

FAQs

1. Who is Alfie Evans?

Alfie was born in May 2016 and at the time of preparing this information is 22 months old. He is a patient at Alder Hey Children's Hospital. He was admitted to Alder Hey in December 2016 with a respiratory tract infection and seizures. Alfie was referred to our neurology team but his condition sadly deteriorated and he was admitted to our Critical Care Unit, where he has remained ever since.

2. What is his condition?

Alfie has a progressive neuro-degenerative disease associated with severe epilepsy.

Neuro-degenerative diseases are conditions that affect the connection of nerve cells and destroy the nerve tissue within the brain and spinal cord. This results in the decline or loss of brain function and motor skills. Those who are affected will gradually lose the ability to eat, smile, communicate, swallow and breathe without ventilator support.

Children with neuro-degenerative diseases are often born with no symptoms of these diseases and appear perfectly healthy. Sadly over time symptoms of the disease develop as vital nerve tissue is destroyed.

The vast majority of neuro-degenerative diseases are irreversible and have no treatment or cure. Most children who are affected with these conditions sadly have a reduced life expectancy.

Due to his epilepsy, Alfie also experiences numerous and regular seizures, particularly when exposed to light or touch.

3. Why can't doctors at Alder Hey diagnose what type of neuro-degenerative condition Alfie has?

Although extensive investigations have identified that Alfie has a neuro-degenerative disorder, it is exceptionally difficult to establish exactly what type of neuro-degenerative condition Alfie has. Many investigations have taken place along with genetic testing but we have not yet been able to confirm a specific condition. This is not unusual when diagnosing neuro-degenerative conditions.

4. What difference would it make for Alfie if his type of condition had been diagnosed?

All treatable neuro-degenerative conditions have been excluded in Alfie's case. Even if more testing is carried out it will make no difference to his treatment. This is agreed by all the experts. Since there is no benefit to Alfie in carrying out further testing, the team treating him do not think it is proper to subject him to additional tests.

5. Why have you 'given up' on Alfie?

We haven't 'given up' on Alfie. We have a team at Alder Hey of the very best neurologists who have made every effort to investigate and find a way to treat Alfie. Because Alder Hey is a specialist centre we have good links with other centres and at an early stage we obtained external opinions to try and inform his treatment. Our doctors also invited the family to suggest experts that they thought might assist. The family identified two independent experts and a team of three experts from a hospital in Rome. We cooperated fully with them all and they are unanimous in their agreement that Alfie's condition is irreversible and untreatable. In those circumstances we have to consider whether continuing to treat Alfie is in his best interests.

6. What treatment has he received?

Alfie has received the full support of Alder Hey's medical and nursing teams since being admitted. He has received numerous antibiotics for infections and a significant number of anti-epileptic medications to treat his seizures. Sadly he has remained unresponsive to treatment and his condition has rapidly declined. He continues to be given the appropriate support necessary on our specialist critical care unit. This includes supported ventilation to allow him to breathe and assisted feeding via a gastric tube.

7. Why can't you find a cure?

Sadly the vast majority of neuro-degenerative diseases are irreversible and have no treatment or cure. We have tried many different treatments to reduce his seizures without success and have explored whether there are any research trials Alfie might be eligible for but there were none.

8. Why do some images show Alfie responding and smiling?

Some of the images that have been circulated are old and may show Alfie either before his admission or in the early days of his admission. Of the more recent, images, children with these conditions can often look well and movements can still be seen, despite the destruction of brain and spinal cord tissue. However EEG (which means testing electrical activity from the surface of the brain) tests and imaging of his brain have confirmed the medical opinion that Alfie's movements or expressions e.g. opening an eye or appearing to smile are related to seizures or reflexes. Alfie has many seizures throughout the day and they are often brought on by touch or light exposure. This can sadly give an illusion that he is moving in response to stimulation.

When Alfie's case was first heard by the Court, the judge asked the family to produce all the pictures and video clips that they thought demonstrated purposeful movement. Those were reviewed (and re-reviewed) very carefully by the doctors and the judge. The conclusion was that given the extensive damage in Alfie's brain, any movements were reflexes and could not be the result of conscious or purposeful movement.

9. Why has his case been referred to Court?

Alder Hey is a specialist children's hospital which means we treat children with very complex and critical conditions. Sadly some of these children are unable to recover from their illness. Medical professionals at Alder Hey will meet to discuss the most appropriate care plan going forward, focusing on the comfort, wellbeing and best interests of the child concerned. The

Trust will also seek advice from specialist clinicians at other trusts as we did in Alfie's case. The care plan is always discussed with the family and we aim to reach agreement between clinicians and parents about the most appropriate care. We also seek input from the families concerned and this may extend to include review by experts instructed by the family.

