Charles Gard and others v. the United Kingdom

Application no. 39793/17 Charles GARD and Others against the United Kingdom

Country: United Kingdom
Region:
Year: 2017
Court: The European Court of Human Rights European Court of Human Rights
Health Topics: Child and adolescent health, Chronic and noncommunicable diseases, Health care and health services, Health information, Hospitals, Informed consent, Medicines
Human Rights: Right to due process/fair trial, Right to family life, Right to liberty and security of person, Right to life

Facts

The second and the third applicants in this case were the parents of the first applicant (CG) who was born healthy in 2016 but encountered severe health problems thereafter, for which he remained hospitalized by the time the case was brought before the European Court of Human Rights (the ECHR). CG suffered from a rare disease named infantile onset encephalomyopathic mitochondrial DNA depletion syndrome ("MDDS") that was caused by mutations in a gene called RRM2B. [Para 4] CGâ€™s brain, muscles and breathing functions were severely affected while his heart, liver and kidneys were mildly affected.

The parents consulted Dr. I who was a professor of Neurology in America about a therapy named â€˜Nucleoside Treatmentâ€™ which he confirmed as not having been tried on mice or humans but could be beneficial to CG's condition. As a result of his epilepsy, CG experienced an episode of brain seizures between January 9 and 27, 2017. At this time, the treating clinicians informed CGâ€™s parents that he was suffering from severe epileptic encephalopathy and that the nucleoside treatment they planned to administer to him in the United Kingdom would be have no benefit but would make him suffer more.Â An expert team in Barcelona considered CGâ€™s case and reached at the same conclusion as his treating clinicians. [Para 6]

In February 2017, the hospital requested the High Court to order the withdrawal of artificial ventilation and provision of palliative care which it claimed was lawful and in the best interest of CG. The parents opposed the request stating that nucleoside treatment was planned to be provided by Dr. I. The Judge heard witnesses and the opinion of experts, including Dr. Iâ€™s, regarding CGâ€™s state of health and the potential benefits/successes of the nucleoside treatment. The Judge then found that the treatment hadnâ€™t been tried on humans or animals with the RRM2B mutation and from Dr. Iâ€™s explanation that it was very unlikely to improve CGâ€™s brain damage apart from improving his weakness, increasing upper strength, and reducing the time he spent on ventilators. Dr. I also confirmed that the structural damage to CGâ€™s brain couldnâ€™t be reversed with the treatment.

The parents didnâ€™t believe that CGâ€™s brain damage was as severe as how the experts explained and stated that CG had no sleep/wake cycle. CGâ€™s guardian appointed by the Court argued that it wasnâ€™t in the best interest of CG to travel to America for an experimental treatment that had no real chance of improving his conditions. The judge recognized that the Court had an overriding control in making an independent and objective judgment in the best medical, emotional, and other welfare interests of CG although the power to give consent for treatment rested with his parents. The judge found a consensus from all expert opinions that â€œnucleoside treatment would be futile, that is to say pointless and of no effective benefit.â€• [Para 21] The judge concluded that the results of nucleoside treatment werenâ€™t predictable with a risk that it might cause CG a pain; the parents had to accept the fact that it was in CGâ€™s best interest to be left to die peacefully than to be put through additional suffering. [Para 23]

The parents appealed before the Court of Appeal arguing that the judge erred when he based his decision only on the â€˜best interestâ€™ test. They argued that their preferred therapy was to be overridden when the therap caused a significant harm to their child. Because the hospital requested the prevention of a therapy that it hadnâ€™t intended to provide, it acted beyond its authority and the lower Court had no jurisdiction to rule over this decision.Â The parents also argued that the â€˜best interestâ€™ test allowed unreasonable interference with th parental rights under Article 8 of the European Convention on Human Rights (the Convention). The Court of Appeal dismissed the appeal stating that the â€˜best interestâ€™ of the child must prevail and be applied even where the parents believed in another alternative. The Court held that even applying the â€˜significant harmâ€™ tes

it was clear that CGâ€™s travel to America for the nucleoside treatment would cause him a prolonged pain and suffering. The hospital hadnâ€™t acted out of its scope of powers as the issue of nucleoside treatment had been raised by the parents. The Court of Appeal also noted that the lower Courtâ€™s decision had evaluated CGâ€™s be interest and the advantages of the treatment.

The applicants appealed before the Supreme Court on the same grounds under Article 8 of the Convention. The Supreme Court held that the welfare of the child was the most important consideration under domestic law, the Convention, the European Court of Human Rights (the ECHR) case law and the Child Rights Convention that the childâ€™s interests were to prevail in case of conflicting interests. The Supreme Court also reiterated the decision of the Court of Appeals as regards the application of the â€˜significant harmâ€™ test.

The parents lodged their complaints before the ECHR on their own and CGâ€™s behalf under Articles 2 (the right to life), and 5 (right to liberty and security) of the Convention. They stated that the hospital prevented CG from receiving a life saving treatment in violation of their positive obligation under Article 2 while the High Courtâ€™s judgment had interfered with CGâ€™s liberty in violation of Article 5. The applicants also complained under Article 6 of the Convention that the Court of Appeal failed to hear witnesses when it decided against their parental choices.

