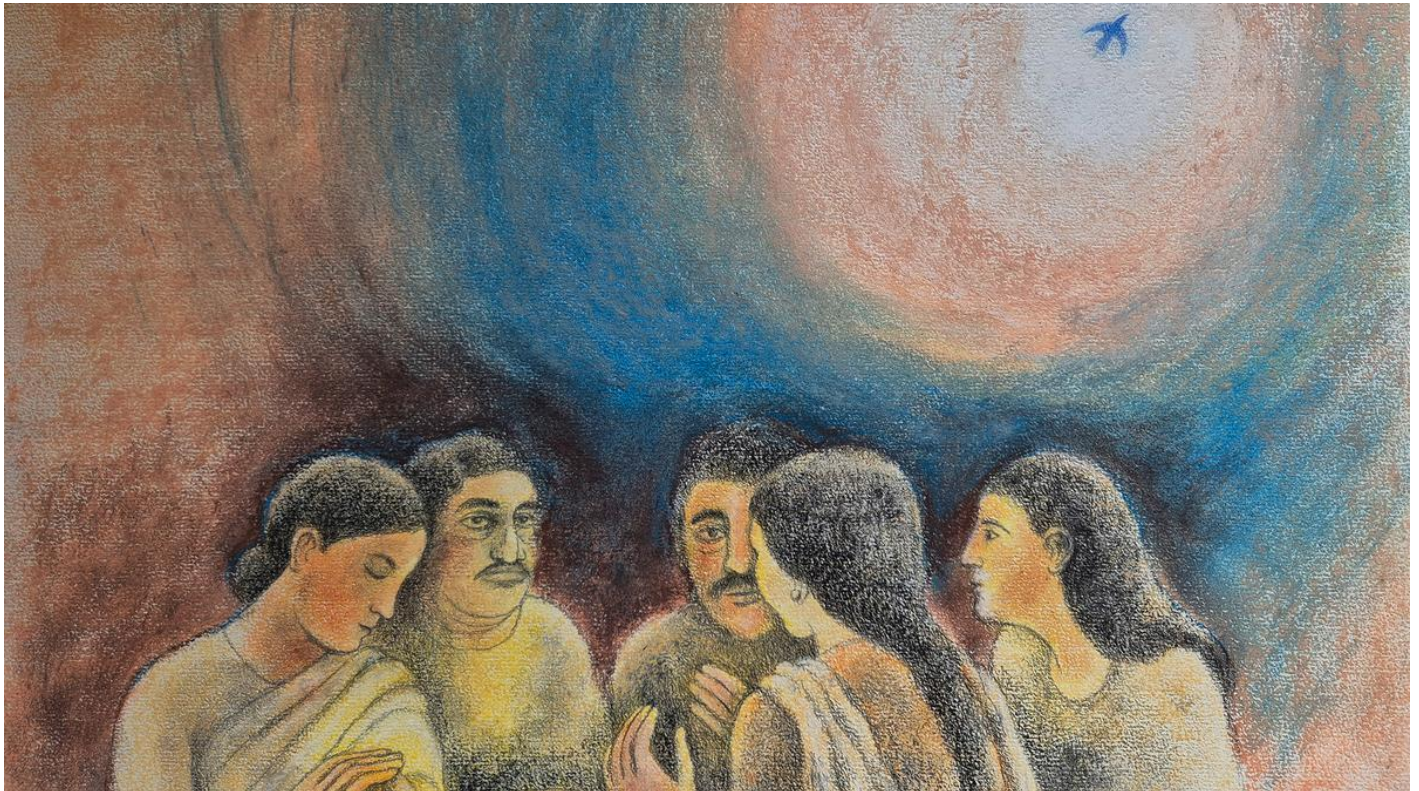


Ever been to a death cafe in India? | Tracking recent initiatives around death literacy in the country

India is a death-avoidant society, but a growing awareness of death literacy is helping change mindsets

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RESHMI CHAKRABORTY



The cultural reluctance to talk about death results in people avoiding important decisions pertaining to their final days. | Photo Credit: Illustration: Priya Sebastian

As primary caregiver to ageing and ailing seniors at home, death is always on my mind these days. I see it inching its way forward, slowly and certainly, as limbs fail and memory fades. How would you like to go, how would you like to be remembered, I want to ask. But like most Indian families, our conversations around death are limited to the medical and pragmatic aspects of it — medication, wills, division of assets... Its emotional aspect remains unaddressed.

