched practices from years of working at St Lawrence's Hospital. There were improvements in A1's daily life as a result of this move, and his brother describes the first few years as a relatively good time in A1's life.

2.4 The lack of a personalised approach to care meant that A1's needs, wishes and preferences were not always 'listened' to or perceived. It was for example, not until a visiting optician diagnosed A1 as blind in his left eye and partially sighted in his right that staff were aware he had any visual disturbance.

2.5 A number of factors contributed to the perceived decline in A1's quality of life. These were:

- Loss of sight and the decision made by staff not to explore the option of surgical intervention
- Poorly managed epileptic seizures
- Lack of stimulation through daily activities and carer support
- The death of his friend/companion
- Lack of attention to physical health needs

- Poor communication between staff within and across organisations
- His friend had died

2.6 A1's quality of life is described by his brother as having declined as he became partially sighted and changes in the management of The Gables meant that there were less resources and opportunities available to him. It is questionable that had A1 been better understood and had his brother had confidence in A1's carers to provide a stimulating and caring home environment, whether the same decision would have been made at the end of his life.

2.7 Throughout this SAR there have been examples of poor communication between professionals and poor record keeping. When a person is unable to communicate their needs it is imperative that time is taken to understand what is important to that person, their care needs and personal preferences. Incomplete annual reviews, confusion over the dates of major life events, the missing Learning Disabilities Passport and a lack of clarity in exchanges between professionals have all had a negative impact on A1.

3.0 Conclusion

3.1 This section explains the rationale for each of the recommendations. The recommendations that follow are grouped together under ten headings, these are:

1. Commissioning and contracts
2. Annual health checks
3. Providing information to carers
4. Responsibilities of care staff in relation to medical symptoms
5. Mental capacity and best interests decision making
6. Learning disability passport
7. Specialist learning disability advice
8. Record keeping
9. Professional roles and responsibilities
10. The SAR Process

3.2 Social workers /care managers and commissioners have a responsibility towards individuals to ensure that they receive person centred care tailored to meet their needs and preferences. From 2008 when the first care assessment was carried out it was evident that A1 was experiencing an institutionalised lifestyle. It took until 2013 for action to be taken to change this situation. Although A1's brother approved of the home, there was no other choice offered.

3.3 Many of the staff at The Gables had worked with A1 for many years and followed him from the long stay hospital to the care home. The staff took with them institutionalised approaches to care. At the time of the initial

transition programme from the long stay hospital to community care homes an organisational development strategy should have been implemented. This should have included an investment in the development of staff to transform their delivery of care. Although this was more than twenty years ago, the importance of organisational development in ensuring that organisational change results in the desired outcomes for people, is still relevant today. Commissioners of health and social care are still working with care homes that have entrenched and institutionalised approaches to care. Commissioners must work with care providers to support the development of staff and improve the quality of care. When care does not improve they need to take timely action to ensure people receive the care and support they need.

- 3.4 A1 had a long history of epileptic seizures. Annual health checks included a review of medication for A1's epilepsy. However, there was a marked increase in the frequency and duration of A1's seizures but this was not followed up with a change in medication or discussion with care staff on what triggered a seizure and how they could be prevented or better managed.
- 3.5 NICE guidance on epilepsy recommends a single anti epileptic drug (monotherapy). A1's prescribed routine medication to control his epilepsy was for Sodium Valproate and Lamotrigine. NICE guidance recommends one of these drugs and only if it is unsuccessful the gradual introduction of the alternative medication and then the first to be tapered off. NICE guidance also recommends that the person's family are involved in discussions about their care if appropriate, and that the options available and side effects are explained to them. A1's brother was never invited to attend any of A1's annual health checks and was not involved in any discussions about the management of his epilepsy.
- 3.6 The staff at Tree Tops seemed more aware of A1's symptoms including constipation than staff at The Gables. On discussing A1's symptoms care home managers at both of the homes were concerned and unhappy with the GP's decision to change the laxative and manage the pain with paracetamol. The GP had not seen A1 but the care home managers had. When the GP made a clinical decision not to carry out a home visit on the 9th July, they did not challenge this decision or request another professional from the joint community learning disability team make an urgent assessment. It is possible that A1 had been experiencing pain and discomfort for some time but a lack of understanding about the symptoms of severe constipation/bowel obstruction meant that it went undetected. Care home staff and social care professionals need to have a basic understanding and awareness of physical health conditions and how symptoms can be detected in people who are unable to communicate. They need to be alert in identifying, recording and reporting such conditions effectively.