Decision and Reasoning

The ECHR first examined whether the parents had standing to bring the claim on behalf of CG and noted from its precedents that two criteria applied in deciding whether a third party could bring a claim on behalf of a victim or a vulnerable person. The criteria are the existence of a risk that this victim would be denied of an effective protection of his/her rights and there is no conflict of interests between the victim and the person complaining on his/her behalf. [Para. 62]

The ECHR noted that the risk of CG being deprived of effective protection had been reduced as he was represented by a court-appointed guardian who had been actively involved in domestic proceedings; it further noted that this guardian could also represent CG in an application before it. Â The ECHR noted that CG there was a conflict of interest between CG and his parents as domestic courts have found his parentsâ€™ claims were not in CGâ€™s best interest although CG hadnâ€™t expressed his views or lived his life independently. The ECHR decided to examine the complaint of CGâ€™s parents under Articles 2 and 5 of the Convention as they are brought on their own behalf and not on CGâ€™s.

As regards the complaint on denial of access to experimental therapy for CG who at the time was terminally ill, the ECHR held that Article 2 couldnâ€™t be interpreted as requiring States to place a special regulation for mandating access to unapproved medical products for terminally ill patients. Regarding the administration and withdrawal of CGâ€™s treatment, the ECHR held that this issue was not to be argued over as the domestic regulatory framework was in compliance with Article 2 of the Convention. The ECHR noted that CGâ€™s views were expressed by his guardian in domestic court proceedings and opinions of all professionals involved in CGâ€™s case had been heard including one given by the expert of the parentsâ€™ choice. Â It further noted that th hospital had responsibly approached domestic courts for an appropriate decision on the next step. The ECHR then held that the complaint was manifestly ill-founded.

As regards the complaints under Article 5 on lack of procedural safeguards against detention, the ECHR noted that the complaint was related to the existence of domestic law and remedy which had been ascertained when it examined the parentsâ€™ complaint under Article 2 of the Convention; the ECHR thus concluded that this complaint was also manifestly ill-founded. Â The parentsâ€™ complaint under Article 6 regarding arbitrary interference in their private and family life was related to their complaint under Article 8. Because it found the interference on the parentsâ€™ private and family life was in accordance with the domestic regulatory framework that was in compliance with the Convention, the ECHR found the it to be in accordance with the law and aimed at â€œat protecting the â€œhealth or moralsâ€• and the â€œrights and freedomsâ€• of a mi applicantâ€•, in accordance with Article 8 (2) of the Convention. [Para. 113]

The ECHR found that domestic courts had thoroughly and diligently examined the case, all concerned people and experts were heard, arguments of the parties were properly examined and reasonable decisions were made at each of the three levels of courts. The ECHR thus found the complaint to be manifestly ill-founded as none of the decisions in domestic courts amounted to arbitrary or disproportionate interference.

The ECHR held the application inadmissible.

Decision Excerpts

â€œConcerning access to experimental treatment, or treatment which is not usually authorised, the Court has previously considered that the positive obligations under Article 2 may include the duty to put in place an appropriate legal framework, for instance regulations compelling hospitals to adopt appropriate measures for the protection of their patientsâ€™ lives..... This caused the Court to note in relation to its finding of no violation of Article 2 in that case, where the applicants sought experimental cancer treatment at a private clinic in Germany, that Bulgaria had in place a regulatory system adopted in line with the requirements the relevant European Directives governing access to unauthorised medicinal products in cases where conventional forms of medical treatment appeared insufficient.â€• [Para. 77]

â€œThe Court notes that no consensus exists among the Council of Europe member States in favour of permitting the withdrawal of artificial life-sustaining treatment, although the majority of States appear to allow it.Â Â While the detailed arrangements governing the withdrawal of treatment vary from one country to another, there is nevertheless consensus as to the paramount importance of the patientâ€™s wishes in the decision-making process, however those wishes are expressed.â€• [Para. 83]
â€œAccordingly, the Court considers that in this sphere concerning the end of life, as in that concerning the beginning of life, States must be afforded a margin of appreciation, not just as to whether or not to permit the withdrawal of artificial life-sustaining treatment and the detailed arrangements governing such withdrawal, but also as regards the means of striking a balance between the protection of patientsâ€™ right to life and the protection of their right to respect for their private life and their personal autonomyâ€¦.... Â However, this margin of appreciation is not unlimitedâ€¦â€¦ and the Court reserves the power to review whether or not the State has complied with its obligations under Article 2â€¦â€• [Para. 84]
â€œAs to the scope of Article 8 in this context, the Court has previously considered that a decision to impose treatment on a child contrary to the objections of the parent gave rise to an interference with the childâ€™s right to respect for his private life, and in particular his right to physical integrityâ€¦â€¦â€• [Para. 105]