

Live Forever, for the Moment

“Never give up on the good times; living it up is a state of mind”

“Live forever, for the moment” is an intense deeply meaningful line from the song “Viva Forever” which was released in 1998. Amongst the many interpretations of this powerful song, in my opinion the one that relates the most to us is about living the life to the fullest in midst of loss and individual’s struggle with emotions. The Chinese word for “crisis” is made up of two characters “danger” and “opportunity”. Our patients with advanced life limiting illness are thick in crisis. They are facing the danger of death and are finite moments away from the inevitable. How many are able to live forever for the moment? What have we done to help them to face danger? What opportunities do they have? Are our patient’s dying well? What are we doing to ensure that our patients die well? Are we doing enough? The list of questions are endless, the answers are yet to be fully known. All efforts until now have only transpired into a modest beginning and we are hopeful that from now on it will be full steam ahead all the way.

In the early 2000, Indian Society of Critical Care Medicine (ISCCM) spearheaded by Dr Raj Mani and others worked on addressing palliative and end-of-life care needs in intensive care unit (ICU) and critical care setting. Two landmark papers were published in 2005 and 2012 in the Indian Journal of Critical Care Medicine (IJCCM) on limiting life-prolonging interventions and providing palliative care towards the end of life in Indian ICU and consensus ethical position statement on end-of-life care and palliative care in Indian ICU setting.

In February 2013, the Indian Association of Palliative Care (IAPC) initiated the process of creating a consensus position statement on end-of-life care policy which gathered momentum in 2014 and a steering committee

headed by Dr Stanley Macaden was formed to create this document. In April 2014, a consortium was created to address the gaps in end-of-life care provision in India. The consortium comprised of members of ISCCM and IAPC led by Dr Shivakumar Iyer, President ISCCM and Dr Nagesh Simha, President IAPC. Over the next few months, a consensus position statement on end-of-life care policy (Stanley Macaden *et al.*) was published by the IAPC in the September–December 2014 issue of the Indian Journal of Palliative Care and joint society position statement of IAPC and ISCCM termed “End-of-life care policy: An integrated care plan for the dying” (Sheila Myatra *et al.*) was published in September 2014 IJCCM. The consortium also created standard education modules and webinar modules for end-of-life care teaching and pilot run of these modules were carried out in few select centers across India during ISCCM Day and World Hospice and Palliative Care Day (WHPCD) in October 2014. These accomplishments were presented in the Inaugural Conference of the International Collaborative for Best Care for the Dying Person, in November 2014 at Sweden.

The February 2015 IAPC conference had a plenary on end-of-life care by Dr Mani and there was a session on joint position statement. The Indian Critical Care Conference in March 2015 had sessions on end-of-life care topics and all the participants of the critical care conference received an end-of-life care tool kit, copy of educational modules, and end-of-life care checklists. IAPC is planning to join the International Collaborative for Best Care for the Dying, which is an international association for continuous quality improvement for the dying. A book on end-of-life care is anticipated shortly and many individuals and institutions are taking up research on end-of-life care. There are also attempts towards unambiguous legal standpoint on end-of-life care policy. With this regard ISCCM has filed a petition in the Supreme Court to be impleaded as a party along with NGO Common Cause in the case on withdrawal of life support to terminally-ill patients.

The economic intelligence unit of Lien Foundation, Singapore is going to release shortly the results of 2015 worldwide quality of death study. The findings of 2010

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study showed that India ranked 40 out of the 40 countries studied. While interacting with some of the researchers involved in the 2015 study, I came to know that the number of countries studied this time is much more than 2010 and India is not fairing as well as we are expecting. We may have to wait for some more months for the actual results.

In the last 2 decades there were some sporadic work on end-of-life care in India carried out by select few individuals. However in last few years we see these efforts slowly consolidating and snowballing. We are at present, at the doorstep that will mark the change in how we care for our patients who are dying with advanced life limiting illness. Accomplishments of 2014 and 2015 on end-of-life care has provided inspiration and rejuvenated hope. Integrated care plan for the dying is the new mantra adopted by the critical care society and palliative care association of India.

We can only hope that in the days to come, joining hands by both societies will facilitate seamless care for the dying. End-of-life care is not just dying with dignity, but also living forever for the moment until the person embarks on his or her last natural process of life.

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