BRIEFING ON SAFEGUARDING ADULT REVIEW FOLLOWING THE DEATH OF "Katherine"

Introduction

A Safeguarding Adults Review (SAR) was commissioned by Cambridgeshire Safeguarding Adults Board (SAB) following the death in 2016 of a woman in her mid-20s. Services had been involved with her since early adolescence, and the SAB suspected that neglect, and possibly abuse, had contributed to her death. Katherine was immobile and lived as a young person and adult in an unsanitary environment that caused significant physical deterioration for her and acute sensory discomfort for staff.

This Summary gives an overview of the case, the learning gained and the recommendations made.

In addition to preparing a chronology, the SAB held a two-day Learning Workshop with practitioners from all agencies that have had contact with Katherine. The purpose of the workshop was to assist practitioners, managers and commissioners who had either directly worked with Katherine or who worked in services where Katherine had received clinical care, to develop a wider understanding of the events that had led up to her death. This also had the benefit for the practitioners to talk through their experiences in a safe and learning environment.

The aim of the SAR as a whole was to learn the lessons from this case and improve the response of services to other people with complex needs by making recommendations for future service development.

Themes under consideration within the SAR

1. Assessments made of Katherine's capacity to make decisions about her treatment and the impact of her physical and emotional context on her capacity.
2. The relevance of legal options to address either a lack of capacity or a lack of freedom to make independent decisions.
3. Katherine's family:
   a) their ability to meet their responsibilities,
   b) the impact on treatment and safeguarding of the relationship between them and professionals,
   c) effective challenge by professionals to their behaviour that caused harm.
4. Katherine's engagement with the education system, including the extent of school contact and education otherwise than at school.
5. Multi-agency working and the coordination of treatment and services for a rare condition in a complex context.
6. The effectiveness of the safeguarding process.
7. Staff knowledge, and how they assessed and conceptualised the relevant factors in this case.
8. Medication management, including parental direction of medication application, reviews of medication usage, and issues with catheter administration.
9. Impact on professionals carrying out medical treatment and assessments in an unhygienic and insanitary home environment that challenged the senses of staff.

Background of Complex Regional Pain Syndrome (CRPS)

CRPS is a rare condition where symptoms begin after a physical injury. The subsequent development of pain and physical symptoms is highly disproportionate to the injury. Affected limbs can physically look like they have had significant nerve damage and may show significant and obvious physical signs. It can lead to multiple medical investigations, most of which return normal results. This pattern means that it can be a considerable time before this diagnosis is reached, though for Katherine in this case the diagnosis was relatively quick.

The symptoms expressed were not purely 'psychosomatic'. However, a history of more complex psychological issues tends to indicate the likely complexity and presentation of pain symptoms. The

psychological focus on physical symptoms and pain, and assuming the 'sick role', can act as maintenance factors which prevent recovery.

The nature of the pain can be extremely severe such that people experience pain in response to trivial sensory changes e.g. slight changes in temperature, or a gentle breeze. Treatment for CRPS involves a complex multi-disciplinary approach, which may commonly include desensitisation. Treatment received earlier in the course of the illness is more likely to be successful.

Brief History

Katherine died in her mid-20s. The coroner concluded that her death was caused by aspiration of gastric contents, intestinal obstruction and CRPS.

Katherine's known contact with services started in her final year of primary school, when she suffered an ankle injury, leading to her receiving extensive rehabilitation during a hospital admission. She made a good recovery from this injury, but then injured herself again. Unfortunately, the outcome from these injuries was the start of a lengthy cycle of increasing physical health problems, decreasing mobility and independence, and increasing reliance on her mother for provision of her emerging long-term care needs. Her diagnosis of CRPS reflected her extreme sensitivity to pain, which was to dominate her life.

The care she had at home was inadequate to the extent it could reflect both physical abuse and neglect. The conditions in the home were unsanitary, unhygienic and malodorous; for instance, with Katherine remaining on a urine soaked mattress for several years; long enough that it caused the metal bed frame to rust. Her bedroom, in which she was confined for the latter years of her life, was perpetually darkened and frequently over-heated. Ostensibly, these conditions were a response to Katherine's physical symptoms and pain (how could her mattress be changed or cleaned if she couldn't move; how could she open the curtains if that caused her pain?). However, Katherine's mother was also described by professionals as resisting attempts to engage in rehabilitation strategies that might have allowed Katherine to have developed a better quality of life.

Katherine's mother was reported to reinforce beliefs that Katherine was incapable and minimised future expectations of improvement. There was evidence that Katherine's mother 'directed' the care that Katherine received, and evidence that professionals did not robustly question this. On many occasions, even as an adult, professionals made adjustments to Katherine's care based only on a conversation with Katherine's mother. This was despite the recognition that when her mother was not present Katherine often spoke differently about her care and wishes for the future. There was also some evidence that Katherine was provided with unnecessary treatments by her mother, potentially with adverse consequences.

The case became seen as one of self-neglect, leading to the implication that Katherine was actively choosing to be neglected or to decline care. This missed the wider point that Katherine's real choices about her care were limited, and that she was fully dependent on her mother to support and implement any recommended intervention plan.

