

THE LATEST THINKING

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What Would Charlie Want?

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There's so much that's disturbing about Charlie Gard's story — the government having jurisdiction over Charlie's medical care, the anguish of his parents and what's really best for the baby.

Ailing infant Charlie Gard has become an international feel-good cause, and his parents have raised close to \$2 million to send him to the U.S. for experimental treatment for his rare genetic disorder — but the British courts have denied permission.

There's so much that's disturbing about this story — the government having jurisdiction over Charlie's medical care, the anguish of his parents and what's really best for the baby.

According to his doctors, Charlie's organs are failing, he has no hearing and eyesight, and irreversible and catastrophic brain damage. He cannot eat without a tube or breathe without a respirator. His muscles lack the cell production to grow.

When the medical staff at Great Ormond Street Hospital wanted to turn off his artificial life-support, the Gards created a website for him, and the money came pouring in. Who isn't touched by the images of the beautiful 11-month-old baby, stricken with an incurable genetic disease, tubed-up and fighting for his life? Even President Trump and the Pope weighed in.

But wait. Let's scrub our kneejerk sentimentality and put on our rational thinking caps. Is it smart — does it actually do good, real good — to throw money at a problem that only a miracle from heaven could solve?

People on all sides of this story are calling moral foul. "Of course a parent needs to explore all options — get a heart, you grey-faced government death panelists!" Or, "It's repugnant that parents choose to prolong their baby's suffering." And, "Waste of money... should be given to babies with brighter prognoses."

So who should decide Charlie's fate? In his case, the British government isn't initially paying for it (although \$2 million dollars go fast when it comes to medical needs). One day the Gards will return to Britain, and we can assume that if the baby survives, he will have chronic lifelong medical needs that will depend on the British National Healthcare System.

But at present, unbelievably generous people have volunteered to foot the bill — it feels good to give, and hey, miracles do sometimes happen, cures are found. It's Orwellian for the government to forbid it. Grief-stricken parents might not make the most objective decisions, but the decision is theirs, not some government officials.

The Gards lost their first two court hearings, the judges deciding that more treatment would only cause further suffering. The case will again be heard before the European Court of Human Rights on July 25, when judges will examine details of the proposed treatment, and decide whether Charlie must be left to die in a British hospital, or given to his parents to do as they wish.

If the Gards win in court, they're in for a lifetime, however short or long, of hospitals with no guarantee of a quality of life. It must be hard for them to see through the groundswell of public goodwill and emotion, and into the future — but it's possible that winning their case means that they, including Charlie, lose in the end.



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