

Living Will and Green Hair

ANIL CHANDRA ANAND

I was mesmerized by her looks. She was dressed in blue denim trousers and a simple white T-shirt which carried a message in bold blue letters, '*It's Always Too Early Until It's Too Late.*' What stood out more was her boyish hairstyle, with hair dyed in fluorescent green. This was Jia, my friend SD's daughter. I was at SD's house having a cup of tea with them one Saturday evening when Jia breezed in with all her seven earrings and several additional rings on her eyebrows, nose and umbilicus. It was sultry outside, and she had beads of sweat over her brow. She made tea for herself, switched on the fan in an air-conditioned room and sat down next to her mother to have tea.

I found the choice of her hair colour unusual. 'Why have you dyed your hair green?' My question was in response to her 'Hi, uncle!' which she had said without looking at me.

Her face showed that she found my question dumb and irritating. 'I like it' was her brief answer as she slurped her tea after blowing air into her cup to cool it.

'Even at the cost of inciting irritating questions like mine from everyone?' I persisted.

'Uncle, some people are more considerate than you.' She smiled as she concentrated on her cup of tea.

It almost shut me up, but my friend SD, her father, picked up from where I had left. 'Jia is too stubborn. She doesn't listen to anyone. I have told her that she looks like an alien.'

I did not know if I was permitted to smile at this comment. But, Jia retorted, 'I am an adult, I am unique and I have autonomy.' She added with a low voice, 'As if you look like Shah Rukh Khan!'

Jia had studied law, but had decided not to practise as a lawyer. She was running a non-governmental organization trying to educate orphaned children. I admired her courage. My own life was more conventional. SD and I belonged to a generation that conformed to what we thought our parents had wanted.

SD continued, as if complaining, 'She has even gone and executed a living will. And she is just 26. On top of that she is refusing to marry.'

'Living will? I thought all wills were written when you were about to die. And what treasures does Jia have that she wants to bequeath,' I wasn't entirely clear on this. I kept the subject of marriage for future discussion.

Jia suddenly cheered up and added, 'I am surprised you don't know. A living will,^{1,2} is also called an advance directive. It is a document that lets people state their wishes for end-of-life medical care, in case they become unable to communicate their decisions.'

I felt embarrassed once again, 'Of course I know, I was just testing your knowledge. But aren't you too young for all this?'

Jia replied, 'Aruna Shanbaug³ was just 25 when catastrophe hit her!'

Aruna Shanbaug's was a story no one can ever forget. She was a nurse at K.E.M. Hospital who was brutally assaulted by

a ward-boy named Sohanlal in 1973, which left her in a vegetative state. A plea for euthanasia submitted on her behalf was rejected by the Supreme Court of India.⁴ She remained in a coma for 42 years and finally died in 2015. Imagine 42 years!

Jia's mother who was quietly sitting there sipping her tea suddenly pointed to SD, 'Ask her not to talk like that. Jia, don't talk about such inauspicious things!'

Jia sharply replied, 'Mamma, inability to talk about the end-of-life situation is the main reason people suffer for many years when the end comes.' Then, she turned to me. 'Uncle have you prepared an advanced directive?'

I had not. But I deflected her question, 'Why did the Supreme Court reject the petition for euthanasia in respect of Aruna Shanbaug?'

It was Jia's home turf. She started by admonishing me. 'Uncle, it's your subject as much as it is mine. I am surprised that you are acting ignorant. It's all about autonomy in relation to medical treatment.'

I replied, 'I do have some idea, but we hardly have any time for discussions on such subjects. Tell me what the legal position is?'

She answered, '*Autonomy* is a principle of medical ethics that allows an individual to decide what treatment can be given to him and her. He has a right to refuse treatment at any time. One caveat to that rule is an *emergency* situation. You, as a doctor, may give treatment to an individual without his or her consent if you think such a treatment can save his or her life in an emergency. And the law accepts that.'⁴

'But you have not answered my question,' I reminded her.

She continued, 'In Aruna Shanbaug's case, the Hon'ble Supreme Court said that one cannot put a person to death even if there is no chance of recovery, unless there is a specific law permitting such an act of commission. Referring to the *Law Commission Report 196/2006*,⁵ the Hon'ble Supreme Court had clarified that *if a person consciously and voluntarily refused to take lifesaving medical treatment, it is not a crime.*'

I asked, 'What was the problem in Aruna Shanbaug's case?'

