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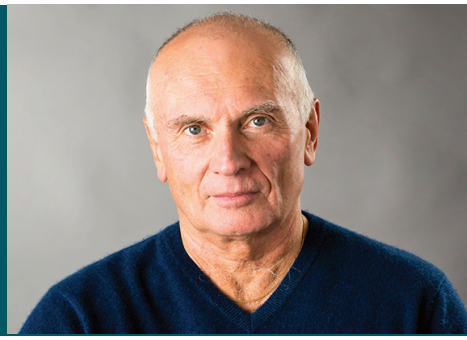
The Dignity and Messiness of Dying

by Dr. Paul Dunion, Transformational Faculty Member



"I don't want to die like an asshole!" an old friend cried out to his spouse several weeks before he took his last breath. My friend was bright, extremely creative and loving, with his last days offering testimony to rejecting an inauspicious death — one without dignity. What does a death lacking dignity look like? Is it protesting the inevitable, even to our last breath?

As Dylan Thomas encourages:

"Do not go gentle into that good night,
Old age should burn and rave at the close of day;
Rage, rage against the dying of the light."

Or could a dignified death be a bit more tranquil and possibly more welcoming as suggested by Emily Dickenson?

"Because I could not stop for Death-
He kindly stopped for me –
The Carriage held but just Ourselves –
And Immortality."

Even those believing in reincarnation likely don't remember how they died in past lives. So how do we prepare for something we do only once in this life? Is there any way to acquire some practice dying?

Practice Dying and Birthing

Living in a death-denying culture places an immense burden upon our relationship to dying. To deny death is to suggest on some level it's simply not real. Our efforts to bring meaning to dying need to be counter-cultural whereby we personalize and reclaim the dying experience. We live with a myriad of euphemisms for the word die. A marriage ends, work is terminated, a project closes, a school year is complete, the weekend finishes and time to register expires. Although there is nothing inappropriate about our euphemisms, when pushed they can mask the loss and grief associated with so many different endings.

Maybe It's not very easy to get honest about life being a series of moments coming (*birthing*) and going (*dying*), or about life offering opportunities to practice closure. Handling small deaths (*closures*) can be messy. We will likely have feelings of not getting it right, not doing enough, or doing too little. We'll feel rejected, forgotten, guilty for leaving or perhaps holding too many regrets to count. And what about being overwhelmed by the uncertainty of the moment? Often a job changes without our really acknowledging the transition. Neighbors die without recognition of those left behind. People move away and nothing is said about the loss.

We often leave relationships abruptly without being clear about our choice. This sudden and undisclosed departure in social media is called ghosting. Isabella Chan's recent Hartford Courant article sites the research conducted by Professor Royette Dubar and Jhanelle Oneika Thomas focusing on this closure avoidant phenomenon so common today. It occurs when a person decides without explanation to cut off all online and/or in-person communications. "When individuals engage in ghosting, they're almost robbing themselves,

and the ghostee, of opportunities to grow, to mature and to have the hard, maybe messy, very important interpersonal labor that will ultimately reveal healthy communication and healthy relationships," says Dr. Dubar.

She concludes that attending to these small deaths allows us to have richer lives. What's more, it's just good death practice! Let's challenge ourselves to possess enough emotional resiliency to feel and metabolize the messy feelings generated by dying and to hold enough receptivity and faith to open to the ensuing birth.

Maybe, we've been haunted by these ghosting experiences since Paul Simon bellowed out the tune, "Fifty Ways to Leave Your Lover" in 1975, none of which suggested something clear and honest. The haunting refrain includes *Slip out the back Jack, make a new plan Sam, you don't need to be coy, Roy, just set yourself free, hop on the bus Gus, you don't need to discuss much, just drop off the key Lee and set yourself free*. It would appear that a successful exorcism has not happened over the past forty-six years.

Dying and Birthing with Sarah

In March of 1975 my daughter Sarah was born. Before her first birthday a diagnosis of cerebral palsy and intellectual impairment became part of her identity. My wish for her to experience a normal childhood began slipping away like my hand growing helpless as it grasps the edge of a slowly sinking boat. The parental confidence attained by fathering her 4-year-old brother was replaced by an indiscernible mistiness disallowing me to identify anything resembling a trustworthy paternal bearing. I was dying on many levels.