Medical care provided to Katherine predominantly focused on treating secondary symptoms and complications as a result of immobility and avoidance; Katherine experienced repeated infections, pressure sores, and for many years required use of a catheter.

The level of clinical attention given to dealing with the long-term maintenance of Katherine's CRPS, and particularly the psychological factors associated with this, was very limited. The first substantial opportunity to do so came after she was seen by a tertiary specialist pain service who made specific recommendations about the need for desensitisation to occur before any long-term progress could be made. Unfortunately, due to a combination of Katherine's ambivalence (partly maintained by her co-dependent relationship with her mother), lack of follow-up by professionals, and lack of appropriate local services to implement them these recommendations were never realised.

Opportunities to intervene in Katherine's decision-making on her behalf using legal options in the Mental Capacity Act (MCA), such as approaching the Court of Protection, or through the High Court's Inherent Jurisdiction, were considered first as early as 2010. Unfortunately, this recognition of the need to do so did not translate into any actual referral to a court. In the last few months of Katherine's life, more focused efforts were being made to gather appropriate information to make such a referral. Unfortunately, this was to be too late. Whilst regular multi-agency meetings were held recommendations from these meetings often consisted of further assessment or review rather than concrete steps to safeguard Katherine.

It is difficult to conclude whether Katherine's death was preventable, or whether her recovery trajectory would have been different in different circumstances.

Summary of Themes of Key Areas of Learning

1. CRPS is a highly complex condition requiring clinical treatment addressing both physical and psychological aspects. In Katherine's case, whilst clear recommendations for treatment were made by specialist services, local services did not or were not able to support a timely package which implemented these recommendations. Physical treatment provided to Katherine focused on treating the secondary symptoms of CRPS rather than addressing core maintaining factors

2. Agencies did not always work together effectively. Katherine's care was not coordinated by a health professional with specialist knowledge of CRPS. In the last few years of her life, the GP assumed much of this role but at a level that went above and beyond what is expected from a GP. Knowledge, awareness and understanding of CRPS was poor.

3. Katherine and her mother had a complex co-dependent relationship. This impacted on the way that services interacted with Katherine as an autonomous and independent individual. Professionals did not always make sufficient effort to determine Katherine's views in the absence of her mother.

4. There were deficits on the approach to assessment of Katherine's capacity. Specifically, in the assessment of mental capacity professionals depended disproportionately on the anticipated outcome of a formal assessment for an Autism Spectrum Condition.

5. In Katherine's childhood, a number of potential concerns that should have resulted in safeguarding interventions were missed. This lack of formal intervention during childhood was potentially a significant contributor to the escalation, development and maintenance of Katherine's problems as an adult. Further passage of time made her situation more entrenched and difficult to extricate herself from.

6. The potential and actual harm being experienced by Katherine as a result of her situation, her lack of control, the potential elements of co-dependency in her relationship with her mother, her lack of ability to engage in appropriate treatment and the fact that professionals reached a wide range of conclusions about Katherine's capacity should, taken together, have acted as a trigger of the need to urgently gain a court's view of the situation.

7. Legal advice was not sought early enough, and when sought was not followed through in a timely manner. The process for dealing with different legal advice obtained by different agencies was not clear.

Summary of Recommendations

TRAINING: There is a need to review training for relevant professionals working with:

a) CRPS,
b) Self-neglect. This training must include reflection and discussion of the extent to which a person is able to make a 'free' choice. Staff should ensure that a decision to decline care is not only given with full capacity, but also without undue influence. Staff working with complex

cases should be reminded that a decision to decline care at one point should not prevent persistence in repeating the offer of care at a later date.

c) The assessment of Mental Capacity and that capacity is assessed specific to a particular decision;
d) clarity about what the 'diagnostic test' may mean for complex conditions and the need to apply the MCA's tests on the balance of probabilities
e) emphasis on the individual responsibility of practitioners to carry out their own assessments of capacity before delivering or providing an intervention. Specialist assessments do not by themselves determine capacity, they can only inform judgements.

SERVICE PROVISION: There is need for a review of service provision in respect of:

a) people with CRPS or Chronic Pain generally, but particularly those who cannot travel to hospital,
b) people who have been assessed by specialist services where specific recommendations for treatment are made to local services,
c) people whose clinical presentation falls between boundaries of different service criteria

LEGAL PROCESSES: There is a need to review legal processes, including:

a) whether legal advice is sufficiently accessible to relevant clinicians.
b) how conflicting legal advice from different organisations is dealt with
c) how practitioners respond to situations where they believe that the recommended course of action is insufficiently rapid to deal with presenting risk

AGENCY RECOMMENDATIONS

Health providers should:

a) review processes for returning unused medication
b) consider whether minimum standards for frequency of medication review should be set
c) should review management support for staff reporting safeguarding concerns

Education services should

a) consider whether there is a minimum standard of review frequency if attendance drops below a certain level

Children's/Transition services should:

a) review current safeguarding processes in light of the numerous concerns in childhood which were not raised as safeguarding concerns
b) review processes for assessment of Mental Capacity at age 16.