

Charlie Gard and Life

by: Rabbi Jeremy Rosen

You may have read about the battle in London over the final days of life for a baby called Charlie Gard. He was born with a form of mitochondrial DNA depletion syndrome that causes increasing muscle weakness and brain damage. There is no known cure. The doctors in Great Ormond Street Hospital in London diagnosed this fatal condition. They put the baby on life support. His situation continued to deteriorate rapidly. There was no brain activity and most of the muscles of his body had stopped functioning.

The doctors of Great Ormond Street concluded that nothing could be done and asked the parents' permission to turn it off. The parents refused. Great Ormond Street turned to the courts, which agreed with them. Despite appeals from around the world and much reconsideration, the court decision stood. The parents gave up the fight and agreed to have the baby moved into a hospice. The ventilator was turned off, and he died.

It was a tragic story, made so much worse by what has become the norm nowadays—an unseemly ideologically- and politically-motivated battle between agitators who got involved in the affair as a matter of principle, arguing for or against intervention. With the usual tools of “debate” we are now used to on university campuses: violence, threats, and public displays of fake blood, angst, and crocodile tears.

The pro-life lobby argued against turning off the ventilator under any circumstances. Others argued that only the parents could decide and against any legal intervention that removed parental rights, on principle. Counterarguments were that courts had ultimate responsibility and some argued that medical opinion should be the final arbiter. The hospital itself and its staff came under threats of violence.

The very public battle raised interesting moral issues. Can we morally terminate a life clearly destined for extinction before it reaches its natural conclusion? Who should decide? The courts? Religion? The parents?

In theory, Jewish law states quite unequivocally that one may do nothing to hasten a person's death. No rabbi worthy of the name would ever sanction hastening a death in principle. But any serious medical issue should be presented to a rabbinic authority (assuming there is time and opportunity). Every situation is different. Jewish law is predicated on offering solutions to specific problems rather than generalized ex cathedra statements of morality. So, can we ever hasten a death?

Like most official positions, there are mitigating circumstances. One may take various measures to reduce pain, even if indirectly that hastens a person's death. One tinkers with feeding systems. One may withhold new intervention, *Shev VeAl Tasseh*, “sit back and not take action” (as opposed to “get up and do something”). One may not turn off a switch on a ventilator

directly. But there are ways of achieving this end indirectly. Even so, the Jewish position is that one consults both medical and spiritual experts.

All the rabbis I know of who are experts in this field consult medical experts or send you to see a medical expert they trust. Yet often one will get different conclusions or interpretations. There are still ongoing debates in Jewish law over how one determines brain death, over when one may harvest organs, and over when and how one can remove someone from a ventilator. Some rabbis are permissive. Others are restrictive. But at least as an individual one can choose which rabbi to follow. You may remember that Arik Sharon was kept alive on a ventilator for eight years.

But who has the final say? In most countries, the state intervenes against the wishes of parents, if the courts deem the parents are withholding treatment or demanding irrational treatment. Classic cases are where Christian Scientists, who generally do not believe in medical intervention, refuse to allow treatment for their children. The courts consider themselves responsible for the ultimate protection of the child or an elderly or incapacitated person. This seems to me to be perfectly reasonable and necessary.

With all kinds of new medical possibilities opening, we could be faced with a huge problem of health systems being crippled by unreasonable demands to prolong life, let alone try to cure the incurable. Someone will have to make decisions. But who?

In Judaism we believe that "the law of the land is the law" unless it directly contradicts our religious fundamentals. The ultimate authority is God's, in other words our constitution, *halacha*. Observant Jews defer to the Jewish law above all else. Yet they too can be coerced by the Law of the Land. Usually rabbinic opinions try to avoid reaching that stage.

Judaism recognizes medical and civil values and takes them into consideration. But ultimately it is the *halacha* that has the final say. The medical and the legal should have their say. But so too should the spiritual. In a secular country the law will be the final arbiter. In a religious country it will be its religious authorities. I am only in favor of religious authority having the final say where the vast and overwhelming majority of citizens want this. Otherwise I prefer leaving it to the secular legal system. This is a purely personal view, because although I do not completely trust either and have seen the ugly side of both, the secular democratic system allows for greater openness and exposure.

Some people might say that I am advocating a theocracy. Indeed, if that is what people want, good luck to them. But there are different kinds of theocracies. What I advocate is a combination that balances—which is, I agree, easier to say in theory than execute in practice. But then no political system is perfect or without flaws.

Nevertheless, I consider combining the secular and the religious to be an excellent solution, because it requires a compromise between two different moral positions. To consider only law or only religion is dangerous because

it gives too much power to the humans on whichever side they stand. Humans are fallible and most human bureaucratic or governmental institutions are prone to error, incompetence, and dogma. To try to reconcile civil, medical, and spiritual values requires sensitivity and openness and provides a check and a balance. This is the very reason I am so committed to and proud to follow Torah: because this is its position on a matter such as this.

But as I would not like to impose religion on anyone, and as England is nowadays no longer a country with one religion (despite the Queen being the head of the Church of England), I believe the courts dealt with this issue with sensitivity, understanding, and integrity. I deplored the circus. I admired the conclusion.