IN THE HON'BLE SUPREME COURT OF INDIA

CIVIL ORIGINAL WRIT JURISDICTION

Writ Petition (C) 215 of 2005

IN THE MATTER OF:

COMMON CAUSE ...PETITIONERS

VERSUS

UNION OF INDIA ...RESPONDENTS

Note on Arguments of the Intervenors 'Vidhi Centre for Legal Policy'

Meaning of Euthanasia:

1. The Oxford English Dictionary defines euthanasia as 'the painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma.'[1] The word appears to have come into usage in the early 17th century and was used in the sense of 'easy death', derived from the Greek 'euthanatos', with 'eu' meaning well, and 'thanatos' meaning death.
2. Euthanasia has since come to be recognised as of two distinct types: the first is active euthanasia, where death is caused by the administration of a lethal injection or drugs. Active euthanasia also includes physician-assisted suicide, where the injection or drugs are supplied by the physician, but the act of administration is undertaken by the patient himself. Active euthanasia is not permissible in most countries. The jurisdictions in which it is permissible are

[1] See <https://en.oxforddictionaries.com/definition/euthanasia> accessed 10 October 2017.

Canada, the Netherlands, Switzerland and the states of Colorado, Vermont, Montana, California, Oregon and Washington DC in the United States of America.

3. Passive euthanasia occurs when medical practitioners do not provide life-sustaining treatment (i.e. treatment necessary to keep a patient alive) or remove patients from life-sustaining treatment. This could include disconnecting life-support machines or feeding tubes or not carrying out life-saving operations or providing life-extending drugs. In such cases, the omission by the medical practitioner is not treated as the cause of death; instead, the patient is understood to have died because of his underlying condition.
4. These distinctions have been documented by the Supreme Court in *Aruna Shanbaug v Union of India* (2011) 4 SCC 454, paras 39-44. The Court, in this case also pointed out the distinction between voluntary and non-voluntary passive euthanasia. In the former, consent is obtained from the patient before the withdrawal or withholding of treatment. In the latter, the patient is unable to give consent or form an informed decision by reason of being in a coma or a persistent vegetative state (PVS).

Right to Refuse Medical Treatment:

5. It is submitted that the exercise of passive euthanasia (both in the voluntary and non-voluntary form) is the same as the exercise of the well-recognised common law right to refuse medical treatment. [Re T (Adult: Refusal of Medical Treatment (1992) 4 All ER 649; Re B (Adult: Refusal of Medical

Treatment) (2002) 2 All ER 449; Cruzan v Director, Missouri Department of Health 497 U.S. 261 (1990); Malette v. Shulam 67 DLR (4th) 321]

6. In fact, the Indian Council of Medical Research (ICMR) has excluded the withdrawal or withholding of life-sustaining treatment from the very definition of euthanasia in its most recent draft of definitions related to end of life care.
7. The ICMR draft definitions define the withholding and withdrawal of life-sustaining treatment as follows:

- *Withholding life sustaining treatment: On a background of advanced life limiting illness, a decision made not to initiate or escalate a life-sustaining treatment, where the patient's chances of survival after initiation or escalation of life sustaining treatment, is dismal, with the burden outweighing the possible benefit, and the fully informed patient or surrogate if the patient lacks decision capacity, would choose the option not to initiate or escalate the said life-sustaining treatment*
- *Withdrawing life sustaining treatment: On a background of advanced life limiting illness, decision made to cease or remove a life-sustaining intervention presently provided, where patient's chances of survival with continued life sustaining treatment is dismal with the burden outweighing the possible benefit and the fully informed patient or surrogate if the patient lacks decision capacity would choose the option to cease or have removed the said life-sustaining treatment.*
- *Terminally Ill Patient: An incurable and irreversible condition caused by injury, disease, or illness that would cause 54 death within a reasonable period of time in accordance with accepted medical standards, and 55 where the*

application of life-sustaining treatment would serve only to prolong the process of 56 dying(19).

