

END OF LIFE

The unlearned lesson of the British child who refuses to die

LIFE AND BIOETHICS

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"This is a highly unusual case and raises some challenging questions for the court which must be addressed openly and objectively." This is British judge Nigel David Poole speaking and the case he is referring to is that of NR, a disabled 4-year-old boy whose

life support was switched off by order of the same judge last April but who survived and is even improving.

It is a case that immediately brings to mind all the previous cases - from **Charlie Gard** to **Indi Gregory**, **Alfie Evans**, **Archie Battersbee** and others - in which doctors and judges intervened against the wishes of the families to hasten the death of their children. And it lends itself to some considerations.

NR (his name is protected by court order) was born without eyes and is probably deaf, but in 2023 he suffered a brain infection which caused two heart attacks: since then he lived with the assistance of life support machines, that is at least until April. Predictably, the doctors, in this case, at King's College Hospital decided to stop the baby's life support, while the parents - Catholics and who had already refused an abortion when an ultrasound had revealed their son's severe disability - objected; and were promptly marched into court. Judge Poole, after visiting the child in hospital, decided that it is in his best interest to die, because "the difficulties he faces far far outweigh the benefits", he said. The parents' request to transfer their son to Italy, to be treated at the Bambin Gesù hospital in Rome is obviously rejected too.

However, surprisingly, NR refuses to die despite no longer being on a ventilator; moreover inexplicably his condition slowly improves: he no longer needs a catheter, he is fed with a tube, he breathes normally. So Judge Poole, at the parents' request, returned to visit the baby boy, took note of the situation, and on 23 September withdrew his earlier ruling, ordering the doctors to provide all the care necessary, and recognising that this case demonstrates that "medicine is the science of uncertainty and the art of probability". On the other hand, Poole, who had previously had life support removed in other similar cases, defended his judgment from April by stating that he "was satisfied it had been justified on the evidence provided".

It's probable that the possible answers to the "challenging questions" posed by the NR case will probably be limited in the future to applying greater caution before deciding for the removal of life supports and perhaps more clinical tests to establish the real chances of recovery.

The fact is that Judge Poole, in justifying his April ruling confirms two fundamental criteria that are deeply flawed.

The first concerns the significance of a parent's love for a child (but applies to love in general). In the April judgement, the judge recognised the parents' great love for

NR saying, "As parents of a severely disabled child they are aware that they will not be able to offer him the same amount of experiences they could give a child without his disabilities, but they can give him unconditional love and the certainty that they will always be with him. (...) NR continues to benefit from the unconditional love and support of his parents. Their devotion to him is truly touching". But in upholding the doctors' decision, confirmed by his own examination, Judge Poole says that love, however uplifting, is an obstacle to lucidly judging what is best for the loved one. As if to say that love is an obstacle to reason and the only way to judge objectively is through indifference to the subject being judged. This is an absurd claim: indifference, the absence of feeling or involvement actually prevents one from knowing the other person and thus being able to judge what is good for them.

Otherwise it would be like saying, for example, that two married people are unable to understand each other and recognise what is good for each other merely because they are in love or affectively involved. Of course one can also have an affective relationship experienced in a distorted manner, but the solution cannot be indifference, it is inhuman. As inhuman as the April sentence.

There is a second criterion stated by Judge Poole that cannot be agreed to. To judge what is "in the best interest" he in fact uses the yardstick of "quality of life". NR's reconsideration is in the face of evidence that his condition has improved and that the doctors' opinion was therefore hasty and inaccurate. But he remains of the opinion that faced with the prospect of a progressive worsening of his condition, it is still right to impose death, precisely because such a life is no longer worth living.

This, however, is precisely the criterion that NR's parents fought against, as well as those of Alfie, Charlie, Archie and the others: they had no illusions about their children's recovery, nor did they count on a long life expectancy, but asked that death come naturally, that God decide and not a doctor or a judge. They asked that the unconditional and natural parental love that nurtured their children until the last moment should not be artificially and brutally interrupted. And this is exactly the "best interest" that the Power of this world does not want to recognise.