



CASE SCENARIO - ALEX
Notification criteria
Complex health needs (child death).
Age
11 years
Theme
Neglect, complex health condition, domestic abuse, mental health.
Case Scenario
<p>Alex was diagnosed with cystic fibrosis (CF) as a one-year-old, and was an active and lively child who enjoyed school. Although he had a common form of the disease, complications set in early, and he wanted to be involved in all aspects of the care provided.</p> <p>Alex's hospital admissions increased after the age of six-years-old and there were 14 admissions, three of which were emergencies in the last four years of his life.</p> <p>Clinical care was led by the local children's hospital and the professionals involved included: physiotherapists, psychologists, respiratory medicine clinicians, endocrinologists, dieticians, diabetic nurses, specialist play and youth services workers and CF nurses. There were also numerous contacts with the GP, social workers and the school.</p> <p>A number of clinical specialists visited the home and school to work with school staff, and in the last year the school provided some elements of clinical care,</p>

including physiotherapy and diabetic care whilst Alex was in school.

Alex's parents, Jessica and Martin, had separated early in Alex's childhood and it was believed that domestic abuse and Martin's alcohol problems were a factor in the break up. Alex continued to have contact with Martin, arranged through the court, and a restraining order was in place due to harassment. During this period Alex was made a Child in Need (CIN) and information was shared from Multi-Agency Risk Assessment Conference (MARAC).

Children's Social Care provided financial support and supported day care for Alex's younger siblings, Bobbie and Stevie. It was assumed that Jessica was able to safeguard the children based on the fact that she reported all domestic violence incidents to the Police.

This meant that only his siblings were considered as children in need and Alex's case was closed, without any contact having been made with clinical staff.

Aiden, his step father, became a key figure in Alex's care and had considerable influence in decision making, engaging with staff in hospital and school, giving the impression that he had parental responsibility.

Clinical staff became concerned about Jessica and Aiden's lack of engagement and alertness to Alex's needs, and he was brought in very late for treatment on one occasion. On another occasion, Jessica had run out of steroids three days previously, and his medical regime had been disrupted due to prescriptions not being renewed.

The paediatrician was concerned about lack of weight gain and failure by Jessica and Aiden to prioritise his needs. The importance of sleep, structure for the day, getting Alex to appointments and paying attention to prescriptions and medication was explained to them.

The school initiated a Common Assessment Framework (CAF) meeting in an attempt to coordinate a family support plan and concerns were raised about whether physiotherapy was undertaken at home. This was essential for his care and later, physiotherapy was carried out at the school.

Martin had told police that Aiden had hit Alex and that he did not have physiotherapy at home. When the social worker made a home visit, Jessica and Aiden provided a plausible explanation and no further action was taken.

At the time Aiden was experiencing suicidal ideation and was finding the children's demands very difficult. He was being treated by the GP and Psychiatrist, and he also spoke of an unhappy childhood.

Concerns continued to mount and the Cystic Fibrosis consultant made a formal child protection referral. The Police also informed Children's Social Care of a call out for domestic abuse toward Jessica from Martin. He in turn, reported that Aiden had been arrested previously for assault towards a minor and that the children had told him that Aiden was 'beating up mummy'.

The referral resulted in an initial assessment by Children's Social Care and a Team Around the Family (TAF) meeting. Jessica fully cooperated with the plan and there were no observations in relation to problems of deficits in the care provided to

Alex.

Further incidents were reported and the children's behaviour at school deteriorated, there were repeated failures to bring Alex to appointments at the respiratory clinic and following a planned admission Jessica did not bring essential medications. The consultant explained that Alex's liver may be deteriorating and Jessica and Aiden responded that 'they were tired of getting bad news'. Jessica complained about 'treatment overload' and that she found Alex's care needs overwhelming and complex.

The pattern of non-compliance continued and the respiratory nurse instigated a CAF meeting with NHS colleagues due to worries about Alex and the family. Jessica and Aiden reported finding the treatment very difficult. They also said that Alex had behavioural issues, including low moods, scratching his arms, leaving marks and inducing vomiting when distressed. He was also not interacting with the family. Aiden asked if insulin could be stopped, as this was seen as a trigger for negative behaviour, it was explained that this was not possible.