8. In contrast, the ICMR definitions define euthanasia as follows: *Euthanasia is the intentional act of killing a dying patient with terminal illness by the direct intervention of a doctor, for the purpose of good of the patient or others. However, allowing natural death, withholding and withdrawing of life sustaining treatment to limit harm and suffering in a dying patient should not be construed as Euthanasia.* (emphasis supplied).
9. This demonstrates that the Indian medical community has moved towards making a distinction between euthanasia and the withholding and withdrawing of life-sustaining treatment.

Right to Die with Dignity under Article 21:

10. In *Justice K Puttaswamy v Union of India* 2017 SCC OnLine SC 996, Justice Chelameswar, at Para 38 in his opinion states that an individual's decision to refuse life prolonging medical treatment or terminate his life is another judgment which falls within the zone of the right to privacy.
11. In *Gian Kaur v State of Punjab* (1996) 4 SCC 648, Paras 24 and 25, the Supreme Court has explicitly recognised the right to die with dignity as part of the fundamental right to life under Article 21. This was reaffirmed by the Supreme Court in *Aruna Shanbaug*, where the Court permitted the withdrawal of life-sustaining treatment from incompetent patients i.e. patients not in a position to make an informed decision.
12. Thus, the Supreme Court also recognises the distinction between the active termination of life and the withdrawal of life-sustaining treatment, with the

latter firmly recognised as an expression of autonomy, bodily integrity and right to life.

Recognition of the Legal Validity of Advance Directives:

13. In light of this, we ask the Court to declare that advance directives are an extension of the right to refuse medical treatment and the right to die with dignity, and recognition of their legal validity is necessary to give effect to the rights of incompetent patients under Article 21.
14. Advance directives are instruments through which persons express their wishes at a prior point in time, when they are capable of making an informed decision, regarding their medical treatment in the future, when they are not in a position to make an informed decision, by reason of being unconscious or in a permanent vegetative state or in a coma.
15. A medical power of attorney is an instrument through which persons nominate representatives to make decisions regarding their medical treatment at a point in time when the persons executing the instrument are unable to make informed decisions themselves.
16. Failure to grant legal validity to these instruments will prevent a particular category of persons i.e. persons who may be unconscious or in a coma or in PVS from exercising their right to self-determination and their right to die with dignity under Article 21. Instead, according to *Aruna Shanbaug*, decisions about the withdrawal of life-sustaining treatment from such persons will be taken by the concerned High Court in the exercise of its *parens patriae* jurisdiction.

17. Clause 11 of the draft Treatment of Terminally-Ill Patients (Protection of Patients and Medical Practitioners) Bill 2016 states that advance directives or medical power-of-attorney shall be void and of no effect and shall not be binding on any medical practitioner. This blanket ban, including the failure even to give some weight to advance directives while making a decision about the withholding or withdrawal of life-sustaining treatment is disproportionate. It does not constitute a fair, just or reasonable procedure, which is a requirement for the imposition of a restriction on the right to life (in this case, expressed as the right to die with dignity) under Article 21.

Possibility of Misuse Not a Valid Ground for Rejecting Advance Directives:

18. The possibility of misuse of these instruments is not a valid reason for refusing to grant *any* legal validity to advance directives. This is the rationale advanced in both the 196th and 241st Reports of the Law Commission of India.
19. It is submitted that the failure to even make an attempt to provide for safeguards for the exercise of advance directives is a disproportionate restriction on the right to die with dignity under Article 21. Other legislation in India, as well as laws in other jurisdictions have robust provisions to prevent the misuse of advance directives.
20. For example, Section 5 of the Mental Healthcare Act 2017 recognises the validity of advance directives for the treatment of mental illness under the Mental Healthcare Act 2017. The draft Mental Healthcare Regulations have recently been made available for public comment by the Ministry of Health and Family Welfare. These prescribe the form in which advance directives

may be made. Part II, Chapter 1 of the Regulations allow a Nominated Representative to be named in the Advance Directive. An advance directive is to be in writing and signed by two witnesses attesting to the fact that the Directive was executed in their presence. A Directive to be registered with the Mental Health Review Board. It may be changed as many times as desired by the person executing it and the treating mental health professional must be informed of such change.

