

Case Summary

Ana was five years old at the time of her death. She lived with her parents, extended family and two siblings aged two and seven, the two-year-old also had additional needs. The family were of Romanian heritage and there was a significant communication and language barrier between parents and professionals. Ana had complex health needs throughout her life and had been seen frequently by community health services and the hospital. There were ongoing concerns about lack of engagement, and she frequently missed health appointments. Health staff were concerned that her parents did not understand the complexity of her health needs in terms of her medication, the need for specialist feeds and specialist care. At the time of her death Ana was open to the Disabled Children's and Young People Team.

Ana was admitted to hospital as an emergency in April 2019 with a lower respiratory tract infection. Despite treatment, her condition worsened, and she was transferred to ITU for intubation. When she was intubated, she went into cardiac arrest, CPR started but was not successful.

Summary of Learning

- The importance of cultural competence across agencies.
- The need to better support families with written and verbal information where there is a language or cultural barrier including health appointments, letters, reports and invitations to meetings. Interpreters should be used for all meetings.
- All agencies working with a child and family should ensure they feed into the plan.
- The risks to a child of not taking medication and not bringing them to appointments needs to be better explained to parents.
- Understanding and use of the escalation procedures and the SSP escalation policy.
- To ensure that there is always a single point of contact/lead worker for the case.
- To find ways to enable parents to help their children rather than being dependent on services to do this for them.
- Joined up planning and communication across agencies.
- For complex patients with chronic conditions who are admitted to hospital, decisions should be based on objective current information on clinical condition including parents' views, rather than assuming it is related to background chronic issues and what is felt normal for that child.