

# The lesson of little Charlie Gard's\*

## La lección del pequeño Charlie Gard\*

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### Abstract

We are facing the legal controversy of Charlie Gard, a 10-month-old baby, affected by mitochondrial deterioration syndrome, to which three courts have ruled to be sedated and deprived of mechanical ventilation as well as feeding and hydration. It has been considered illegitimate any action that would keep him alive, even at the request of the parents to apply an experimental protocol of nucleoside therapies that could save him but that has been considered futile. It seems a case of thanatological cruelty where the authorities seem to be in a hurry to end their suffering, silencing the parents' hopes. It is not the therapy or the disease that we want to discuss, how much when and how to end the life of a helpless human being. Some principles are exposed: Incurability

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should not be confused with intractability. Everyone has the right to be served. Right that resides in its human dignity. Feeding and hydration should not be considered as therapy. The patient is never an anonymous individual object of therapies. There is no justification for a form of passive euthanasia in favor of which the English courts and the European Court of Human Rights have opted.

*Key words:* Right to life, euthanasia, court, suffering, thanatological cruelty.

Nowadays we have attended, mourners and powerless, to the latest evolutions and to the fatal circumstances which have accompanied the little Charlie Gard controversy, the English neonate of 10 months affected by a genetic syndrome of mitochondrial decay, that causes the progressive muscular weakening, and that doesn't leave hope of life for the little boy. Based on the various judicial statutes issued by three different English courts, of various degrees, and lastly by the same European Court of Man's Rights, he should be accompanied to death by means of his separation of the machine which ensures him the mechanical ventilation and of the contextual interruption of the artificial nutrition and hydration, not before having provided him with a deep sedation state.

In the different degrees of judgement, the English Courts have ratified that the general decay process of Charlie's clinical conditions and, with that the progressive and unstoppable decay of the organ's functionality which preside over the vital functions, first of all the breathing, lead to believe that any decision related to ulterior actions which would extend such life conditions, would be judged illegal, given the fact that it is not assumed in the mayor effective interest of the little boy, but rather directed to increase, throughout the time and in the intensity, the pain and suffering of the same. What is more surprising is that the very same idea of submitting Charlie to an experimental protocol of nucleoside thera-

pies which are being prepared in the United States, a proposal presented in several occasions by the parents, has been considered unachievable, more over “futile”, by the medical advisors questioned by the judges, before the demand, this one impelling, as to perform an immediate and final execution to the unanimous dispositions of the sentences so far pronounced.

*It seems like everything has concurred, in the last six months, to perform a kind of “thanatological cruelty” regarding little Charlie, a competition, by judges and physicians, directed to ensure the fastest possible solution to the case, silencing every stat-up of hope by the parents, as well as every flash of light on the success possibility of a therapy that, even though experimented only on mice and for a diverse illnesses typology of the one suffering by the English neonate, according to what was said by the same professor responsible for the ongoing research in the USA, AD HOC questioned (regarding specifically to this case) by Charlie’s parents, could have at least theoretically, provide benefits to this health general conditions. It is true that after being requested the authorization to proceed the therapy’s experimentation in Charlie, in January 2017, the epileptogenic encephalopathy which he is suffering, created through the repeatedly crises, ulterior and severe brain damages; nevertheless, what is here to be discussed is more related, and again, to the possibility to decide when and how to put an end to the life of a defenseless human being. Necessarily it seems proper to consider some critical points that arise from the full assessment of this controversy, in many ways paradigmatically, that are valuable therefore for this case, but also as elements to be considered in questions of the end of life.*

1. Incurability, can never be confused with intractability: for example, a person affected by an illness which is, considering today’s state and advancement of medicine, incurable, ironically or in more scientific terms paradoxically, the subject who has more than any other one, the right to ask and even demand and get help, assistance and treatment for such illness, and be provided with a proper and continuous attention and dedication; it is a fundamental axis in a therapy’s ethics, which has as main recipients, precisely those people who are in a state of vulnerability, and/or of mem-

ber of a minority, and/or of a greater weakness. Therefore, Charlie represents paradigmatically an example of somebody who has the right to be helped and assisted in every stage of his illness, due to his state of need, linked to the age and to the illness he is suffering. The human face of medicine is shown precisely in the clinical practice of “taking care of somebody” of the suffering person’s life and of a patient.

2. The right to become continuously the object, or even better to become the subject of attention and caring by relatives and other people, is based on the dignity of a human person or a human being, which even if the subject is a neonate, an ill and suffering person, never ceases to possess or have it. It is the substantial being of man and his potentials, what gives support and a basis for this dignity, not only his concrete and accidental situations. This is what it is understood as “purely ontological dignity of a person”, a status that completely foregoes the possibility of actively using the exquisitely own faculties and powers of a rational being, being enough or suffice to say that the same must exist as actual potentials and eventually performable by the rational being himself.

3. The artificial feeding-hydration by means of a nasal-gastric tube, cannot be considered in any case as a therapy. It is not such a thing, due to the artificiality of the means used to provide it, given also that, feeding milk to a neonate with the help of a bottle, is not considered a therapy. Also, processes through which these foods are produced, are the reason for not considering them as a therapy, given that milk powder is not considered a therapy, because its production process is a long industrial and completely automatic one. It is not a therapy, due to the fact that the parenteral sac is prescribed by a specialist physician, in view of that the same artificial milk is subordinated to the medical prescription of a pediatrician. Water and food do not become medical instruments just because they are fed artificially; therefore, interrupting them is not the same as suspending a therapy, but let somebody die of hunger

and thirst, simply because he is not capable to feed himself autonomously.