21. Similarly, Section 3 of the Transplantation of Human Organs and Tissues Act 1994 allows persons to authorise the removal of human organs and tissues from their body before death. The form in which this authorisation is to be made is prescribed in Form 7 of the Transplantation of Human Organs and Tissues Rules 2014. This is also to be in writing and in the presence of two witnesses. A copy of the pledge is to be retained at the institution where the pledge is made and the person making the pledge has the option to withdraw the pledge at any time. Where such authorisation had been made, the person lawfully in charge of the donor's body after his death is required to grant the concerned medical practitioner all reasonable facilities for the removal of human organs or tissues, unless such person has reason to believe that the donor had substantially revoked his authority.

Safeguards for Advance Directives in other Jurisdictions:

22. There are several countries that recognise and give effect to advance directives. They provide safeguards in the following ways: by prescribing the form that the directive must take, by specifying who may act as witnesses, by

allowing the possibility of amendment and by allowing the validity of the directive to be challenged.

a) In the UK, under Section 24 of the Mental Capacity Act, 2005, a person above the age of 18 years who has capacity may execute an advance directive. A person is said to lack capacity if in relation to a matter at the material time, he is unable to make a decision for himself because of an impairment of or disturbance in the functioning of the mind or brain. In Netherlands, under Article 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, patients aged 16 or above may make advance directives. In Germany, the authorisation of the court is required for the termination of treatment in the case of minors. In Switzerland, persons with mental illnesses are considered exceptions and cannot discontinue medical treatment if it is an expression or symptom of their mental illness. In Hungary, pregnant women may not refuse treatment if it is seen that they are able to carry the pregnancy.

b) Section 25 of the Mental Capacity Act, an advance decision to refuse life-sustaining treatment must be in writing. It must be signed by the patient or someone on his behalf and signed by a witness. It must also include a written statement by the patient that the decision will apply to the specific treatment even if the patient's life is at risk. Under Article 7:450 of the Dutch Civil Code, an advance directive should be in written form, dated and signed to be valid. Section 110Q of the Western Australia Guardianship and Administration Act, 1990 requires advance directives to be signed in the presence of two witnesses, who must both be at least 18 years of age and one of whom must be a person authorised to witness legal documents under the relevant law.

Section 15 of the South Australia Advance Directives Act 2013 sets out requirements for ‘suitable’ witnesses under the Act. A person may not be a witness if she is appointed as a substitute decision-maker under the advance directive, has a direct or indirect interest in the estate of the person executing the advance directive or is a health practitioner responsible for the health care of the person executing the advance directive. Similar disqualifications for witnesses are prescribed in the Oregon Death with Dignity Act 2002 when a person makes a written request for medication for the purpose of ending her life in a humane and dignified manner.

c) Under Section 24(3) of the UK Mental Capacity Act, 2005, a person may alter or withdraw an advance decision at any time he has the capacity to do so. Under Section 25(2)(c), an advance decision will not be applicable if a person has done anything else clearly inconsistent with the advance decision. Under S. 3.06 of the Oregon Death with Dignity Act 2005, a person may rescind her written request for medication at any time regardless of her mental state. To allow for a change of mind, S. 3.08 also requires at least 15 days to lapse between the patient’s initial oral request and the writing of a prescription, while a minimum of 48 hours must elapse between the patient’s written request and the writing of a prescription. Under Section 110S of the Guardianship and Administration Act 1990, a treatment decision in an advance directive does not operate if circumstances exist or have arisen that the maker of that directive could not reasonably have anticipated at the time of making the directive and that would have caused a reasonable person in the maker’s position to have changed her mind about the directive. While determining whether such circumstances have arisen, the age of the maker and the period

that has elapsed between the time at which the directive was made and the circumstances that have arisen are factors that must be taken into account while determining the validity of the directive.

d) Section 26(4) of the UK Mental Capacity Act permits courts to make a declaration as to whether the advance decision exists, is valid, and applicable to a treatment. Under Article 373 of the Swiss Civil Code, 'any person closely related to the patient can contact the adult protection authority in writing and claim that...the patient decree is not based on the patient's free will.' Under Section 110V, 110W, 110X, 110Y and 110Z of the Western Australia Guardianship and Administration Act, 1990, any person who has a 'proper interest' in the matter, in the view of the State Administrative Tribunal, may apply to it for a declaration with respect to the validity of an advance directive. It can also interpret the terms of the directive, give directions to give effect to it or revoke a treatment decision in the directive.