That is why Manisha Sheth's story strikes a chord with me. A Pune-based environmentalist who runs the social enterprise eCoexist, Sheth grew up watching her mother, Dr. Madhuri Sheth, care for sick and dying relatives at home. She watched as they passed on, removing the unfamiliarity around death. "I grew up in a family where death was a very common topic of conversation. My mother wanted to normalise death and familiarise us with it. It was not a taboo topic," she says.

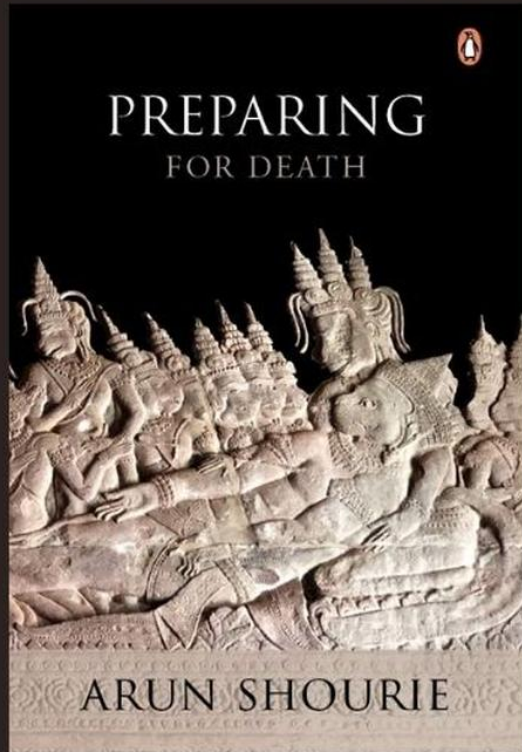
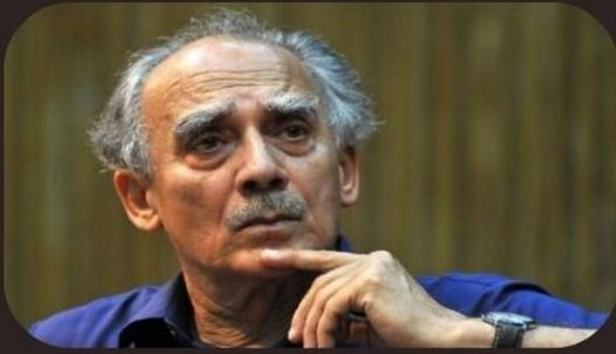
When Dr. Madhuri was diagnosed with a tumour at 86 and chose not to get any invasive treatment for it, Sheth had had a lifetime of preparation. Her mother eventually passed away at home, in her arms. "Even on her last day, she didn't want a doctor. She had brief panic attacks, just once or twice. I could only stand and watch without getting carried away by my own emotions or fear, because all my life she had prepared me for it. In her final moments, I was telling her 'ma, let it go now, please, don't hold on anymore', and she nodded and left. So, we walked through it together. This was all only possible because we were death literate," Sheth says. She calls her mother's passing the most powerful experience of her life.



Manisha Sheth (right) with her mother, Dr. Madhuri Sheth.

Inspired by how talking about death with her mother enhanced her caregiving journey, Sheth now supports others to do the same through a close-knit online study group of 50 members, called Dying To Learn. Few of us grow up with the exposure to death that Sheth received. On the contrary, many in India consider death inauspicious to talk about, making us a death-avoidant society. This cultural reluctance to talk about death results in people avoiding important decisions such as end-of-life care, organ donation, and even funeral preferences. To add to that, information about options such as Advanced Care Planning, Advanced Directives (AD) and eco-friendly funerary practices is inaccessible and scattered. In the 2015 Quality of Death Index, which ranks end-of-life care globally, India was 67th out of 85 countries. In another ranking, the 2021 Outcomes of Quality of Death Index, India was at no. 59.