- 3.7 There were two occasions when a best interests decision was needed on A1's behalf. The first when he would not cooperate to have his eyes examined with a view to surgical intervention, and the second when a decision was needed on whether to operate on his bowel obstruction. On the first occasion the need for a mental capacity assessment and a best interests decision was completely overlooked. The ophthalmologist's report that he could not examine A1's eyes and so could not make a recommendation on whether he would benefit from surgery, should have been challenged. Alternative ways of examining A1's eyesight could have been explored. If the ophthalmologist felt that surgery could improve his vision then a best interests decision should again have been followed. There was no evidence in A1's records of a mental capacity assessment or best interests decision making process being carried out at any time prior to A1's admission to hospital on the 13th July. Nor is there any recorded evidence of supporting A1 to make such decisions or to understand the implications of his decision making.
- 3.8 On both of the occasions that A1 was admitted to Croydon University Hospital it was the weekend when the Learning Disability Liaison Nurse was not on duty. Although one care review states that A1 had a Learning Disability Passport and a Communication Passport these were not presented with him when he visited the hospital. A well informed Learning Disability Passport developed over time with the person can reflect a sense of the person. It can give an impression of the life that they live and what is important to them. It is also a way of helping staff to think about the person, to improve their understanding of what makes that person unique and what is important to them. All staff have a responsibility to be proactive in presenting and seeking out such passports.
- 3.9 The record keeping of all of the organisations that participated in this SAR would benefit from improvement. Actions have been picked up by individual organisations such as the Birdhurst Medical Practice and Totem Care. The recording as made available to this review of the best interests decision in hospital at the end of A1's life would have been enhanced by giving greater detail on all of the considerations taken into account. Across organisations important information was not recorded, verbal reports were inaccurate or incomplete. Good communication and record keeping is essential to achieving good quality care. There were different communication issues for each organisation which have been addressed in the IMR action plans. The Safeguarding Adults Board will seek assurance that key actions in this respect have been addressed within individual organisations.
- 3.10 The GP practice, care home and Joint Community Learning Disability Team (JCLDT) ¹do not always come together to review and plan care.

¹ Since writing this report it has come to light that until September 2013 both the social care learning disability team and the health community learning

Professional reports from the JCLDT did on occasions inform care home staff on how to improve A1's independence. However, professionals did not work together around A1 and his brother. An example of this is the increase in the frequency of seizures. The GP noted it in the annual health check but no action was taken. Professionals in the JCLDT such as the learning disability nurse and psychologist could have helped staff to understand changes in A1's behavior and discussed ways of preventing and managing his seizures.

- 3.11 Another example is the delayed response to A1's reduction in laxatives. Care home staff did not let the GP know that the prescription change was implemented several months later than requested. A1's response to the changed medication was therefore not monitored. JCLDT staff could have helped care staff to gain some insight into changes in A1's behavior as part of this process. The learning disability nurse could have explained to staff symptoms to be aware of in severe constipation/bowel obstruction such as the overflow of faeces as a result of impaction.
- 3.12 This review showed the need for co-ordination, communication and joined up working. The social worker under the professional code of practice is the voice of the vulnerable adult and therefore has a statutory role in the co-ordination of services around the person.
- 3.13 In times of austerity organisational change may gradually strip away essential care and support around the most vulnerable people. When this is done in stages by different management teams and organisations, the overall impact on individuals may not be apparent until it is too late. Understanding the impact of organisational change on safeguarding adults is the responsibility of all organisations.
- 3.14 There is always something to be learnt from the safeguarding adult review (SAR) process. This learning can help to improve future SARs. Overall this SAR was well managed with a committed SAR panel and chair. The engagement of the two care home providers with representatives on the SAR panel helped the learning from this SAR immensely. NHS England (London) also played an important role on the SAR panel and provided an important check and balance in oversight of the GP practices IMR. Inclusion of independent care providers and NHS England should always be considered when forming a SAR panel.
- 3.15 The SAR took place after a serious incident review had commenced and a Section 42 enquiry had been completed. The interface between these approaches should be understood by the safeguarding adult board and safeguarding leads to maximize learning and reduce duplication.

disability team were co-located but under separate management. They operated different policies and had different management arrangements

3.16 The SAR overview report writer and SAR panel Chair met with A1's brother at the start of the review. This meeting provided valuable information about A1 and his earlier life. As a result the scope of the SAR changed significantly. It would have been helpful if this meeting had taken place before the scope of the SAR was agreed.

3.17 The recommendations that follow draw on the multi agency learning from this review. Each of the organisations involved in providing care to A1 also has recommendations and actions from their own independent management review. The following recommendations are multi agency in nature and for the Croydon Safeguarding Adults Board to receive assurance on.

4.0 Recommendations

Recommendation One Commissioning and Contracts

4.1 There is a focus in commissioning and in contracts on key issues raised in this review including:

- Transition
- Person-centred care
- Learning Disability passports
- Mental Capacity Act, including best interests decision making and supported decision-making
- The necessary shift away from institutionalized practice.

4.2 Learning from this review in respect of these key issues will be:

- Integrated into new contracts and those that are renewed
- Integrated into a framework and guidance for contract monitoring so that contract monitoring staff are clear as to what to look for
- Integrated into service reviews

Recommendation Two Annual Health Check

4.3 Annual health checks are carried out in accordance with best practice and with reference to existing guidance, for example Royal College of GPs annual health check template/ checklist.

