Ending discrimination against cancer survivors

The right to be forgotten as a human right - Françoise Tulkens

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Thank you for inviting me to take part in this conference on a very sensitive subject of great individual and social importance. In 10 minutes, I'm going to get straight to the point, to the heart of the matter.

What does the right to be forgotten mean and what does it cover? This concept has many aspects and its indeterminacy is often highlighted by legal scholars. In fact, the right to be forgotten is a protean right that covers several dimensions, especially in the digital sphere, and it has been interpreted in a "variety of ways". I am not going to address these questions here1, but I will consider here the right to be forgotten by virtue of its purpose in our context.

A right under construction

In the case of cancer survivors, the right to be forgotten is not yet guaranteed, as such, by the European Convention of human rights. Neither the European Court of Human Rights nor the Court of Justice of the European Union have yet been called upon to deal with this issue. But it is now recognised by the European Court of human rights in a recent judgment of 4 July 2023 (Hurbain c. Belgique) that the right to be forgotten " (...) is "still under construction and that its application in practice has already acquired a number of distinctive features"(§ 194). 2This is what I am going to examine here.

In a nutshell, the right to be forgotten is a component of the right to privacy protected by Article 8 of the ECHR and Article 7 of the European Charter, a right whose enjoyment must be guaranteed to everyone without discrimination, as indeed are all the rights guaranteed by the Convention (Article 14). The right to privacy is closely linked to the right to protection of personal data, which is based on an individual's interest in limiting access to, modifying or deleting information that affects his or her individual or social existence

[1] . Fr. Krenc et Fr. Tulkens, La protection des données à caractère personnel et le droit à l'oubli », *Mélanges en l'honneur de Dean Spielmann*, Oisterwijk, Wolf Legal Publishers, 2015, pp. 289-306

[2] . See *d*, 2022/1

The right to protection of personal data
Foundation of democratic society

Since the Rotaru v. Romania judgment (GC) of 4 May 2000, but even more since the S. and Marper v. UK judgment (GC) of 4 December 2008, the Court has acknowledged that "the protection of personal data is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention (...). Therefore, the domestic law must afford appropriate safeguards to prevent any such use of personal data which undermines this protection and the need for such safeguards is all the greater where the protection of personal data undergoing automatic processing is concerned. In particular, the domestic law should notably ensure that such data are relevant and not excessive in relation to the purposes for which they are stored and preserved in a form which permits identification of the data subjects for no longer than is required for the purpose for which those data are stored" (§ 103). On the basis of these principles, interference with privacy must meet the classic conditions of legality, legitimacy and proportionality.

But case law evolves over time. The Court held in 2017 that Article 8 of the Convention provides for the right to a form of informational self-determination, allowing individuals to rely on their right to privacy as regards data which, albeit neutral, are collected, processed and disseminated collectively and in such a form or manner that their Article 8 rights may be engaged (Satakunnan Markkinapörssi Oy and Satamedia Oy v. Finland [GC], 27 June 2017, §§ 136-37). In 2023, the Court "further reiterates that where there has been compilation of data on a particular individual, processing or use of personal data or publication of the material concerned in a manner or degree beyond that normally foreseeable, private-life considerations arise (Hurbain v. Belgium, 4 July 2023, § 190).

The protection of personal data is one of the foundations of a democratic society and is a limit to the development of the collection and use of such data[3].

[3] R. Tinière, « Article 8. Protection des données à caractère personnel », in *Charte des droits fondamentaux de l'Union européenne. Commentaire article par article*, 3ème éd., Bruxelles, Bruylant, 2023, pp. 203-204.

Medical data

Against this background, particular attention must be paid to medical data (L.H. v. Latvia judgment, 29 April 2014), the confidentiality of which must be ensured (Y.G. v. Russia judgment, 30 August 2022). Information about a person's health is an important part of his or her private life. Respecting the confidentiality of such information is vital not only to protect the privacy of patients, but also to preserve their confidence in the medical profession and health services in general. The interest in protecting the confidentiality of such information will therefore weigh heavily in determining whether the interference was proportionate to the legitimate aim pursued, bearing in mind that such interference can be reconciled with Article 8 only if it is aimed at protecting an overriding aspect of the public interest (Z c. Finland, 1997, § 96).

