

ZOOM IN

The question:

Dignity and end-of-life issues. Some open questions in light of the European Court of Human Rights' recent case-law

Introduced by Flavia Zorzi Giustiniani

As a consequence of the unrelenting advances in medical sciences, end-of-life situations are raising, more and more frequently, sensitive moral and ethical issues to which existing legal frameworks are often unable to offer clear-cut solutions. Limiting the scope of analysis to the European continent, there is still nowadays no common consensus among ECHR's States parties on how to approach such issues. Nonetheless, in the last few years there have been some relevant changes, at both the normative and jurisprudential level, in various European countries which, it could be argued reveal a tendency to give priority to individual autonomy over other considerations. Three prominent examples of the said changes are worth mentioning.

One example concerns Italy, which on 14 December 2017, after a long and troubled legislative process, adopted a statute allowing its citizens to make a biological testament (Law no 219/2017). The law allows adults to decide, in concordance with their doctors, their end-of-life medical care, including the terms under which they can refuse treatment and have access to deep and continuous sedation. It also allows nationals to write living wills whereby they may refuse medical treatment, artificial nutrition and hydration.

Another important change has occurred in Germany, where on 2 March 2017 the Federal Administrative Court, reversing the lower courts' decision, ruled that, in extreme situations, the State cannot deny an incurably ill, mentally sane, adult access to medication that would allow a painless and dignified death. Although the Act on Narcotic Drugs prohibits the acquisition of drugs for the purpose of committing suicide, the Federal Administrative Court held, in the case at hand, that the general right of personality as provided under Article 2.1 of the Basic Law read in conjunction with its Article 1 (which includes the right to self-

determination) must prevail. The judgement concerns the well-known *Koch* case, relating to a German citizen whose wife had unsuccessfully applied to the Federal Institute for Drugs and Medical Devices for permission to acquire a lethal dose of medication that would have enabled her to end her life at home. After Mrs Koch's death, which occurred in Switzerland with the assistance of the Dignitas association, and after unsuccessful appeals by her husband, the case reached the ECtHR. The Court in May 2013 finally held that there had been a violation of Mr Koch's own procedural rights under Article 8, and that it was primarily up to German courts, in accordance with the subsidiarity principle, to examine the merits of the case (*Koch v Germany* App no 497/09 (ECtHR, 19 July 2012) para 71).

A third case concerns Noel Conway, a British national suffering from an incurable degenerative disease. Contrary to Mrs Koch, the 'Swiss option' was not even practicable for him, since he was not self-sufficient and a third person helping him would have risked prosecution for assisted suicide under the Suicide Act 1961. As a consequence, he brought an application seeking a declaration of incompatibility with Article 8 ECHR of the 'blanket ban' on assisted suicide provided under Section 2 of the Suicide Act. In October 2017, the High Court rejected his application by arguing *inter alia* that Section 2 served a legitimate aim under Article 8(2) ECHR by protecting the weak and vulnerable, and that the prohibition achieved a fair balance between the interests of the wider community and those of people in the applicant's position (High Court of Justice, *Noel Douglas Conway v The Secretary of State for Justice*, Case no CO/6421/2016, 5 October 2017). Quite unexpectedly, on 18 January 2018 the Court of Appeal granted Mr Conway the right to challenge the High Court's judgement (Court of Appeal (Civil division), *Noel Douglas Conway v The Secretary of State for Justice*, Case no C1/2017/3068, 18 January 2018). Clarifying the distinction between assisted suicide and euthanasia, the Court of Appeal's Senior President affirmed that '[Mr Conway's] rights under article 8(1) ECHR are both engaged and interfered with. There must accordingly be anxious scrutiny of the proportionality of the interference' (ibid para 22).

For its part, the Strasbourg Court has always shown a certain self-restraint when dealing with end-of-life situations. Not coincidentally, it was only in 2015, in *Lambert v France*, that the Court eventually declared



as admissible an application concerning the withdrawal of medical treatment, and finally decided to address these issues (*Lambert and Others v France* App no 46043/14 (ECtHR [GC], 5 June 2015)). The case was about a French national, Vincent Lambert, who was in a vegetative state and received artificial nutrition and hydration through a gastric tube. Controversy arose between some of Lambert's relatives, who wanted him to be kept fed and hydrated, and his other relatives and assisting doctors who wanted instead the removal of the gastric tube, which would have resulted in his death.

