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Diagnosing dying: is it time for doctors to write “dying certificates”?

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“Humans are gardens to tend, not machines to fix.”
 Source: *One of the author’s Mums....and she was right.*

Few people are scared of being dead, but many of us fear dying. This is because death is a pain free point in time, whereas dying is a process. Despite the fact that all of us will face both of those “D words,” many doctors, nurses, patients, and families overdo a third “D word”—denial. In this biotechnologically obsessed world, we are becoming increasingly less able to countenance a “natural death,” or to understand what truly matters in our final days.

It feels like patients and practitioners now increasingly channel Dylan Thomas’s poetry as we *“Rage, rage against the dying of the light.”*¹ The intensive care units that we work in are a technical marvel, no question. But for those who are already dying when they arrive it comes at a huge cost—both literal and figurative. At a time when community and connection matter most, we too often default to high-tech and low-touch. Moreover, misguided heroism on the part of medicine can mean whisking people away from those they love, and from the homes, and familiarity that they deserve. When the dying should be unencumbered, instead we insert more tubes than the average bagpipe. These well intentioned “medical assaults” help all claim that we “fought hard” and mean nobody is accused of “giving up.” The discrepancy between what so many people want at the end of life and what they may receive is something we should all be raging about.

When it comes to death, making the diagnosis is emotionally draining, but has been central to the doctor’s job for centuries. Ever since bodies could not be left to rot, doctors were called on to confirm no pulse, no breathing, no reaction, and then to write that down—unequivocally. This confirmation takes approximately two minutes, but can be chilling. Your mind can even play tricks as you feel your own pulse and hear your own heartbeat. Regardless, you soldier on because it’s important and because society needs to know. Which brings us to the second D word—dying. In other words, what does society need from its doctors now that patients can be kept going long after the point of no return? Perhaps we need to start issuing something akin to “dying certificates,” not just death certificates?

Modern medicine is a marvel, but can be a curse, especially for frail, older people, and especially those with terminal disease. A “dying certificate,” or at least unequivocal communication, helps everyone understand that the end is approaching and is likely unavoidable. If a certificate seems too dramatic, too certain, then at least let us commit to speaking and writing more clearly. As the type of doctors who are called at the 11th hour, we can tell you there is often no end of obfuscation in that lead up. For example, “the prognosis is guarded” should be reserved for

those rare cases where things really are uncertain and all bets off. If instead the patient is actually in “terminal decline,” and most likely approaching death, then write that instead. Take a leaf from palliative care physician Kathryn Mannix and say: “they are sick enough to die.”² Communication has always been the most important procedure in medicine. Let’s move beyond euphemisms. Let’s prescribe compassionate candour.

Those who scoff at “dying certificates” are likely to point out that prognostication is imperfect. Fair enough, but imperfect is not the same as impossible. They may also exaggerate the risk of litigation, or highlight their fleeting involvement, or state that “one case.” This means that the default is to prescribe “everything” without admitting that the current “everything” is pitifully limited to pills and machines. Patients and families really want memories, connections, and meaning, but there the medical toolbox is comparatively bare. Instead of 30 minutes of conversation we default to two weeks on machines. Without something akin to a “dying certificate,” we merely repeat data such as oxygen levels and urine output. We write a long note that communicates little.

Not only are too many patients not getting what they deserve, it’s also not happening where they want. For example, once upon a time, humans died at home, surrounded by family, friends, neighbours, and pets. As the mortician Caitlin Doughty has explained, “Home was where the death was.”³ The wider community came together, and spent the time—whether hours, days, or weeks making sense, finding courage, teaching, and learning. In those days, a “dying certificate” was not needed, because dying was accepted, and machines could not prolong. Instead, hands were held, tea was poured, cakes were baked, and dogs were petted. Nowadays, dying hides in plain sight. It is institutionalised, technologically-mediated, and obscured by monitors and Latin words. In hospitals, the tea, cake and pets are frequently banned, and family visitation is policed. Doctors still claim expertise because we know the pills and machines. However, let’s admit our amateur status when it comes to helping families make sense, connections, and meaning. Dying should be nurtured by society, instead it has been highjacked by “big medicine.”

For balance, it is important to understand that we have also institutionalised death because it can be so traumatic when it happens at home; especially without basic resources, whether suction, analgesia, oxygen...or other humans. It’s rare for ICU doctors to argue for a smaller budget, but we would have few complaints if resources were reallocated towards home care, palliative care, and keeping people in their communities and alongside friends. Moreover, while intensive care medicine was established to offer

short term organ support to those with reversible disease, it is now increasingly providing expensive terminal care, and venerating life-extension over quality. It's never too late to do the right thing. We mean this both for our specialty and for our patients.

Perhaps the change was inevitable. Circa 1950, critical care's early physicians warned that "At the beginning of ICU it is a problem to keep the patient alive, eventually it will be a problem to let them die."⁴ We may not be great at prognostication, but our forefathers sure called this one. Regardless, it took courage to grow intensive care into a specialty that has saved countless lives. It will take the same candour to mature into a specialty that saves as many deaths. Despite his initial protestations even Dylan Thomas came to realise this. The poem's early denial of his dad's death may have inspired "rage," but even this firebrand eventually admits that: "wise men at their end know dark is right . . ." The trouble nowadays is that wise men and women may not be the ones doing the resuscitation—they may be the ones forced to receive it.

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- 1 Dylan Thomas. *Do not go gentle into that good night*.
- 2 Mannix K. *With the end in mind*. William Collins, 2018. https://books.google.co.uk/books/about/With_the_End_in_Mind_Dying_Death_and_Wis.html?id=XcEuDwAAQBAJ&printsec=frontcover&source=kp_read_button&redir_esc=y#v=onepage&q&f=false
- 3 Caitlin Doughty <https://caitlindoughty.com/>
- 4 Brindley PG. *The Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionized Modern Medical Care* | *Canadian Journal of Anesthesia/Journal canadien d'anesthésie* (springer.com) Volume 70, pages 1711-1712, (2023).