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Frequently asked questions about the Charlie Gard court case

Great Ormond Street Hospital has been contacted by many people who share our concern for Charlie, and his parents, and ask for information about the very difficult decisions surrounding Charlie's care.

As this is a very complex case, we have provided the information below in the form of an FAQ to help those contacting us to understand how Charlie is being cared for at Great Ormond Street Hospital.

Full details about Charlie's treatment remains confidential and the content of the FAQs is based solely on information that is already in the public domain as a result of the court process. No new information is included out of respect for Charlie and his family.

We hope that those contacting the hospital respect the confidentiality of Charlie and his family and so appreciate that we cannot respond to individual requests for information.

If you would like to read the full details of the legal decisions, please refer to the following sources:

[High Court decision](#) on the British and Irish Legal Information Institute website.

[Court of Appeal decision](#) on the British and Irish Legal Information Institute website.

[Supreme Court decision](#) available from the UK Supreme Court's You Tube channel.

Who is Charlie Gard?

Charlie Gard is a GOSH patient who is currently in our intensive care unit.

What is his condition?

Charlie's condition is exceptionally rare. He suffers from an inherited mitochondrial disease called infantile onset encephalomyopathic mitochondrial DNA depletion syndrome, referred to generally as "MDDS". Charlie suffers specifically from the RRM2B mutation of MDDS.¹

Charlie's brain, muscle and ability to breathe are all severely affected. In addition, Charlie has congenital deafness and a severe epilepsy disorder. Charlie's heart, liver and kidneys are also affected.¹

Charlie has severe progressive muscle weakness and cannot move his arms or legs or breathe unaided.¹

Charlie's eyelids cannot stay open and his eyes point in different directions because of muscular weakness. Charlie's retina would struggle to develop and his brainwaves suggest that he is not going to be able to lay down normal visual patterns that should be learned at an early age. Eyesight is not something you're born with, it develops over time.²

Why is there no treatment available at GOSH?

There is no cure for Charlie's condition which is terminal. GOSH explored various treatment options, including nucleoside therapy, the experimental treatment that one hospital in the US has agreed to offer now that the parents have the funds to cover the cost of such treatment. GOSH concluded that the experimental treatment, which is not designed to be curative, would not improve Charlie's quality of life.

How did GOSH come to this decision about his treatment?

GOSH's clinicians had to balance whether this experimental treatment was in his best interests or not.

One of the factors that influenced this decision was that Charlie's brain was shown to be extensively damaged at a cellular level. The clinician in the US who is offering the treatment agrees that the experimental treatment will not reverse the brain damage that has already occurred.

The entire highly experienced UK team, all those who provided second opinions and the consultant instructed by the parents all agreed that further treatment would be futile – meaning it would be pointless or of no effective benefit.¹

Why is there a court process?

When parents do not agree about a child's future treatment, it is standard legal process to ask the courts to make a decision. This is what happened in Charlie's case.

What is the legal process?

GOSH applied to the High Court for judges to decide whether withdrawal of ventilation and providing palliative care instead of experimental treatment was in Charlie's best interests.¹

The High Court ruled this was in Charlie's best interests on 11 April 2017.

Charlie's parents then appealed to the Court of Appeal.

The Court of Appeal ruled on 25 May 2017 that the High Court decision still stood and that it would be in Charlie's best interests to be allowed to die with dignity.

The parents have applied to appeal to the Supreme Court. The Supreme Court ruled on 8 June 2017 that the Court of Appeal and the High Court decision still stood and that it would be in Charlie's best interests to be allowed to die with dignity.

Why has the legal process lasted so long?

Legal processes take time and the courts are doing their best to expedite the process. All parties are adhering to the legal process.

The parents have raised money for the treatment, why can't it take place?

The High Court and the Court of Appeal have ruled it is not in Charlie's best interests to receive the experimental treatment in the US.

Even if the treatment does not work for Charlie, won't it help other children in the future?

The courts base their decisions for treatment on what is in Charlie's best interests, not what is in the best interests of medical science.¹

What about the parental rights?

Although Charlie's parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child's best interests.¹

For more details on parental rights during medical treatment, please access the [British Medical Association website](#).

What can you tell us about Charlie's care?

While we cannot discuss confidential information about Charlie's care, any child who is as unwell as Charlie will receive round the clock care from a team of highly experienced and specialised nurses, doctors and other health professionals.

Care for children who are ventilated, as Charlie is, might include suctioning to take out extra fluid when a child is not able to cough for themselves, having their vital signs constantly monitored, regularly turning a child to try to prevent pressure sores if they are unable to move independently and trying to ensure a child's skin is in optimal condition even though they are constantly connected to a ventilator.

In his High Court ruling, 11 April 2017, Mr Justice Francis said: "Charlie has been served by the most experienced and sophisticated team that our excellent hospitals can offer."¹

In the Court of Appeal ruling, 25 May 2017, Lady Justice King said: "Charlie and his parents have the benefit of being treated at not only the centre of excellence that is Great Ormond Street Hospital, but of his having been under the care of a world-leading expert on mitochondrial disorders. I would wish to acknowledge the skill and care given to Charlie by the doctors and nurses at Great Ormond Street."²

If the court rules in favour of a withdrawal of treatment order will the life support machine be turned off straight away?

At Great Ormond Street Hospital, our priority in situations like this is to work closely with the family to discuss the next steps in their child's care. In Charlie's case we have been discussing for many months, how the withdrawal of treatment may work. There would be no rush for any action to be taken immediately. Discussions and planning in these situations usually take some days – based on the experience of our clinical teams.

References

1. The judgment delivered by Mr Justice Francis in the High Court of Justice Family Division on Tuesday 11 April 2017.
2. The judgment delivered by Lord Justice McFarlane, Lady Justice King and Lord Justice Sales in the Court of the Appeal on Thursday 25 May 2017.

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