We will always seek to reach agreement with parents of the child concerned. However in Alfie's case we are in the very unusual situation where agreement has not been reached following many discussions and mediation meetings. The clinical team believe that continued active treatment is futile and not in Alfie's best interests. In those circumstances we refer the case to the Family Division of the High Court where a Judge with great experience of these cases has considered all the relevant evidence and determined whether active treatment is in Alfie's best interests.

10. Why isn't the decision on his care left to the parents?

Children of Alfie's age cannot speak for themselves and cannot decide whether or not they should continue to have medical treatment. Usually a parent will take that decision for them. Where there is a disagreement about a child's treatment and the court intervenes, the Judge focuses on the child's best interests. The views of the parents will be very important in reaching a decision on 'best interests' but they do not give the parent an absolute right. Decisions relating to medical treatment in children have been taken on this basis for many years. In Alfie's case, his parents tried to challenge that approach in their appeal from the decision of Mr Justice Hayden. That appeal was dismissed by the Court of Appeal. The parents then tried to appeal to the Supreme Court but this application was also rejected.

11. Have you consulted other experts/opinions?

Yes. Alfie's condition and treatment have been discussed in multi-disciplinary team meetings at Alder Hey which has included specialist neurologists and radiologists. Alfie's case has also been discussed with various other clinicians at Alder Hey.

At the beginning of last year, Alder Hey approached experts at Manchester Children's Hospital and later on at Great Ormond Street Hospital. We have also liaised with other specialist centres regarding Alfie's treatment.

Alfie's parents have also asked for further opinions from hospitals in Stoke, Rome and Germany. We have welcomed this and arranged for these clinicians to visit and investigate Alfie's case.

As we indicate above, all the experts are agreed that Alfie's condition is untreatable and that there is no benefit to him of further investigation. All have agreed with our team at Alder Hey that in the tragic circumstances of Alfie's case there is sadly no hope of recovery.

12. Why won't you let him to go to Rome for treatment?

Three clinicians from Rome visited Alfie in September 2017, discussed his case with the team here and reviewed his notes. Following their detailed assessment, they agreed with the conclusions of the Alder Hey team that Alfie's condition was effectively untreatable. Significantly, they noted that given Alfie's epilepsy, there was a risk of him suffering further

brain injury if he was transferred abroad. They have offered to take him to their hospital but agree there is nothing they can do to help or improve his condition. Further invasive procedures have been suggested but these will not help him recover.

Our clinicians are professionally obliged to always consider what is in a patient's best interest. We do not believe that it is in Alfie's best interests to go to Rome and be subjected to invasive and procedures when there is no hope of recovery or a cure.

13. What is the standard and quality of care received by Alfie at Alder Hey?

Alfie has been cared for at Alder Hey since December 2016 by our team of highly qualified, dedicated and caring professionals. We endeavour at all times to ensure that the care all of our patients receive is of the highest standards.

In his recent judgement at the High Court, Mr Justice Hayden noted that Alder Hey Children's Hospital is a recognised centre of excellence for brain conditions and neurosciences and specialises in investigating and treating children with the most complex neurological disorders.

He added that that the facilities at Alder Hey, can be said to be world-class and he paid tribute to the diligent professionalism of some truly remarkable doctors and the warm compassionate energy of the nurses whose concern and compassion is almost tangible.

Our priority is to continue providing Alfie with the best care possible.

14. What happens now?

Unless Alfie's parents pursue a further appeal to the European Court of Human Rights, Mr Justice Hayden has ruled that continued ventilation is not in Alfie's best interests so the plan would be to arrange for its withdrawal. This will allow Alfie to pass away peacefully. This process will not be rushed and we will meet with his family to openly discuss how and where this should happen before drawing up a palliative care plan. Alder Hey has a wealth of experience in providing the highest standards of end of life care and we will ensure that Alfie does not suffer any pain or distress. Our clinicians and our bereavement team will also provide his parents with any support they need for as long as they wish.

We ask that the privacy of Alfie and his parents are fully respected at this time.

Links to judgments below:

<https://www.judiciary.gov.uk/wp-content/uploads/2018/02/alder-hey-v-evans.pdf>

<https://www.supremecourt.uk/news/permission-to-appeal-determination-in-the-matter-of-alfie-evans.html>