


Forcible “euthanasia”: the ECtHR’s Charlie Gard Decision

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When – first in the Netherlands, and later in other countries such as Belgium and Luxembourg – laws were adopted to legalize euthanasia, the selling argument was that this was a decisive step forward in order to ensure everyone’s self-determination. The ECtHR’s recent decision in the case of Gard and Others v. the United Kingdom reveals quite a different reality.

The decision is lengthy and contains a lot of medical terminology, but the underlying facts are simple: a child suffers from a medical condition that the treating doctors qualify as terminal, and for which no recognized treatment exists. Not only for argument’s sake, but also because we really have no reason to believe otherwise, let us assume that that assessment is correct and has been made by experts *lege artis*. Yet the child’s parents place their desperate last hope in an experimental treatment, which has so far never been tested on human beings (and, to believe what is noted in the ECtHR Decision, not even on animals). That treatment would have to be carried out, either in the UK or the US, by a leading researcher and expert on this kind of therapy, who has declared his willingness to administer it even though he qualifies the chances of success as “theoretical” and, on another occasion, as “unlikely”.

Given the unlikelihood of success, the treating doctors do not lend their support to the new therapy being applied to the child, but instead have filed an application to the competent Court, requesting authorization for life-sustaining treatment (artificial ventilation) to be withdrawn, so that the child might die. The Court granted that authorization. The desperate parents, who (quite bizarrely) were not considered to be the child’s natural representatives in this case, appealed this decision and fought their way up to the UK Supreme Court, but lost in all instances. They then filed an application with the ECtHR, but again remained unsuccessful. The outcome of all these decisions is that all involved law courts, as well as the guardian who had been appointed by the UK Court to supplant the parents in representing the child, are in agreement that it is “in the best interest” of their child not to undergo any further treatment, but to be euthanized.

It appears that in all these decisions a remarkable amount of words is spent on proving a point that nobody has seriously disputed: that “the best interest of the child” should be the paramount consideration. But the parents have never argued that *their own* interests should prevail over those of the child: this is simply a non-issue. The notion of a “conflict of interest” (see § 67 of the ECtHR’s decision) is apparently misconstrued. It is absurd, and indeed defamatory, to insinuate that the parents in this case are pursuing anything else but what they believe to be in their child’s best interest. They may hold a different view on what this interest comprises, but there is no reason to question their good faith.

Also, there is no dispute on who possesses the better medical expertise. Nobody doubts that the doctors know better than the parents which therapies are, or are not, likely to help. Besides, there appears to be an understanding shared by everyone involved, including the parents, that the chances for the experimental (“nucleoside”) therapy to save the child’s life are, at best, very faint. But the dispute in this case is not about *which* therapy should be applied – it is about whether *any* therapy should be applied at all. Even more than that, it is about whether the life-sustaining treatment, which is itself *not* a therapy but simple care-giving, should be ended.

In short, this is in fact a euthanasia case.

Euthanasia is not a therapy. It is a *lifestyle choice*. As such, it is contingent on certain moral and philosophical convictions that some people may have, but which others don’t share. Is it a choice that a law court, or a court-appointed guardian, are allowed to impose on someone?

Supporters of liberal euthanasia laws have always pitched euthanasia as a supreme form of self-determination. But this pre-supposes that euthanasia will take place only if the person to be euthanized has expressed a clear and determinate wish to die. It must be a will that is unambiguously expressed by the person itself, not by anyone else. But what has happened in the Charlie Gard case? Very obviously, the child itself has not expressed any will – it is unable to do so, given that it is less than one year old. His parents, if this is of any relevance, have expressed their opposition.

The ECtHR’s landmark case on euthanasia until now was Lambert and Others v. France, which is quoted extensively in the Charlie Gard Decision. The Lambert case was about a man who had fallen into a coma following a motorcycle accident, and whose close relatives were quarrelling whether the life-sustaining treatment should be continued or not. Like in the Gard case, the ECtHR decided that it shouldn’t. But the difference is that in the Lambert case there were claims according which Vincent Lambert, prior to his accident, had allegedly stated that in the (then hypothetical) case of him becoming permanently dependent on intensive care he would prefer to die rather than being kept alive. The Lambert Decision remains highly controversial until today, given that the alleged statements of Vincent Lambert, which some critics doubted he had ever made, provided only a very weak argument for assuming that he actually wanted to be killed. But at least there were allegations, however spurious, that such a statement had been made, which offered some kind of justification, if only a weak one, for claiming that euthanasia was what he wanted.