Any clarity about how to relate to her and care for her remained just out of reach. My identity as a father was dying. How would I know what she needed and what comforted her? How could I effectively let her know I loved her? Each passing year another dream died. Dreams of her education, her professional life, her loves, marriage, grandchildren, the typical life crises and their remedies all began to fall away like autumn leaves drifting away from a sturdy limb. Cursing the gods, I took on a ritual of walking the streets of the neighborhood with a glass of whisky, seeking a much needed measure of sedation.

Loss had a way of dropping a shroud of dispiritedness and victimhood over any flicker of buoyancy. Clinging to a victim identity offered a temporary entitlement that Sarah and I deserved more. Mine was a voice gone unheard, preventing me from seeing what was being birthed.

Sometime before Sarah's tenth birthday the alleged value of victimhood began to thaw like a Spring snow. It simply lost its luster. I recalled a mantra that Victor Frankl (Man's Search for Meaning) employed while in a concentration camp. He would simply wonder: "What is this situation asking of me?" I began to use this watchword rather than continue to condemn the derelict attitude of the gods.

Slowly, two births became clearer. I had asked Sarah to carry my unpresentable traits. I had handed over my vulnerability, fragility, clumsiness, lack of verbal fluency, as well as a dependency with obvious needs. Reclaiming that dependency challenged my tightly held bravado. I became determined to liberate both Sarah and me by reclaiming what belonged to me. That was my first birth. With new vision, I could see Sarah's tenacious survivor, her determination to have a life, and her strength to persevere.

Our choice to keep Sarah at home rather than institutionalized had forced me to either work harder to pay for more assistance or become more of a caregiver myself. After stepping over a mind-numbing insistence to complain about it, I accepted the birth of a monastic calling I had previously rejected. Caring for Sarah was a metaphor for "chopping wood and carrying water." My life took on a new level of simplicity, asking me to drop into new dimensions of responsibility and acceptance.

Meanwhile, there was a knowing insinuation occasionally welling up in my chest suggesting Sarah was my teacher. My sizable measure of pride had easily dismissed any thought of being Sarah's student earlier.

Sarah's Big Death & Birth

Little did I know that an immense death and birth was about to befall Sarah and the entire family. Shortly before Sarah's 16th birthday, a local speech pathologist named Joe called and asked if he could do some work with Sarah. He explained that he had acquired a new communication technique while in Australia and wanted to explore it with her. While we appreciated

Joe's rapport with Sarah, we had no expectations that she might acquire real communication skills. So, we encouraged him to go ahead. Several days later Joe called reporting that Sarah had just spelled the names of her parents on a special keyboard. I simply saw Joe's report as a humanitarian's idealism coupled with unbridled hope.

A week later a call came from Sarah's special needs teacher asking us to attend a PPT (Pupil Planning Team) meeting. These were regularly planned meetings to evaluate a student's progress and recommend some possible new learning protocols. Normally included were her teacher, a physical therapist, an occupational therapist and possibly the coordinator of the special needs program. Instead, we received an unexpected greeting by the Superintendent of Schools along with an assemblage of some two dozen professionals. I'm sure that the shock and disorientation on my face was far from being appropriately veiled.

The Superintendent asked us to have a seat, the only thing that felt appropriate given what mysteriously was to take place next. He proceeded to say, "Yesterday, Sarah hung a banner in the cafeteria which read: 'My name is Sarah Dunion and I deserve your respect.'" My first thought was: *Has the entire room succumbed to professional fatigue or burnout, disallowing them to make cogent assessments of students?*

He continued, "I know this must be shocking to you. Employing the new facilitated communication approach, we gave Sarah a battery of tests which revealed that her verbal acuity is well above average. When we asked how she had acquired her verbal skills, she replied, 'My father placed me in front of our TV to watch *Sesame Street* twice daily.'"

We left the meeting numb, excited, and curious. I had many questions. Who was my daughter? How could I gently get to know her? What was it like to be locked in a body without a voice to the outside world? What was it like to be in a family where no one believed that you could take in and understand what was transpiring between them? What does Sarah want us to know about her? Having a non-communicative daughter with "little or no intelligence" was dying. Sarah was birthing a new identity — someone who could express needs, opinions, preferences, and dislikes. She could explore the nuances of human interaction such as levels of trust, kindness, estrangement, mistreatment, and making plans. Meanwhile I was birthing Sarah's new father in me and wondering what this was asking of me. When I asked her what it was like to be stuck inside and unable to get our attention, she said, "I almost went away." Although I heard the ominous implication of "I almost went away", I wasn't clear about where she would have gone. Nor was I clear now about what her new found presence would mean.

