

## **Case Study**

Adam was 16 years old with complex health needs. Adam had severe cerebral palsy and had epilepsy and several other complex conditions. Adam died in December 2019. A SUDIC was held. The cause of death was Sudden Unexpected Death in Epilepsy (SUDEP). There had been concerns about Adam's care from Health professionals over several years. At the time of Adam's death, he was on a Child in Need plan. Adam's mother struggled with her mental health and could be hostile to health staff and resistant to changes in his medical care. This impacted on Adam's health and wellbeing. Adam was clearly loved by his by his parents and family. His mother took the lead for his healthcare. His father wasn't actively involved in his healthcare. Adam's mother felt that professionals weren't always listening to her and that her hostility and passion was misinterpreted by professionals.

## **Summary of Learning**

- Knowledge of when to use the MCA as a legal framework when working with 16- and 17year-olds with complex needs. An MCA assessment should have been completed as soon as Adam turned 16. This would have given a legal framework to support his needs.
- Adam's human rights needed to be prioritised.
- Early discussions and supervision with the Designated Doctor for Safeguarding Children should have been sought.
- An advocate should have been accessed for him as soon as medical teams became concerned that his health was at risk if his mother did not give consent to treatment.
- The need for awareness of the process for the escalation of cases within agencies and within the Suffolk Safeguarding Partnership.
- For Health and CYP practitioners to come together for some joint learning to explore how they could better support and prioritise the needs of children and young people with complex health needs and to include the use of legislation, MCA, human rights and safeguarding.
- Understanding of how childhood trauma impacts on parenting behaviour and capacity.
- Quality and analysis of chronologies.
- A need for the right Health professionals to attend Child Protection Conferences.
- Meeting the nutritional needs of children should form part of any Child Protection or Child in Need Plan.
- The implications of zero tolerance policies on a vulnerable child, family, adult.
- To ensure that practitioners involve and engage with both parents and that they seek the views of both parents.