By a 12 to 5 margin, the Grand Chamber found that the French regulatory framework fully satisfied Article 2's positive obligations to protect life. The Grand Chamber argued so on the basis of three criteria, concerning respectively the legal framework, the decision-making process, and the legal remedies available to the applicants. Such criteria, of essentially a procedural character, are based on the premise that in end-of-life situations States must be afforded a margin of appreciation. This margin of appreciation is relevant not only as to whether or not to permit the withdrawal of artificial life-sustaining treatment and the arrangements governing such withdrawal, but also as regards the means of striking a balance between the protection of patients' right to life and the protection of their right to respect for their private life and their personal autonomy. This derives from the lack of consensus among the Council of Europe's member States on whether to permit the withdrawal of artificial life-sustaining treatment, although the majority of States appears to allow it (*ibid* para 148). Nonetheless, the Grand Chamber found the existence of a consensus in relation to the paramount importance of the patient's wishes in the decision-making process (*ibid*).

As to the first point, the Court affirmed that the provisions of the Act of 22 April 2005 (Loi Leonetti), as interpreted by the *Conseil d'État*, constituted a legal framework which was sufficiently clear to regulate with precision the decisions taken by doctors in situations like the one at hand. Concerning the decision-making process, the judges remarked that all the different points of view were considered during the procedure, which had been lengthy and meticulous, even though it did not satisfy the applicants as to its outcome. As to the legal remedies, the Court concluded that the case had been the object of an in-depth examination which carefully took into account all the relevant aspects and in the course of which all points of view were expressed.

Apart from the said criteria, the judgement is remarkable because, despite the lack of unanimity within the Chamber, it sets an important precedent with respect to the relation between Articles 2 and 8 ECHR. While the judges declared that the complaint under Article 8 was absorbed by the one under Article 2, they acknowledged the potential relevance of Article 8 considerations (including questions of quality of life) and the notion of personal autonomy which Article 8 encompasses.

The three criteria established in *Lambert* have been applied, for the first time, in two recent decisions rendered in *Gard and Others v the United Kingdom* and *Afiri and Biddarri v France*.

The first case concerned a child, Charlie Gard, who suffered from a rare and fatal genetic disease. In February 2017, Charlie needed artificial ventilation. The treating hospital applied to the High Court for confirmation that the removal of ventilation would be lawful, after having considered that this was in the child's best interests. This was contested by the parents, who instead asked the Court to consider whether it would be in Charlie's best interest to undergo experimental treatment in the United States. The decision of the High Court, which was later upheld by the Supreme Court, ruled in favour of the treating hospital by arguing, on the basis of extensive, high-quality expert evidence, that it was most likely that Charlie was being exposed to continued pain, suffering and distress, and that undergoing experimental treatment with no prospects of success would offer no benefit, and would continue to cause the child significant harm.

Before the European Court Charlie's parents claimed, also on behalf of their son, the alleged violations of Articles 2, 5, 6 and 8 ECHR. They claimed *inter alia* that Article 2 had been breached because the hospital had blocked access to life-sustaining treatment. Consequently, according to the applicants, the UK was violating its positive obligations to protect life. They also claimed, on their own behalf, that a violation of Article 8 had occurred because the domestic courts' decisions amounted to a disproportionate interference with their parental rights.

The ECtHR, by endorsing the approach of the domestic courts, declared the application inadmissible by a majority (*Gard and Others v the United Kingdom* App no 39793/17 (ECtHR, 27 June 2017)). With respect to the violation of Article 2, it emphasized that, although there is still no consensus among States parties in favour of permitting the withdrawal of artificial life-sustaining treatment, the majority of States appear



to allow it (ibid para 83). Consequently, ‘in this sphere concerning the end 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 patients’ right to life and the protection of their right to respect for their private life and their personal autonomy’ (ibid para 84).

An analogous reasoning was applied by the ECtHR on 23 January 2018, in the case of *Afiri and Biddarri v France* (App no 1828/18). The case concerned the decision, reached by doctors without the parents’ agreement, to bring to an end the life-sustaining treatment being administered to a 14-year-old girl who had, for some months, remained in a vegetative state. In this case the Court, after having applied the *Lambert’s* criteria, concluded unanimously that, given the margin of appreciation available to domestic authorities, the legislative framework in force complied with Article 2.

The attitude of the ECtHR in these recent cases, along with the legislative and jurisprudential changes occurring in several Council of Europe countries over the last few years, raise various important questions revolving around the role of self-determination, human dignity and States’ margin of appreciation in decisions concerning end-of-life issues. In order to tackle such issues, QIL has invited Jean Morange and Daria Sartori to offer two different perspectives. In his contribution, Jean Morange illustrates the risks that the various developments with regard to the recognition of a ‘right to die’ occurring at the national and international level could bring about. He points out the resulting incoherence which could infect the most fundamental human right – the right to life – and ultimately the whole legal order. Daria Sartori, for her part, undertakes a very detailed analysis of the ECtHR’s case-law in order to identify the progressive development of the Court’s position on end-of-life issues and on the balance between the competing interests at stake in cases on assisted suicide and passive euthanasia.