

## The Advance Directives and Foregoing of Life Support: Where do we Stand Now?

### (For End of Life Care India Task Force [ELICIT])

In the wake of the recent judgment on advance directives (ADs) and foregoing of life support (FLS) (the so called “passive euthanasia”),<sup>[1]</sup> the medical community finds constitutional and legal validity for its widely accepted ethical position on FLS when inappropriate. The Indian Society of Critical Care Medicine (ISCCM) took a far-sighted initiative in publishing its ethical position paper on limitation of life support and palliative care toward end of life (EOL) in 2005,<sup>[2]</sup> in 2012,<sup>[3]</sup> and then as a joint statement with the Indian Association of Palliative Care (IAPC) in 2014.<sup>[4]</sup> Ethics must precede law since the latter exists essentially for the safe application of the former. In being open to misinterpretation, ethically aware physicians were somewhat arguably wary of taking FLS decisions.<sup>[5]</sup> At the outset, no legal or societal awareness existed for the possibilities of withholding or withdrawing life support in terminal illness, often mistaken for suicide or euthanasia.<sup>[6]</sup> Physicians and hospital authorities were fearful of being accused of abetting suicide or of culpable homicide.<sup>[7]</sup> Faced with a moral dilemma of allowing futile care to continue or against their better judgment, to send patients away with the families signing “Left Against Medical Advice” or “Discharged Against Medical Advice” forms, physicians experienced moral distress. Safety of the latter practice was presumed, never having been tested in court. Recent media allegations against hospitals and subsequent litigation despite such signed forms put paid to seeking refuge in such easy solutions.

The ISCCM proceeded to apprise the Law Commission of India of the huge lacuna in medical jurisprudence. Justice M Jagannadha Rao submitted a scholarly 196<sup>th</sup> Report titled “Medical Treatment to Terminally Ill patients (Protection of patients and medical practitioners).”<sup>[8]</sup> The landmark report reiterated the common law right to refuse treatment even if lifesaving, separated euthanasia and suicide from legitimate withdrawal and withholding decisions and declared the state interest in protecting life as not absolute and thus obliged not to intervene in individual FLS decisions. It interpreted the Gian Kaur judgment<sup>[9]</sup> as a citizen’s right to a death in dignity being a part of the right to life guaranteed in Article 21. It defined competency and affirmed a physician’s duty to respect autonomy. However, the report lost its way when it came to laying down the procedure for FLS in incompetent patients. Relying on neither the family nor the treating physicians, it mandated a procedure involving the High Court. Contrary to its support for Autonomy, the report explicitly disallowed AD as it was argued that the provision could be misused. This, when AD and appointment of health-care proxy or Durable Power of Attorney had been in use

for two decades in the US and was being increasingly utilized.<sup>[10]</sup> The 196<sup>th</sup> report was never tabled in parliament and did not prove helpful in resolving physician and family dilemmas.

The Aruna Shanbaug was the first Indian case law directly addressing the issue of withdrawal of artificial life support.<sup>[11]</sup> However, the judgment only held as reference the persistent vegetative state and delivered an overarching opinion that allowed passive euthanasia but complicated the implementation of FLS by prescribing a court procedure. It is no small wonder that not a single appeal has been made under the provisions since 2011.

The Law Commission of India, under the chairmanship of Justice AR Lakshmanan, submitted a revised Report (241<sup>st</sup>)<sup>[12]</sup> that incorporated the legal position in the Aruna Shanbaug case. The Ministry of Health and Family Welfare (MoHFW) prepared a draft Bill “Medical Treatment of Terminally ill patients (for the protection of patients and Medical practitioners) uploading the same at its website for public comments in May 2016.<sup>[13]</sup> As per the earlier Law Commission reports, the Bill laid down a court procedure and disallowed legal validation of AD. In a significant development, for the advocacy to bring in reform and legislation, the IAPC and ISCCM jointly published a position paper on the care of the dying.<sup>[4]</sup> For the first time, integrating the principles of critical care and palliative care, it presented a comprehensive, 12-step approach for EOL decisions and compassionate care that included care for the families. In 2015, with the initiatives of the Indian Academy of Neurology, a broader advocacy group was formed called the End of Life Care India Task Force (ELICIT). Guided by expert legal advice, ELICIT drafted an alternate draft Bill that was submitted to the MoHFW. The ELICIT core committee also published opinion pieces to generate awareness and stimulate debate.<sup>[14,15]</sup> Under the aegis of ELICIT, a symposium on EOL care (EOLC) was conducted in April 2017 that had faculty drawn from multiple medical specialties, sociology, social work, laypersons, public servants, journalists, and writers. The symposium culminated in a call to action for improving the quality of EOLC in India through appropriate legislation and dissemination of the awareness of death in dignity. A Citizens Action Needed for Dying in Dignity (CANDID) forum was initiated. The “Mathura Declaration” a Call to action was signed by all members of ELICIT and CANDID.<sup>[16]</sup>

Against this background, two recent developments in Law are path-breaking. The first was the right to privacy judgment in 2017 that unequivocally declared privacy an unalienable and independent fundamental right.<sup>[17]</sup> As autonomy flows from this right, it follows that the patient’s right to control how he

may be treated toward EOL, even when not competent, would continue to be protected by law. Justice Chelameswar of the Supreme Court had opined that this judgment would have a positive impact on laws for the right to refuse life support in terminal illness.

The most recent judgment on ADs and passive euthanasia by a 5-judge Constitutional Bench under Justice Dipak Mishra, the Chief Justice of India, is the most historic of all.<sup>[1]</sup> Addressing a petition by the NGO Common Cause, in which the ISCCM and ELICIT were impleading parties, it has unequivocally upheld the legal validity of AD and the right to forego artificial life support which they termed as “passive euthanasia” when applied to patients in the incompetent state. They held autonomy as a fundamental right and that AD should be accepted within a framework of strict safeguards.

Would this judgment enable access of terminally ill patients to compassionate and less burdensome care? Yes, it has great potential, but only if the procedure prescribed is less daunting in its complexity. First, the continued use of the misleading term “passive euthanasia” remains a serious barrier to widespread understanding of the ethical basis and moral justification for FLS. The terminology should be brought up to date in the forthcoming legislation, in keeping with the latest published document under the aegis of the Indian Council of Medical Research (ICMR).<sup>[18]</sup>

Second, AD can only be executed in writing in a prescribed format to be signed by two independent witnesses. It has to be further submitted to a registry in the office of the Jurisdictional Judicial Magistrate of First Class who in turn must submit a copy to the district judge. Further, when it comes to implementing an EOLC decision, there are two levels of procedure: a medical board in the hospital and another by the District Collector. Lengthy procedure is untenable in the face of decisions to be made within hours or days which would form the bulk of the candidates for EOL decisions in an Intensive Care Unit. EOL decisions need expertise, experience, and repeated conferencing between caregivers and the next of kin.<sup>[4]</sup> This would not be easy for the families with a procedure involving too many opinions. The problem of legal procedure overriding care imperatives has, alas, remained. The procedure is only marginally less unworkable and cumbersome than the Aruna Shanbaug ruling.<sup>[19]</sup> For compassionate care to be legally well supported, we need realistic modifications. Medical care is moving toward greater patient and family centrality.<sup>[20]</sup> The principle of FLS is that suffering can be mitigated by avoiding disproportionate medical interventions. We have a historic law which respects our rights to autonomy and privacy, but we must also work toward making the exercise of those rights possible at the bedside.

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