4. The main idea which gives support to an informed consent, has to do with the principle by which, the patient is never an anonymous individual to whom specific technical knowledge is applied to, but a conscious and responsible subject, that must be called upon to share the tuning and reshaping of all that it is necessary, in order to promote an increase in the well-being and good health, and eventually reaching a proper treatment and a healing objective. All this implies that, there is a need for the subject to be included in the decision making processes about his situation, in a dialog relationship which would prevent for him to find himself under such a condition as to have to suffer in a passive manner, decisions and elections made by somebody else. Little Charlie's controversy proves the opposite, how through time, a dynamic of total disagreement was generated between the medical team decisions and the parents' will, as apparently shown by the last prohibition imposed on them, which was the one that of being able to take their child back home, to see their own child die (even though we do not know if this possibility was really feasible from the clinical point of view).

5. The prohibition to submit Charlie to an experimental treatment, in no case could be justified appealing to the suffering state in which he is currently living. It is very possible that the experimental therapy would not have given the expected medical results, but it is equally true that Charlie's sufferings demand an integral and systematic palliative approach which hypothetically could have been able to accompany the experimentation itself. The preclusion of access to such experimentation has been motivated both in the name of the useless prognosis of the same, an aspect whose risk is included in the absolute uncertainty parameters and ordinarily distinctive of any experimental therapy which would have even been able to anticipate death, as in the name of the need to save the subject those ulterior sufferings, that by prolonging the life in such

conditions could have generated: on one hand the perspective even remote to keep Charlie alive, or even extend the time of his life by means of an experimental therapy, it seems that it had been considered a priori as a non-feasible perspective, in the name of the need to prevent him of ulterior sufferings, and this not through proper palliative solutions, but by means of an induced death.

6. The principle of the highest interest for the child, that International Letters put at the center of the guardianship procedures of the same, and that the English Courts themselves have assumed as a cardinal justification of their decisions, we believe that it hardly implies or even legitimates a form of passive euthanasia such as the one that it has been decided to practice on little Charlie. We believe that his best interest has to go in the direction to ensure the most possible dignified assistance, by means of a timely analgesic strategy that would allow to have the pain under control, if truly should result as not possible to go through the path to access the experimental protocol already been tested in the United States. This is exactly as much Charlie's parents have continuously requested up to this day.

7. The European Court of Human Rights has unbelievably excluded completely all the aspects of the content enlisted up to here, and even it seems that it has gone further, assuming a position merely of procedure, in the name of the principle of appreciation margin. If on one hand has pointed out, in the sentence issued dated on the last June 28, that the decisions of the English National Courts in no way integrated a violation of articles 2, 6, and 8 of European Convention of Human Rights, therefore confirming the formal correction of their actions. On the other hand it has considered it should not enter in the controversy about the suspension of the artificial feeding –hydration– breathing in the name of that sovereign autonomy of the member States which would authorize them to regulate at will the issues regarding the most ethically complicated aspects, such as the case of the practicing or not the passive euthanasia in a neonate. This regardless of the fact

that the combination set by articles 2 and 8 of the Convention would establish clearly the prohibition to deliberately prevent anyone of the fundamental good of life.

8. It does not exist anybody who does not see behind every aspect of this controversy, a trick, even though it has not been mentioned, an idea of efficiency in the health resources management, which induces to dispose of the same in a way that cannot avoid to generate a crawling disposal culture. In a society that considers an increasing phenomenon of illness medicalization, and together with an increasing number of elderly people, with entourage of degenerative illnesses that they carry with them, plus the shortage of resources every time more scarce, committed to the sanitary system by national governments, feeds a treasury culture which makes of effectiveness at all costs, its main, vital and exclusive objective, highly increasing as a consequence, the number of those who, marginalized due to their lives expectancy, which are identified as waste to be eliminated, if it is possible.

9. It is even more disturbing, the lightness with which the quality of life paradigm is accepted, or else that cultural model which is inclined to recognize the no dignity of some human existences, totally identified and mistaken with the pathology from of which they are porters, or with the sufferings they accompany. Never, at no time an ill person can be reduced to his pathology, because every human being does not stop, a single instant, and regardless of his illness and/or suffering condition, of being a highly immense universe of feelings, which deserves at all times the fast attention of whom unconditionally wants his wellbeing, and does not give up himself to consider his existence as a B type series just due to the fact of being homeless, in a profound need, or in suffering. An existence to which a favor could be done to, by ending it definitely. All this is worth that much more in the case of those who cannot, or cannot anymore, to express all that what they are and what they feel, as in the case of little Charlie.

10. In the transparency of the schizophrenic stands implicated by these new cultural paradigms, it can be detected the ambivalence of who, in vindicating the freedom of total and indiscriminate access to euthanasia, based exclusively on the predominance of individual autonomy, denies at the same time that decisional autonomy in other cases, as the one which is examined, where it is considered that the physicians are the only legitimate people to decide, without including the parents. The ambivalence of who thinks that it is fair for the physicians to be in a condition to allow the parents a time margin, in order to let them go through the separation process from their child, allowing this way to remain in his company, and doesn't think in how much the surrogated mothers would need it when they are deprived of their fetuses, immediately after birth, to support wishes of the "the womb placers". The ambivalence of who thinks in guardian the dignity of the life of a subject, denying him life itself, which is a paramount basis for not only men's dignity, but of every other recognition that could be made in his favor. The ambivalence of who debates for judicial, institutional, and international defense of the weakest people's rights, under a frame of democratic regulations, and then accepts in good spirits seeing euthanasia legalized or justified, practiced even in the most little ones, in the weakest, in the most needed.