The right to obtain erasure

The right to be forgotten is often understood as a right to erase digital traces. In this respect, the right to be forgotten appears to be a tool for defending cybercitizens against the infallible and unlimited virtual memory that is the Internet. In judicial practice, "the right to be forgotten on line, has concerned requests for the removal or alteration of data available on the Internet or for limitations on access to those data" (Hurbain v. Belgium, § 196).

I refer back to this judgment which opens the way to the right to be forgotten and which can/should be used mutatis mutandis. « For a number of years now, with the development of technology and communication tools, a growing number of persons have sought to protect their interests under what is known as the "right to be forgotten. This is based on the individual's interest in obtaining the erasure or alteration of, or the limitation of access to, past information that affects the way in which he or she is currently perceived. By seeking to have that information disappear, the persons concerned wish to avoid being confronted indefinitely with their past actions or public statements, in a variety of contexts such as, for instance, job-seeking and business relations" (§ 191). And the Court continues: "There is also a risk of other harmful effects, by the aggregation of information, which may lead to the creation of a profile of the person concerned (§ 192). Against this background, "the question to be addressed by the Court is whether Article 8 affords protection against these negative effects and, if so, to what extent (§ 193).

Discrimination

This leads me to the question of discrimination which, according to the European Convention of Human Rights (art. 14) consists of a difference in treatment, "based on any ground such as age, sex, etc. or any other status (toute autre situation", without objective and reasonable justification, between people who are in a sufficiently comparable situation. Article 21 of the European Charter must also be analysed in depth and is considered by some scholars as "un potentiel emergent , encore sous- utilisé en pratique" 4.

Discrimination on the basis of health could be considered. The Resolution of the Parliamentary Assembly of the Council of Europe on Discrimination against persons dealing with chronic and long-term disease (6 January 2021) rightly points out that que" because of their direct and indirect effects, these diseases interfere with the full and equal enjoyment of all human rights and fundamental freedom. (...) These diseases are obstacles to individual well-being and fulfilment which no-one should be deprived of. It is not for these people to adapt to society but for society to adapt to them" (summary).

Against this background, the Assembly notes that chronic and long term diseases are "sources of discrimination and hinder the affected who may be deprived of their autonomy, their participation and their full integration into society" (A. Draft resolution, 2.), the first discrimination concerns employment and access to credit and insurance market. The Assembly suggests " fighting against discrimination suffered by patients because of their status and recommends evaluating patient protection system such as the right to be forgotten" (A. Draft resolution, 7.)

Based on the European social charter, at the request of civil society, some countries (analysed by Grazia) have adopted laws concerning the "right to be forgotten" in order to permit cancer patients to stop declaring the illness after a certain time lapse, thus allowing access to loans or life insurance. This right seems to now exist almost uniformly across Council of Europe member States and has been integrated into the European Union legislation. However, in order to measure the truly beneficial effects and to assess the guarantees proffered

[4] . E. Bribosia, I., Rorive, J. Hislaire, « Article 21. Non- discrimination » in *Charte des droits fondamentaux de l'Union européenne. Commentaire article par article*, sus le direction de F. Picod et al., Bruxelles, Bruylant, 2023, pp. 627-652.

as concerns the integration of patients, the Council of Europe should be able to support the efforts of civil society, following an assessment of the exercise of this right.

Conclusion

* The right to be forgotten is a basic and legitimate human right.
* It is a right under construction, but one that will result from a fruitful synergy between different sources and different players (national, European and International courts).
* The exercice of this right shoud not ne based on compassion but on evidence.
* Policy and science shoud work together
* It is not only a question of equality but of justice

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