

SEEING THE WORLD

WITH 2020 VISION

By Ira Byock, MD, FAAHPM

It's already getting difficult to recall how things looked before. The events of 2020 have dissolved collective illusions of longevity, racial equity, rational governance and economic stability.

Sudden deaths and rapidly progressive illnesses have always occurred, but they've been sporadic and, for most people, ignorable. That's changed. No matter how often we wash our hands, wear masks and maintain physical distancing from others, COVID-19 can find us. We can reduce our risk, but not to zero. Dramatically higher rates of infection and death from COVID-19 have revealed stark, long-standing health disparities suffered by Black and Latinx Americans, people who work or live in crowded conditions, those who live paycheck-to-paycheck, or depend on their employers for health insurance or have no insurance at all. Failures of basic responsibilities by federal and state officials have cost many thousands of lives. People across the political spectrum are appalled by the blatant malfeasance of elected officials.

Remember when "2020 vision" was something desirable?

This new clarity reveals essential truths about the nature of being human. Foremost is the fact that we matter to one another. And that, one way or the other, we will all lose one another. Either I will

die before you or you will die before me. No longer is death awareness confined to those of us who work in hospice and palliative care.

Hospice and palliative caregivers have always known that loving relationships are essential to human wellbeing and that separations cause suffering. Now, these primal facts are shown in endless variations in stories on our screens.

In the cold light of the present-day realities, the fundamental social question that confronts human beings is now before us in bold all-caps: **HOW THEN SHALL WE LIVE?**

Responding defines the creative work of community. At an elemental level, the answer is straightforward and frames the work ahead. Whatever else we choose to do and be, we must be kind and generous with one another. With those stipulations, professional and cultural communities can go about assigning tasks and accountabilities, developing policies and practices, and evolving behavioral norms and traditions. The results – the details of public policies, regulations, payment mechanisms, professional and business norms – will speak for us. Communal efforts grounded in fairness and generosity are needed our actions to state without shame, "This is how we live."

The pandemic's long-term impact on health care will be profound. The plight of our countrymen has persuaded many Americans that health care must be considered a human right, rather than a perk of employment or privilege of the well-to-do. Suddenly, universal access to health care and extending Medicare and Medicaid to uninsured Americans are not polarizing ideas. Increased federal oversight and financial support for research and public health measures are widely discussed as sound policies. Temporary waivers of regulatory restrictions in health care delivery will result in durable improvements that have been long in coming. Look for cross-state licensure for doctors, nurses and other clinicians to be



Whatever else we choose to do and be, we must be kind and generous with one another.

codified in federal and multi-state compacts. Seemingly overnight, telehealth was established as fully legitimate and, in some applications, an advantage over face-to-face care. Beyond health care's walls, Americans increasingly recognize that social determinants – racial equity, nonviolent neighborhoods, adequate housing, and safe working environments – are more important to people's health than is medical care.

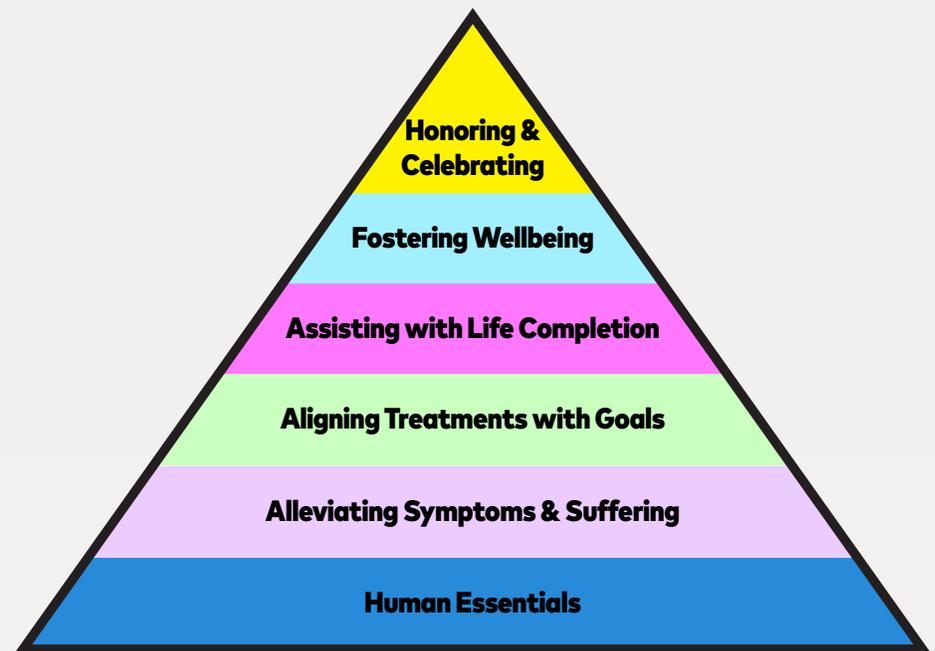
Health care workers have been elevated in public esteem. Hospice and palliative care providers have been recognized as essential workers and the services we provide are widely viewed as critical components in the care continuum. Nurses are now rightly seen as heroes. So, too, are nurse aides.