In the Gard case, by contrast, there is absolutely no claim at all that Charlie, who at the time of writing this is not yet one year old, has ever expressed such a desire. His parents, whom conventional wisdom would suppose to be best placed to speak for him, are clearly opposed to him being euthanized. What is happening here is that the doctors at the hospital, the guardian who has been appointed by the law court, and finally the judges in the UK and at the ECtHR make their decisions on the basis of pure presumptions, substituting their own moral and philosophical opinions for those allegedly held by Charlie: it is in his best interest to be left to die rather than undergo a therapy that in all likelihood will remain unsuccessful. (An interesting question here: how can it be inferred that an 11-months-old child has opinions that differ from those held by the persons whose natural right

is to educate him? Is he already so emancipated from them? Is it implied that their education is in fact a dangerous manipulation which would cause him to have different opinions than he “naturally” would have?)

But although the ECtHR Decision makes abundant, if not outright repetitive, references to what it alleges to be “the child’s best interest”, it never comes out quite clearly who made determination and on which basis. No doubt, the experimental therapy that Charlie’s parents want for their child will very likely remain ineffective – there is no reason to doubt this. Yet conventional wisdom would hold that a therapy with a very low likelihood of success is *ceteris paribus* still better than certain death. The ECtHR Decision gives no hint as to why that should be different in Charlie’s case.

One is thus left to guess. Perhaps the doctors or the guardian believe that the therapy would cause immense pain and suffering to Charlie, and consider that this certain suffering outweighs his uncertain chances of being healed? Or perhaps what they really fear is *not* that the therapy would be unsuccessful, but that it would be *successful* – with the result that Charlie, due to the damage he has already suffered, would be condemned to live a (potentially long) life as a handicapped person in a wheelchair? It never comes out quite clearly. But what does come out clearly even for someone who does not have the same medical expertise as the doctors who believe that Charlie should be euthanized is this value judgment: *freedom from suffering is valued higher than life*.

This is a very debatable world view, and certainly one that is not shared by everyone. On the basis of which authority can the UK judiciary, or the ECtHR, impose it on Charlie Gard and his parents?

What is striking about this case is that not even an argument is provided. Instead, the ECtHR reduces the “child’s best interest” to a merely formal requirement: the UK court has appointed an expert to be Charlie’s guardian, and he has decided that Charlie, if he could be asked, would want to die. So everything is in best order from a legal point of view, and no further questions must be asked.

This is not only callous, but it is outright absurd. At the hands of the ECtHR, the seemingly benevolent principle of “the child’s best interest” is turned into a weapon *against* the child and its parents. It is used to prevent a final desperate effort to save the child’s life from being made. It is used to dispossess the parents of their natural rights as parents: those who must be expected to love the child more than anyone else are replaced by a bureaucrat who, even in the best of cases, cannot be expected to have any particular feelings for the child. Indeed, he is praised precisely for this (cf., *inter alia*, § 65): he has no personal attachment to the child, so he can decide more “objectively”.

With all this I am not saying that in situations such as the one at hand parents are always right, and that States should never intervene to defend a child’s best interest against its own parents. I remember a case in Austria, more than twenty years ago, in which a 9-year-old girl was suffering from kidney cancer, and was treated with chemotherapy. Yet the parents had lost all confidence in classical medicine; they demanded that therapy to be stopped and instead wanted their daughter to be treated by a spurious “miracle healer” without any medical credentials. The public authorities thus suspended their parental rights

and appointed a guardian, who decided that the girl should continue to be treated *lege artis* with chemotherapy. The whole incident then developed into a week-long saga, with the parents kidnapping the daughter from the hospital and bringing her to Spain, from where the family finally was extradited. No doubt the Austrian authorities' intervention in that case was legitimate, and indeed life-saving. But the situation was different, indeed the very opposite, of the Charlie Gard case: in the Austrian case the dispute was not on *whether* the girl should receive therapy, but on *which* therapy it should receive – and there was no doubt that this was a question the doctors were better placed to answer than the parents; in the Charlie Gard case the question was whether Charlie should be given a therapy *or be killed*.

I also know of another case, one that took place in my own wider family: a young girl was diagnosed with an aggressive form of leukaemia, which at that time (in the early 1970s) was considered incurable. Yet her father had heard of a new therapy that had been developed somewhere abroad (whether in France or the UK I don't recall), and managed to get his daughter accepted in the test program. And lo and behold, she was healed: she is still alive today, leading a completely normal life. Every new therapy is, at some stage, new and "experimental". With every new therapy, someone will be the first to whom it is applied, or who is healed by it. This is what they call progress.