23. In light of the above discussion, it is open to the Court to lay down guidelines to give effect to advance directives, keeping in mind the different kinds of safeguards that are available.

Guidelines to be laid down by the Court on Advance Directives:

24. We submit that the Court's guidelines ought to cover the following aspects:

a) Who will be competent to execute an advance directive?

b) In what form will an advance directive have to be issued in order to be valid?

c) Who is to ensure that an advance directive is properly obeyed?

d) What legal consequences follow from the non-obedience to an advance directive?

e) In what circumstances can a doctor refuse to enforce an advance directive?

25. In response to these aspects, we submit that:

a) Only adult persons, above the age of eighteen years and of sound mind at the time at which the advance directive is executed should be deemed to be competent. This should include persons suffering from mental disabilities provided they are of sound mind at the time of executing an advance directive.

b) Only written advance directives that have been executed properly with the notarised signature of the person executing the advance directive, in the presence of two adult witnesses shall be valid and enforceable in the eyes of the law. The form should require a reaffirmation that the person executing such directive has made an informed decision. Only those advance directives relating to the withdrawal or withholding of life-sustaining treatment should be granted legal validity. The determination that the executor of the advance directive is no longer capable of making the decision should be made in accordance with relevant medical professional regulations or standard treatment guidelines, as also the determination that the executor's life would terminate in the absence of life-sustaining treatment. The constitution of a panel of experts may also be considered to make this determination. The use of expert committees or ethics committees in other jurisdictions is discussed at Para 28 of these written submissions.

c) Primary responsibility for ensuring compliance with the advance directive should be on the medical institution where the person is receiving such treatment.

d) If a hospital refuses to recognise the validity of an advance directive, the relatives or next friend may approach the jurisdictional High Court seeking a writ of mandamus against the concerned hospital to execute the directive. The High Court may examine whether the directive has been properly executed, whether it is still valid (i.e. whether or not circumstances have fundamentally changed since its execution, making it invalid) and/or applicable to the particular circumstances or treatment.

e) No hospital or doctor should be made liable in civil or criminal proceedings for having obeyed a validly executed advance directive

f) Doctors citing conscientious objection to the enforcement of advance directives on the grounds of religion should be permitted not to enforce it, taking into account their fundamental right under Article 25 of the Constitution. However, the hospital will still remain under this obligation

26. The sanctity of life cannot be advanced as a reason for the refusal of recognition to advance directives. It is evident that this principle is not absolute in the Indian context. Section 302 of the Indian Penal Code permits the award of capital punishment, while the Medical Termination of Pregnancy Act, 1971, permits abortion. Most recently, Section 115 of the Mental Healthcare Act 2017 states that a person who commits suicide shall be presumed to be suffering from a mental illness and the act will not be considered a crime within the meaning of Section 309 of the Indian Penal Code.

Safeguards for Refusal of Medical Treatment through Experts:

27. It is also instructive to look at other jurisdictions to understand their use of experts or ethics committees in making decisions about end of life care. Relevant examples are provided below:

a) In the Netherlands, under the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, the medical practitioner makes the final decision regarding active euthanasia as well as physician-assisted suicide. However, every such case must be reported to a Regional Review Committee which will pass a decision whether or not 'due care' has been observed by the physician. If a finding of due care is not reached, the Committee is to notify the Public Prosecution Service

b) In Hungary, Section 20 of the Health Act, 1997, creates a right to refuse treatment. A Committee of Physicians is to examine whether the patient suffers from serious illness, which, according to the state of medical science will lead to death within a short period, even with adequate medical care, and is incurable. This Committee must also examine and declare unanimously that the person took her decision in full cognizance of its consequences. On the third day after such declaration, the patient must make such declaration again in the presence of two witnesses.