She replied, 'Aruna Shanbaug was in coma and was unable to express her will. The Supreme Court directed that such cases with a request to withdraw life support will be decided by the High Court on the basis of the invited opinion of a committee of medical experts and after giving notice to all relatives and stakeholders. It was subsequently incorporated into the *Law Commission Report 241/2012*.'⁶

I retorted, 'But that is a cumbersome process!'

She chirped, 'There is another interesting judgment in *Common Cause (A Regd. Society) versus Union of India* case⁷ by a five-judge bench of the Supreme Court of India, which may be considered a landmark in a way. Here, different judges gave different reasoning to arrive at the same conclusion. The judgment clarified the following points:

1. "Right to live with human dignity" cannot be construed to include within its ambit the right to terminate natural life, at least before the commencement of the process of certain natural death.

Department of Gastroenterology and Hepatology, Kalinga Institute of Medical Sciences, Bhubaneswar, Odisha, India;
anilcanand@gmail.com

2. Physician-assisted suicide has not been accepted in India as legal though a few countries have accepted it and made necessary legislation to regulate it. Switzerland, the Netherlands, Belgium, Luxembourg and the American states of Oregon, Washington, Montana and Columbia have permitted physician-assisted suicide under statutory regulations.
3. The right to die with dignity as a fundamental right has already been declared.
4. Persons of deteriorated health or terminally ill should be able to execute a document titled "*My living will and Attorney Authorisation*," which can be presented to the hospital for appropriate action in the event of the executant being admitted to the hospital.
5. There is a need to have a law to protect patients who are terminally ill. They can take decisions to refuse medical treatment, including artificial nutrition and hydration, so that they may not be considered guilty of the offence of attempting to commit suicide under Section 309 of the Indian Penal Code, 1860.
6. Withdrawing and withholding life support have the same connotations.'

This information was new to me. 'Who can execute a living will?' I asked.

Jia gave a naughty smile as if saying '*Ab aya oonth pahar ke niche* (now you are coming to your senses).'

'Anyone can. There are two situations when one thinks of drawing up a living will.'

I looked at her as a keen student.

'First situation is when you are diagnosed with an incurable disease and you know your end is near. This is logical for everyone and does not need any explanation,' she said.

'I fully agree,' I concurred.

'We do have examples of different approaches taken by different people. Let me tell you about three well-known people who died in 2018. Former US President George H.W. Bush (Senior) died in November 2018⁸ and his wife Barbara died earlier in April 2018.⁹ Both died peacefully at home, surrounded by their whole family and pets, because they had chosen to die like that by a living will.'

'Okay.' I knew something more was coming.

'Then, there is another famous personality, Shri Atal Bihari Vajpayee, former Prime Minister of India, who died in August 2018.¹⁰ He spent the last few weeks in the intensive care unit of AIIMS¹¹ and the last few days on an extracorporeal membrane oxygenator (ECMO). Do you know what this approach meant?'

I shook my head in a negative way.

Jia answered her own question, 'First, it led to spending a huge amount of taxpayers' money. Use of ECMO itself costs over ₹100 000 per day. Second, it made him uncomfortable with repeated intravenous injections and insertion of tubes in almost every body orifice. And lastly, it led to his isolation from his near ones by many large beeping machines. This is the usual end result when you do not talk about death/dying while you are alive.' And she looked meaningfully towards her mother. SD's wife got up in a huff, to go to the kitchen without saying anything. But Jia was not affected, 'Reports indicate that around 25% of Medicare spending in the USA occurs in the last year of people's lives.'¹²

She took a deep breath and continued, 'Second situation, where you can draw up a living will, is whenever you realize that

life is uncertain. One example is the German motor-car racing star, Michael Schumacher, who was a seven-time Formula One champion. He remained fairly safe during all his dangerous races, but had a skiing accident on one of his holidays to become unconscious. Family and close ones have spent over 25 million dollars on his care since the accident in 2013. We do not know much about his health¹³ or whether he had written a living will or not, but it's an example of the fact—*how uncertain life is.*'

I added, 'Even our scriptures describe this life as a water bubble!'

She found an opportunity to strike, 'So uncle, what are you waiting for? Why have you not made the living will.'

I replied, 'Jia, you are a lawyer and you know how to draft in legal language. I am a simple clinician who only knows how to write prescriptions.'

Jia laughed. 'Uncle, everything is available on the internet these days. Go to www.POLST.org. It gives you all the aspects that need to be covered. Even an Indian website called www.onelittlewish.org* gives you all the information.'