The COVID-19 pandemic may have brought death into focus, forcing many of us to face our mortality. But did it make us more death literate? Perhaps from a practical point of view of organising assets, but a lot still remains to be done. This is where the growing number of death literacy initiatives can help.



In his book, **Preparing for Death** (Penguin Random House), **Arun Shourie** writes, “Death is certain; its time, place, manner completely uncertain,” adding that one way to prepare for the inevitable is to get to know it — to look upon death, as has been said, not as a destination that we will one day reach, but as a companion that is always walking arm-in-arm with us. The politician-economist picks five persons from history and discusses their last few months and days in detail to provide a perspective on death: Gautama Buddha, Ramakrishna Paramahansa, Ramana Maharshi, Gandhi and Vinoba Bhave.

Memory as a tool

In 2020, researcher Kritika Sharma who works in behavioural design launched Maajhi, a death literacy platform, to spread awareness of the concept. “Death literacy is the development of knowledge, skills and language that individuals need to understand, access, and make informed choices about their end of life and to support their loved ones,” she says. Maajhi means ‘ferryman’ in Hindi. “Many cultures believe that the ferryman takes the soul across after death,” explains Sharma, whose father, Retd. Wing Commander Rakesh Sharma, the first Indian citizen in space, suggested the name.

Maajhi offers people a chance to write their obituary and conducts death meditation sessions, among other resources. There is also a toolkit called ‘Last Dialogue’ to help the bereaved navigate their loss. The 21 prompts of Last Dialogue were inspired by conversations at the Bengaluru hospice, Karunashraya, and developed in assistance with individuals in design, psychology, medicine and academia. Sharma’s favourite prompt is ‘What was the one thing that your loved one never took credit for?’ It gently nudges participants to remember a loved one, not with a heavy heart but with a fond memory.



Kritika Sharma, founder of Maajhi, a death literacy platform.

When Benna Fathima, 25, a research scholar at Ashoka University, lost her friend Muhammed Fasil to muscular dystrophy in 2019, it came as a complete shock. Fathima was a high-schooler when she met and became friends with Fasil. Though she knew his days were numbered, she pushed that thought to the back of her mind as the two went about town, spending time at the beach and with other

friends. When Fasil passed away, Fathima was studying in Delhi. "I could not take one last photo with my friend. That's when I first realised the suddenness of death." Despite their deep friendship, Fathima and Fasil had never spoken about his imminent death. She now wonders how Fasil would have liked to be remembered and wishes they had spoken about it.





(Top) Research scholar Benna Fathima; and (above) with her friend Muhammed Fasil.

Memories can help us process grief. And talking about grief and death, while helping us face our own mortality, can also provide the tools to support others in their loss.

It is with this intention that Kozhikode-based Institute of Palliative Medicine (IPM) started a two-day workshop in Bereavement Companionship, in collaboration with Death Literacy Institute, Australia, in 2021. The programme runs every month, with online and in-person sessions, and offers training modules around different stages of grief. Saif Mohammed, academic consultant at IPM, says that despite its famed palliative care system and strong community support for families of the dying, the state of Kerala is not death literate. “When someone dies, food is cooked for the family by friends and neighbours, and children are cared for. The wrong notion was that this was bereavement support.”

Even support systems that take care of basic necessities can miss out on the emotions that the demise of a loved one can evoke in their near and dear ones. “People are not aware of how to address grief beyond practical help,” says Mohammed, who also facilitates workshops and ‘death cafes’ — the latter is a gathering of strangers talking about death over tea and cake, a concept first introduced in London in 2011, inspired by Switzerland’s Café Mortel movement.



The student volunteer team of the Palliative Care Programme at Institute of Palliative Medicine in Kozhikode.