c) The Constitutional Court of Colombia (T-970 of 2014 and C-239 of 1997) has held that the right to die with dignity includes the right of the patient to waive/withdraw/stop treatment in a voluntary manner and in advance from unnecessary medical treatment. If there exists controversy about the diagnosis of a terminal illness, a second opinion or the opinion of a group of

experts may be required. A medical doctor will determine the conditions of terminal illness and present the evidence to an interdisciplinary committee set up by the institution providing health services. This committee will certify that the patient is a major, has a terminal illness, and will confirm the will of the patient. It will have 10 days within which to verify such information, and after confirming the will of the patient to die an assisted death, will enforce this within 15 days or on the date indicated by the patient.

d) In Norway, Section 4-9 of the Patients' Rights Act, 1999 states that a dying patient has the right to refuse life-prolonging treatment. National GUidelines have also been issued by the Norwegian Directorate of Health on decision-making processes in the limitation of life-prolonging treatment. The law and these guidelines state that health care personnel have the final say in medical decisions. However, this is to be based on discussions in a multi-disciplinary care team assigned to the patient. If disagreement within the team cannot be resolved, another expert opinion is to be obtained or a referral made to a clinical ethics committee. This committee involves all stakeholders in discussion and its function is only to provide guidance. It has no decision-making authority.

Withdrawal of Life-Sustaining Treatment in the Absence of Advance Directives:

28. The submissions so far have argued for the recognition of legal validity of advance directives. However, there will also be cases, like *Aruna Shanbaug*, where there is an incompetent patient who has not previously expressed her wishes about the withdrawal of medical treatment.

29. In *Aruna Shanbaug*, the Court held that for such patients, the decision regarding withdrawal or withholding of life-sustaining treatment could only be made by the High Court in the exercise of its *parens patriae* jurisdiction. We submit that this is an unreasonable and impractical procedure and does not allow for the effective exercise of the right to die with dignity under Article 21.
30. We would like to point to different standards and procedures applied in other jurisdictions while considering cases like *Aruna Shanbaug.*
31. There are three possible standards: *Best Interests* (see UK Mental Capacity Act, section 4 and F v West Berkshire Health Authority [1989] 2 All ER 545, opinion by Lord Bridge of Harwich), *Substituted Judgment* (see South Australia's Guardianship and Administration Act, 1993, section 5) or a *mixed approach* (see New South Wales' Guardianship Act, 1987, section 4- guardianship decisions are guided by consideration of the person's welfare and interests, their freedom to make decisions and the view of the person)
32. The substituted judgment test requires a surrogate to make a decision regarding the withdrawal of life-sustaining treatment as if the patient herself were making it. In one of the landmark cases on the subject, i.e. *Airedale NHS v Bland*, Sir Tom Bingham M.R. held that while making an objective judgment regarding the patient's best interests, it would be legitimate to take into account not only pain and suffering but also wider, less tangible considerations. Mere prolongation of life, with no hope of recovery, could not necessarily be held to be in the patient's best interests.

Determination of Death:

33. The Hon'ble Court must also decide the issue of determination of death. Currently, the standard for determining death is 'brain-stem death' (as recognised under the Transplantation of Human Organs and Tissues Act, 1994). However, Section 2(b) of the Registration of Births and Deaths Act, 1969 defines 'death' as the 'permanent disappearance of all evidence of life at any time after live-birth has taken place'. The term is also defined under section 46 of the Indian Penal Code, 1860 as 'the death of a human being, unless the contrary appears from the context'.

34. Brain-stem death may have occurred in a person, even though there has not yet been a 'permanent disappearance of all evidence of life'. A common manifestation of this inconsistency is patients in whom brain-stem death has occurred, but who are plugged to a ventilator or other forms of life support. They may, therefore, continue to show signs of 'life', such as a heartbeat, a pulse, and in some cases even involuntary movement.

35. As a result, even when a person is brain dead, doctors are forced to keep them on life support/ventilator, as removing them from life support could potentially attract criminal liability under the IPC. There is therefore a need to explicitly waive criminal liability for any medical practitioners withholding or withdrawing treatment.