I added, 'In our own culture, certainty of death has been repeatedly stressed. Even the famous *Yaksha–Yudhishter* dialogue in *Mahabharat* brings out the fact that we see everyone dying all around us and still we function as if we are never going to die.¹⁴ Surely, I will write my will soon.'

Jia again laughed and pointed to her T-shirt, 'Remember uncle, *It's Always Too Early Until It's Too Late.*'

'Okay,' I relented. 'I will write today.'

'Writing isn't everything. You could start by talking today about death and dying. *Baat to karo*. You also need to identify surrogates who will make decisions on your behalf when you are unable to. It could be your lawyer, your spouse, your daughter, your son, your friend or anyone you can trust your life with. You must express your wishes explicitly in front of all such surrogates. You should also identify surrogates in your living will.'

I saw the wisdom in her statement. 'So what should be my first step?'

She smiled victoriously, 'Call my mother in and let's start talking about it.'

There was silence in the room for several seconds. Then I said, 'Jia, you have had education as per western standards and hence you grasp everything quickly when it comes from that type of thinking. But I feel you have not understood the nuances of Indian culture.'

'What do you mean?' there was an edge to her voice now.

I explained, 'If you look at the dynamics of western or developed countries you will see that more and more people are now living alone. They are either divorced or are shunning marriage. In Denmark, Finland, Germany, Sweden, etc., nearly half the households are single-person households (in India, it is still <10%).¹⁵ Hence, they are used to making all decisions independently. The dominant thoughts in their mind are autonomy, liberty and equality. Increasingly, community, family and friends play a relatively minor part in their lives.'

'But I am in India!' She retorted.

'Being in India is different from understanding what India means.' I suggested. She did not appear convinced. But I carried on. 'Traditional Indian thought is the opposite of western outlook. Family, fraternity, duty, patriotism and hierarchy are the dominant thoughts in traditional Indians. Sanctity and purity of mind is respected above all. Individual autonomy plays a much smaller part in an Indian's life. What happens to

me is everyone's business in a village. What the village decides for me, I will find difficult to deny!

SD also chipped in, 'What uncle just said is true. We would never have thought of colouring our hair green, for the fear of upsetting our parents.'

But his remark was not taken kindly. 'Da...aad! Why does my hair colour crop up in every conversation of yours? You want me to be in a *ghoongat* (veil) and follow in my husband's footsteps to the jungle? It's not going to happen!'

'SD, don't.' I did not want the conversation to be hijacked in a different direction. I added, 'No, I was not talking of your hair colour. What I said was that in our villages, it's pretty much my community or fraternity that will take most of my personal decisions, because I am going to be looked after by them if something goes wrong.'

'As if someone will really help!' She was sceptical.

I said, 'Well, in cities we all are moving towards the western social order. Some of us have moved faster. Like you, if I may say. I don't blame you because you have never been exposed to the village atmosphere. We, of the older generation, just shuffle slowly towards modernity.'

She seemed to agree, 'Mamma has not moved at all.' She laughed at her own joke.

She quickly added, 'But our judiciary is rapidly accepting these values. I told you about the *Common Cause versus Union of India case (2018)*⁷ which allowed the living will, then there is the *Puttaswamy case (2017)*¹⁶ which has given us the right to privacy, and now this *Navtej Singh Johar case (2018)*¹⁷ which has decriminalized all consensual sex among adults in private, including homosexual sex.'

I said, 'Nothing unusual! Judges are also urban-bred. Have patience, we all will eventually reach where you are, but it will take many more discussions and convincing. So, what you said sometime back is important.'

'What did I say?' She raised her eyebrows.

'*Baat to karo* (At least let us start talking about it).'

Note: The characters are fictitious. The subject matter of living will was discussed by Dr Roop Gursahani, MD, DM, FAAN, Consultant Neurologist and Epileptologist, P.D. Hinduja National Hospital, Mumbai, and Professor O.V. Nandimath, Professor of Law, National Law School of India University, Bengaluru. Many points presented above are inspired by this discussion. They were speakers at a workshop on 'Death and Dying' on 6–7 November 2019 arranged by Karunashraya, Bengaluru, Karnataka, India.

* At the time of writing this article, the website www.onelittlewish.org was active. Unfortunately, the website is no longer active due to shortage of workforce. Similar information can be obtained from the following websites: (i) www.palliativecare.in; (ii) <https://palliumindia.org>; and (iii) <https://vidhilegalpolicy.in> (for legal aspects) till such time as www.onelittlewish.org is reactivated.

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