The Kerala model

Kerala is the only state to develop a globally acclaimed community-led palliative care model. The first initiative was set up in 1993 with the establishment of the Pain and Palliative Care Society, spearheaded by Dr. Suresh Kumar of the Institute of Palliative Medicine and Dr. M.R. Rajagopal of Pallium India. A Neighbourhood Network for Palliative Care was set up for community support, home care, and volunteering. It aims to enhance the lives of the terminally ill and their caregivers through pain management and the asocial and emotional welfare of patients. The palliative care system comprises local authorities, non-profits, community-based groups, and over 4,000 volunteers. A large network of doctors and nurses supervises over 5,000 patients — possibly the world's most extensive community-run palliative care network, say experts.

Ritual books and death cafes

Every time Minakshi Dewan does a talk around her meticulously researched book *The Final Farewell* (2023), she has a packed house. The book explores rites and rituals associated with death across India, and it has generated curiosity across age groups, she says. "I get questions around theological concepts, body donation, why Hindus prefer cremation, why Parsis are not open about cremation and burial, and so on. This is because avenues to talk about death are limited."

Dewan became interested in the subject after she performed her father's last rites. She recalls feeling a little lost because there was no accessible information or conversation. "I wasn't even aware of the alternative, environment-friendly funeral options back then. Since we don't know, we can't make informed choices. We need to start creating that awareness and initiate those discussions," says the writer-researcher, a Ph.D in Social Medicine and Community Health.



Minakshi Dewan discusses her book 'The Final Farewell'.

Common queries heard at Minakshi Dewan's book talks

- Can a Hindu opt for burial, or a Muslim for cremation?
- How does one price various funeral services?
- What are sky burials and why do some communities such as the Parsis or Tibetans opt for them?
- What happens to the soul if some rituals are not followed? Do these practices stem from superstition?
- What is body repatriation?



(Dewan addresses these questions in her book, **The Final Farewell**).

Ravi Nandan Singh, author of *Dead in Banaras* (2022) and professor at Delhi's Shiv Nadar University, says that much of his research has been around funerary practices in Europe, where people are more open about discussing death. "They decide whether to be buried or cremated and even choose the font of inscriptions on their tombstones!" He attributes it to the fact that in the western world, there are agencies that enable such conversations — societies hold regular meetings and museum spaces conduct discussions on death. "In India, there is now a small space for conversations around death but often that does not get connected to a larger one within the community," says Singh, who organised an International Death and Grief Conference at his university in January this year.



Ravi Nandan Singh, author of 'Dead in Banaras'.

Forums where one can share and discuss mortality, death and dying are emerging in India, nonetheless. Death cafes are organised in some states, with regular sessions being held in Kerala. "These are two-hour-long gatherings with no more than 20 people," says Mohammed. With a facilitator to guide the conversation, everyone in the group is encouraged to share their thoughts and worries. Mohammed says the death cafes he has hosted have seen a mix of young and older participants. "They reflect on personal topics such

as their legacy, how they wish to die, and the importance of discussing these matters with family members. There may be hesitation at first, but eventually participants realise that discussing death is not a bad thing and go home and talk about it. It is a chance to reflect on life.”

Sharma agrees. “Conversations around death actually lead to thinking about your life purpose and your priorities.” One of Maajhi’s popular offerings is the death meditation, which Sharma describes as an extension of the *savasana* (corpse pose) in yoga. “I walk the person through what it would feel like to die from a physical, mental, emotional, spiritual, and psychological state. I take them through the process of the body shutting down as some functions fail. It’s experiencing what the last few hours of one’s life might look like.”