The Merger of Birthing and Dying

I have learned that birthing and dying can easily cascade swirling around the same event. The Parisian obstetrician Frederick Leboyer (1918-2017) reminded us that what we define as the birth of an infant child is likely a death for that child — a loss of the womb, the most connected and secure environment it will ever know. As well as a mother giving birth and sliding into Postpartum Depression as grief announces the end of a pregnancy.

So, it was with the emergence of Sarah's voice. She was still a 16-year-old teenager with severe disability, reflected in her compromised gross and fine motor skills, who reported feeling dangerously out of control of her body. We were quickly reminded that the acquisition of her voice would not necessarily vault her into mainstream society. For instance, when Sarah enrolled in a literature class at a local community college, the instructor made it clear that she would have to withdraw because her uncontrollable sounds and utterances were too disruptive to the class.

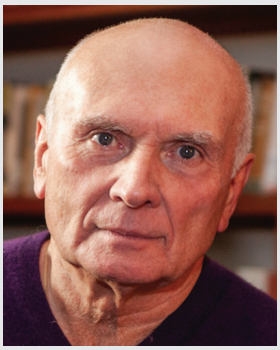
Integrating Sarah into society and family reflected the continuance of the dying and the losses, while her creation of poetry and art revealed a touching birth. Invited to London to address parents of disabled children, Sarah was becoming a teacher not only to me but to others. This kind of opportunity continues to delight Sarah and gives her an active voice in making a difference for others. Nonetheless, the loss of my fatherly dreams has remained close, only to be mitigated by witnessing the flowering of a beautiful, unique young woman.

With Sarah as my teacher, I remain a novice and an apprentice to Sarah's capacity to endure and be gentle, accepting, patient, kind and grateful. I have learned how to relate to diversity and the weight of my ableism, previously unaware of the challenges facing disabled folks. When Sarah and I travel into public places we often receive stares and gestures. Over time my annoyance

has subsided. I have gradually become comfortable with the gawking and petrified faces peering at us as if viewing strangers from a strange land. I have seen how much I am invited to make peace with my own limitations.

Birthing and dying are both unique and dynamic expressions of life. Could it be that Dylan Thomas' heartening us to "rage, rage against the dying of the light" allows what's messy to honor and celebrate what is lost? And Emily Dickenson's acceptance shown in her words "he kindly stopped for me" also captures a supple spirit capable of dignity.

I have seen myself indulging in both objection and submission as I have experienced dying and birthing with Sarah. I often hoped we could skip the messy parts when I felt defeated, inadequate, and lost. The seizures that wouldn't stop, fevers that would not break, the caregivers we could not find. I now look back and wonder if simply honoring our most genuine responses, some messy and some more refined, yields something approaching dignity. This is what's most important.



PAUL DUNION, Mobius Transformational Faculty, Senior Expert, and track leader at the Next Practice Institute, earned his Doctoral degree in Counseling and Consulting Psychology from the University of Massachusetts at Amherst and his M.A. in Philosophy from the University of Connecticut. He taught Philosophy for thirteen years at the University of Connecticut and Three Rivers Community College.

He has been in private practice for the past thirty-seven years. As a holistic psychological healer, employing an existential modality as well as a somatic approach to treating trauma, Paul is trained in EMDR and is a graduate of the Somatic Experiencing Institute.

From its early beginnings, Paul represented the State of Connecticut at the national gatherings of the mytho-poetic men's movement, sponsored by Wingspan. As the founder of Boys to Men, he created a mentoring community for teenage boys. He is the co-founder of COMEGA (Connecticut Gathering of Men), having served over 6,000 men since 1992, which continues to offer biannual retreats. In 2013, Paul established the Croton Mystery School and designed its curriculum with a focus on teaching students how to make peace with life's mystery and unpredictability. He has offered over 200 workshops on topics related to Human Potential. Currently, Paul offers supervision for younger psychotherapists.

Paul has published six books: *Seekers – Finding Our Way Home* (2016); *Dare to Grow-Up – Become Who You Are Meant to Be* (2016); *Path of the Novice Mystic – Maintaining a Beginner's Heart and Mind* (2013); *Shadow Marriage – A Descent into Intimacy* (2006); *Temptation in the House of the Lord* (2004); and his latest offering *Wisdom – Apprenticing to the Unknown and Befriending Fate* (2021).

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