COVID-19 hasn't changed the fundamentals of human caring that we know so well. It has, however, highlighted a hierarchy of human needs and potential. The biological and social necessities of life form the base of a Maslowian pyramid: providing a clean, dry bed, something to eat and drink, and when needed, help with eating, drinking, and eliminating. These rudimentary responsibilities define a caring society. On this foundation, health care, particularly hospice and palliative care, adds therapeutic layers of interdisciplinary expertise.

People in our field begin, as we

always have, by showing up. We lean in to poignant and often tragic situations from which others tend to flee. We treat pain and alleviate the symptoms and suffering that often accompany illness and dying. With skillful questions and listening ears, we identify people's personal values and priorities. We invite patients and their families to share decision-making, ensuring that medical treatment plans are consistent with what people want.

Dying Well in the Era of COVID



During COVID-19, palliative care and hospice caregivers have utilized novel ways of transcending physical separations, enabling families to visit, say things to one another that might otherwise have been left unsaid. Nurses and others are holding the phones and video tablets that enable people to share precious moments, tell stories, offer and ask for forgiveness, and express gratitude and love for one another.

Despite the barriers to human contact that PPEs and pandemic visitation policies impose and the discomforts and dependencies of serious illness, people can be made to feel wanted, worthy and dignified in the way they are touched and the tone with which they are spoken.

People who feel at peace within themselves, right with those they love and within their communities, and right with their God, can feel loved and, sometimes, experience at least moments of joy.

Stories of caring in this pandemic will be told visually as much as in words. Anyone reading newspapers or watching the news has seen



People in our field begin, as they always have, by showing up.

iconic photos and video clips showing gowned nurses, respiratory therapists, aides and doctors turning intubated patients in careful synchrony, and caregivers wearing “Face Behind the Mask” posters on their hospital gowns as they introduce themselves to patients. In one photo a hospice nurse stands outside a building looking up to her patient on the second floor. She’s waving a paper heart she holds in her left hand while her right rests over her own heart. A chaplain prays with patients who are safely behind nursing home windows. A large church congregates in a vacant field, praying together safely from their respective cars. A daughter holds a “We love you, Mom” sign from outside the front door. People blow kisses across FaceTime screens. Screen shots show families gathered by Zoom: one in mid-sentence; another trying to smile while holding back tears; a couple cradling their infant before the camera; a teenager staring in wide-eyed silence; all honoring and celebrating a person they love who is ill and may not survive. Our field bears witness to the potential for well-being in dire predicaments.

Hospice and palliative caregivers in every corner of our country are, once again, teaching by example and adding to an experiential curriculum that was not wanted, but is, nevertheless, invaluable.

People in the United States have been harshly taught, once and for all, that American exceptionalism is just a phrase. We’ve been forcefully reminded that human beings are inextricably interconnected. What happens in China doesn’t stay in China. What happens in New York City, Los Angeles, Detroit, Minneapolis, Miami, Houston or Atlanta matters to us all. And what our leaders in Washington, DC and our state capitals do – or fail to do – affects us all in the most intimate of ways.

Through countless acts of skillful caring and kindness, people who comprise our field are acting clinically and locally and contributing culturally and globally. Because, after all, we are all in this together.

With 2020 vision, that much is now clear.

Ira Byock, MD, FAAHPM, is the Founder and Chief Medical Officer with The Institute for Human Caring.

Dr. Byock to be Opening Keynote

2020 Virtual Interdisciplinary Conference

Ira Byock, MD, FAAHPM, will deliver the opening keynote presentation at NHPCO’s [2020 Virtual Interdisciplinary Conference](#). Join us live on October 14, 2:00 p.m. ET for “Back to the Future - Fulfilling the Promise of Human Caring.” Registration for the VIDC is open now.