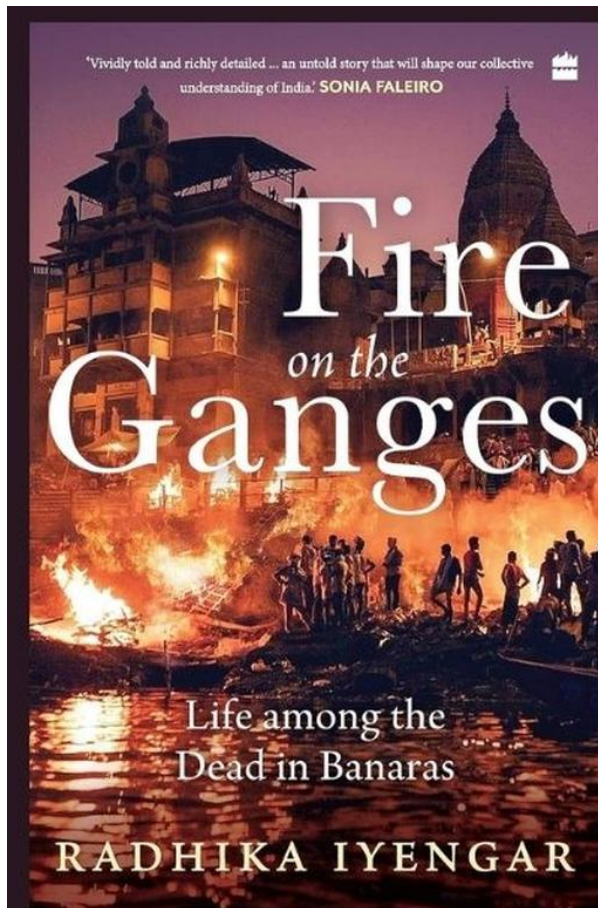
A self-obituary themed art installation by Maajhi.

Talking about death may be triggering for someone already in a dark space, so Sharma emphasises mental health awareness and support in facilitating a safe and meaningful death meditation experience. She sends clients a questionnaire co-developed with a psychologist to establish boundaries and ensure that participants are adequately supported after the session if needed.

Starting early

Mumbai chef Gaurika (name changed on request) went to a death cafe as a student in London because she was curious. “I had fears it would be morbid but it was like a hobby club meeting in a cafe, except that some people came with objects their late loved ones had left behind, and some came because they were curious like me.” Gaurika says she came away from it with a new appreciation for life.

Getting comfortable with the concept of death may thus be an essential life lesson for young people. In nuclear families of today, children rarely see death, making it both alien and fearsome. In his book, *Walk With The Weary: Life-Changing Lessons in Healthcare* (2022), M.R. Rajagopal, a palliative care pioneer and Padma Shri awardee, writes how “modern families shield children from inconveniences such as death”. He talks about witnessing an uncle’s death as a child and being involved in the mourning process that taught him a valuable lesson — accepting death as a natural part of life.



In her deeply researched book, **Fire on the Ganges** (HarperCollins), Radhika Iyengar documents the lives of the Doms of Banaras who have been performing a specialised funerary practice for generations, but have yet to see upliftment in their lives, and continue to be regarded as untouchables. She bears witness to the non-stop fires burning at Manikarnika Ghat, one of the most important Hindu cremation sites in the world. Her story is about the everyday existence of Doms, a Dalit sub-caste that remains “isolated and unseen”.

This is the idea behind IPM’s Students in Palliative Care Programme that has volunteers from colleges across Kerala. They organise a cultural festival, help facilitate death cafes and encourage conversations around death and dying. Such initiatives, says Mohammed, help in fostering a culture of understanding around death and dying, and every age group needs to have these conversations. He recalls a death cafe in Amritsar, attended by senior professors from a medical college. “Some of them started crying and said it was the first time they were having such a discussion. These are people who teach daily about diseases and cures, but they were unaware of the need to talk about death.”

Sheth, who is now a caregiver to her 90-year-old father after her mother’s demise, says she continues talking to him about dying as she did with her mother. She sends me short videos of his views on death and living a rich, fulfilling life, even as they joke about “going *upai*”. She believes that discussing death openly can demystify it and help others cope with their fears too. “Healing can come from very unexpected sources if you stay open.”

The writer is a freelance journalist and the co-author of 'Rethink Ageing' (2022).

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