4.4 Health and social care commissioning in Croydon review the annual health check template to be used by GPs and LD community nurses in the light of available guidance and as part of this process ensure that NICE guidance is implemented in respect of epilepsy.

4.5 Learning Disability nurses and GPs have to carry out specific annual health checks. Commissioners in Croydon will audit this area of practice to make sure that these are being completed appropriately.

**Recommendation Three
Providing Information to Carers**

4.6 GP practices to work closely with family members/ care staff and those who know the person best in respect of individuals with a learning disability. This includes making available to those individuals specific information including, contact details/ numbers and detail of roles of relevant professionals, to make it easier for them to make contact with the right person when necessary.

**Recommendation Four
Responsibilities of Care Staff in Response to Medical Symptoms**

4.7 The responsibilities of care staff in managing the care of people with specific medical conditions, to be made clear through learning and development opportunities and in policies and procedures/guidance.

4.8 As set out in 8.26 non-medical/nursing staff must not accept responsibility for formal diagnosis or make assumptions. Rather they must listen, observe, record and report medical issues to appropriate medical or nursing professionals. Person-centred practice will support timely identification where something is wrong. If they are not satisfied with the response then detailed records of observations will support effective challenge of medical/nursing colleagues. Staff must persist in making such challenges. Escalation to senior managers may be necessary where challenge does not elicit a satisfactory response and safety is felt to be compromised.

4.9 An appropriate level of awareness of constipation and the factors that put individuals at greater risk, will support appropriate levels of vigilance with those at higher risk of constipation and identification of those in need of medical/nursing support and appropriate reporting to health colleagues.

This case review will be used to support learning and development in the Care Forum on these issues.

**Recommendation Five
Mental Capacity and Best Interests Decision Making**

4.10 To improve the practice of all professionals and care home staff in respect of the Mental Capacity Act in particular in respect of:

- Assessment and review of mental capacity
- Principle 2 of the Act on supported decision-making
- Best Interests decision making

4.11 The Board will seek assurance that awareness of the primary care MCA self-assessment tool developed by Croydon CCG is raised in the independent care sector and across Health providers.

4.12 Initially there will be a particular focus on the aspects of it relating to the above three areas of practice. Implementation of the tool and the associated MCA/DoLS framework amongst health and social care providers in respect of these three areas will be supported and monitored. The appropriate Safeguarding Adult Board subgroups will work together to produce an action plan to make this happen.

Recommendation Six Learning Disability Passport

4.13 To highlight the importance of the Learning Disability Passport for hospitals and care homes and more widely across all organisations including GPs and other health professional e.g dentists, opticians etc. To identify best practice including ensuring the passport conveys the severity of the learning disability including best method of communication and any significant co-morbidities, the need to keep these passports up to date and for all professionals and staff to be proactive in presenting and seeking out passports where a individual is admitted to a new service or setting.

Performance and quality assurance and commissioning processes to have a focus on this.

Recommendation Seven Specialist Learning Disability Advice

4.14 To review the role of the acute liaison service at CHS to ensure access to necessary expertise/advice outside of normal working hours. CHS will ensure that specialist advice for learning disabilities is available when the learning disability specialist nurse is unavailable. Development of learning disability champions on wards will take place.

Recommendation Eight Record Keeping

4.15 All organisations to pay particular attention to meticulous record keeping during periods of transition between care homes and services and the sharing of information between organisations during this critical period. This issue will be highlighted using this case review at the Care Forum and in other appropriate forums and training.

Recording in the context of Best Interests decisions / meetings will be underlined in training and monitored by commissioners.

Recommendation Nine Professional Roles and Responsibilities

- 4.16 There is clarity around which professional is coordinating at key points of change in a individual's life. The social worker/ Care manager ensures that the person has the care and support around them to meet their needs. They take a coordinating role particularly at significant points such as transition from one care provider to another.
- 4.17 The joint commissioner for learning disabilities, in reviewing arrangements for community learning disability services, ensures there is clarity on professional roles and responsibilities and how to access them and this information is widely disseminated. There is a particular focus on ensuring that the specialist knowledge of the Community Learning Disability nurse is understood and brought into play appropriately.
- 4.18 That the Safeguarding Adult Board seeks assurance that the level of integration of practice across health and social care learning disability services is effective in addressing the issues that arose in this case around communication, coordination and joined up practice. A paper will be brought to the Board outlining how the issues are addressed/to be addressed in an action plan.

Recommendation Ten SAR Process

- 4.19 NHS England to be invited consistently as a representative to future SAR panels.
- 4.20 Independent care providers to be invited to send a representative to a SAR panel when their organisation is involved in the SAR.
- 4.21 The SAR protocol to make clear the interface between serious incident reviews, Section 42 enquiries and SARs.
- 4.22 Meetings with relatives should ideally take place before agreeing the scope of a SAR.

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March 2016