

5.2 Charlie Gard & Alfie Evans

Charlie Gard

What can you tell me about the Charlie Gard case?

- **Who is he?**
Baby born in 2016 with mitochondrial disease (MDDS) which is genetic, incurable and fatal due to progressive brain damage
- **Why is this case important?**
Controversy as disagreement between medical team at GOSH and his parents in regards to if experimental treatment was in the best interests of the child
 - Parents wanted to travel to United States with Charlie to receive an experimental treatment
 - Medical teams wanted Charlie to remain in the UK and receive palliative care (withdrawal of life support) as the trauma of traveling and getting treatment with no proven benefit would cause unnecessary harm. In addition the suffering caused by artificial ventilation and suction was greater than the benefit of keeping him on these machines. His condition was fatal so their opinion that continuing life support was futile.
 - Parents appealed to Court of Appeal, Supreme Court and European Court of Human Rights
 - Court upheld the hospital's decision and life support was removed. He died 28th July 2017 at 11m of age

What ethical considerations does this case raise?

- **Autonomy - parents** wanted to make decisions based on Charlie's behalf - should parents have the right to consent to experimental treatment?

- **Non-maleficence** - being ventilated and sedated is a deeply unpleasant experience. While Charlie cannot display any signs of discomfort is it right to subject him to this for an extended period of time? Would Charlie want to be suffering - is the decision made the best with his interests in mind?
 - **Charlie's quality of life is very low** - At what point is it in the patient's best interest to remove life support and accept death may be a less-harmful alternative?
 - **Financial motivation** - the doctor offering experimental treatment admitted to having financial interests in the company - should this be allowed? Is this indirectly causing Charlie harm?

- **Beneficence** - highly linked to non-maleficence
 - **Could Charlie survive?** - parents argued that experimental treatment had the potential to benefit Charlie. Even though this was a small chance, it was a greater chance than leaving him on life-support or accepting palliative care. Should having only a small chance of success deem a human life untreatable?

- **Justice**
 - **Law** - what role does the law play? Who should be in charge of making these decisions when medical teams and parents disagree?
 - **Resource allocation** - is it just to allocate a ventilator, life-support and ICU bed ****to a child with no hope of recovery? Would these resources be better used on another child?

Charlie's Law

His parents have been working on "**Charlie's Law**" to create a better environment in hospitals for parents of very sick children. Working with medical professionals, medical ethicists and politicians.

- **Currently, judges assess "best interest" of child.** Currently, judges must assess only what is in the best interest of the child.

- **Should parent's choice play a bigger role?** But Chris Gard and Connie Yates want judges to ask instead if the parent's choice of treatment would cause significant harm to the child. If not, they think families should be allowed to try their option.
- **Or are these cases a rare exception?** Doctors and charities stress that these cases are the exception to the rule. There are at least 49,000 children and young people in the UK with illnesses that may cut their lives short.

Alfie Evans

Golden Tip: Similar case ethically to Charlie but slightly more recent so worth knowing the details

What can you tell me about the Alfie Evans case?

- Alfie Evans was born in 2016 who was the centre of a medical-legal case in 2018 regarding his care
- Was a patient at Alder Hey Children's Hospital (Liverpool) due to an undiagnosed **neurodegenerative disorder**
- His parents wanted to take Alfie to **Italy** for treatment however NHS medical teams believed Alfie too unwell to travel. The team assessed Alfie's condition to be futile due to extensive brain damage and recommended withdrawal of life support which was contested by his parents.
- The case went through the courts with his father sought private prosecution for "**conspiracy for murder**" against several staff members at Alder Hey
- **Ventilation** was removed on 23 April 2018 leading to Alfie's death on 28 April 2018

What influence did social media have in these cases (Charlie and alfie)?

- **Both cases had huge social media support.** Parents used social media to rally huge support around the world including Donald Trump and the Pope.
- **Unfavourable depiction of NHS doctors involved.** The medical teams were unable to speak out due to confidentiality so their arguments were largely unreported. This led to damaged to reputation of individual doctors, the hospitals and NHS as whole. Some doctors even received death threats. What effect does this have on public perception of the medical profession?
- **Cost-driven aspect of the NHS.** Some people (particular those abroad) argued that the decision to withdraw treatment/deny experimental treatment was cost-driven due to the NHS being state funded. How does the effect reputation of our health service?

Questions to Discuss

“Should patients be allowed to take hospitals to court?”

“Should parents be allowed to make decisions based on the “best interests” of a patient?”

MMI Station: Charlie Gard

Station Brief: The Charlie Gard case was a case that divided the public’s opinion and received extensive media coverage. Discuss what influence cases like this might have on the NHS as well as the medical profession.

Good Answer

- **Media coverage** – the facts presented in the media may lack factual accuracy, misleading the general public. The way the information is presented may also influence the people’s perception of the case and their opinion on it.
- **Transparency** – as medical professionals we have to be transparent about our decisions. During cases like this, other doctors working in similar environments

might find themselves under increased public scrutiny and stress even though they are not directly involved in the case.


- **Trust in the medical profession** – cases like this often result in decrease of trust in healthcare professionals and increased negative attitudes towards the staff.
- **Debate** – the complexity of the Charlie Gard case led to extensive discussions. ****Making doctors reconsider the principles by which decisions are made and the best course of action.

Bad Answer

- **Complexity of the case** – not acknowledging that the Charlie Gard's case was complicated dividing not only the public but also the healthcare professionals.
- **Best interests** – forgetting that the medical professionals are acting in the best interest of the child.
- **Being judgmental** – assuming that either the medical professionals or Charlie Gard's parents are automatically in the wrong.
- **Prominent figures** – even though, famous people such as the Pope have stated their opinion on the case, we cannot follow their views blindly and need to consider the expertise of the healthcare professionals.
- **Not acknowledging the effect of the case on attitudes towards health staff** – cases like this often result in increased negative attitudes towards staff, making them feel uncomfortable, stressed and endangered at work.

Additional Discussion Points

- What causes patient-doctor relationships to breakdown to the degree that legal action is required?
- How would you approach this situation?
- How would you prevent escalating to court involvement?
- Would the ethics of these cases be different if it were an adult involved?

 Written by official university examiner	Marking Criteria	Candidate makes no reference to this (0)	Candidate makes some reference to (1)	Candidate formulates an eloquent answer and provides good reasoning behind answer (2)
	Candidate introduces themselves.			
	Candidate gives a clear outline of what the case entailed.			
	Candidate states that the case was complicated.			
	Candidate explores different views on this case and discusses why they thought a specific course of action should have been undertaken.			
	Candidate acknowledges that cases like this have influence on both the NHS and the medical professionals.			
	Candidate says that media play an important role in such cases.			
	Candidate discusses the impact it might have on the confidence level in healthcare professionals.			
	Candidate mention and/or refers to acting in the best interests of the patient.			
	Candidate discusses the impact such cases have on the working conditions of doctors.			
	Candidate states a conclusion.			