

LORETTA DOWNS

*“THE MYSTERIOUS METAMORPHOSIS AT THE END OF LIFE”*

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As a child growing up in the city of Chicago, it was easy to find caterpillars, and even an occasional chrysalis hanging safely under a leaf or on the corner of a picnic table in a park. Bright orange and black Monarch butterflies were everywhere, a part of life in the Midwest where they flourished in the prairies on the abundant milkweed plants that fed their caterpillars. The mysterious metamorphosis of the Monarch butterfly, and its epic migration story, captivated me more and more as I went through my own metamorphosis of growing up and changing.

Fifteen years ago I met a woman who taught me how to raise Monarchs from the tiny eggs found on milkweed. There was no milkweed in my neighborhood so I scoured the local empty lots. That summer I raised 11 butterflies, rearing them from eggs to caterpillar to chrysalis and 10 days later joyfully released a Monarch butterfly for its first flight.

The lots go built on. They are now retail stores. I planted milkweed. In the summer of 2008 I released 300 butterflies. Last summer, just 12.

The Monarch population is rapidly declining to a worrisome low due to lack of milkweed and natural habitat, and too much pesticide.

In response to the fearful loss of these essential pollinators, [Monarch Watch](#) at the University of Kansas has mounted a social movement to protect the Monarchs through education, advocacy and changing our behaviors.

That's not unlike the social movement that started in the United States 20 years ago and is now spread across the world. That's a movement to change the contemporary end-of-life experience and to improve the quality of our deaths.

70% of us say we want to die at home with loved ones, yet 70% of us are dying in hospitals and nursing homes, often after receiving unwanted treatments.

Every living thing has a lifeline, from birth to death. Sometimes it's very short, like the butterfly's. Sometimes it's very long, like my 93-year-old mother's was.

Even after 20 years of being with the dying, people living the end of their lives, I never related mortality to myself. I had not thought about my own impermanence.

Until the Thanksgiving after my mother died.

I was sitting at the table with twelve of my close loved ones, from my twenty two-year-old godson who was on his way to Iraq with the Marines, and my 92-year-old aunt Vera, the last of my mother's four siblings still living.

The head of the house slowly said grace, "God, grant me the serenity to accept the things I cannot change, the courage to change the things that I can, and the wisdom to know the difference."

As he said those words, I suddenly came to the awareness that one of us at that table will be the first to die, and one will be the last. I started to have a panic attack, realizing I could be the first or last.

Fortunately they were passing the platters and bowls full of food and I decided to be present in that moment and enjoy this time with my family. I filled my plate. Twice.

Driving home I started to think. What if I died today? What would happen if I was on life support? What would my family do? Who would make decisions for me if I couldn't speak for myself? Would they know what I want?

I decided there was something I could do. I could prepare to die. Today.

So, I set Valentine's Day as my deadline to write a will, make a list of accounts and passwords, and take the first steps to considering advance healthcare directives by making my In Case Of Emergency decisions like life support and organ donation, and to choose someone I trust to be speak for me in case I can't speak for myself.

That was easy. My big sister would do it! When I called her to ask if she would, I was shocked to hear, "Oh. Loretta, you're my baby sister. I don't want you to ever die."

I responded immediately, "Then you can't have my Power of Attorney. I need someone who will allow me die peacefully under certain conditions."

I chose a good friend and included my sister and one more friend on the list as back-ups, a special team to watch over me ICE. I got free forms and guidance from the [National Healthcare Decisions Day](#) website and recorded my choices and gave copies to everyone who would be involved.

Then I had conversations with each and all of my surrogates. Just to be sure they understood what I want and don't want if my lifeline suddenly shrinks.

These conversations are the most important part of the ongoing process of normalizing death in our lives. The [Conversation Project](#) website offers toolkits for having these conversations with your loved ones, and even your doctors.

Advance care planning is empowering. It takes some of the fear out of dying. It's an opportunity to consider the quality of your death with the same regard you give to the quality of your life. It gives you some control, and it definitely spares your loved ones suffering.

Now if my relationships change or I'm diagnosed with a life-limiting illness, I'll complete a more extensive form, something like the Five Wishes, that talks about how you want to be treated, what kinds of things you want to say to your loved ones.

I've added, "Give me chocolate ice cream not vanilla and, please put socks on my feet."

If nothing changes, I'll look at my plan every few years to be sure I haven't changed my mind about my choices. Because you *can* always change your mind. Just make a new document.

The final step of defining the quality of your death is when your life approaches the end of the line, when it's clearly in sight. It's time to look at what options you have and complete a [POLST](#) form, a doctor's order for Life Sustaining Treatment.

And if you ever hear, "There's nothing more we can do," don't believe it. You have options.

There's palliative care, a medical specialty practice that focuses on pain and symptom management. You can enter palliative care before you need hospice care.

The modern hospice movement was founded in 1967 by Dame Cicely Saunders in England, on the philosophy that, "You matter because you are you and you matter to the end of your life. We will do all we can not only to help you die peacefully, but to live until you die."

Hospice offers an individual and their loved ones a whole team of trained professionals and volunteers, like myself who provide the holistic care for mind, body and spirit that is so essential to ease the suffering that is sometimes present at the end of life.

Even though a person is eligible for six months of hospice care or even longer if necessary, like my mother who was in hospice three times in the last year of her life--she just couldn't make up her mind. Nearly 40% of patients enter hospice care less than a week before death.

We use hospice as a last resort when it's a last reward.

Another option as death gets closer, is to voluntarily stop eating and drinking ([VSED](#)). This takes a lot of care and a lot of patience, and it's done all the time by people who have grown exhausted trying to stay alive. It's legal and it's done with the support of loved ones and hospice care.

In fact, not eating or drinking is part of the natural dying process for everything. The caterpillar stops eating before it goes into chrysalis stage. Leaves are changing colors and dehydrating before they fall from the branches. Every living thing stops taking in nutrition as it goes through its dying process. It's the way of nature.

We Baby Boomers want *more* legal options. Five states now have laws for [Physician Aid In Dying](#), allowing doctors to write prescriptions for a terminally ill person to hasten their death, without fear of prosecution. [Oregon has had a Death With Dignity Law](#) for 17 years and they've kept careful records. Few people actually take advantage of the law and there has been no slippery slope that opponents feared.

Unlike suicide, which is committed alone, and usually violently, and always leaves loved ones with guilt and anguish, [Death with Dignity](#) includes loved ones in the process with the goal of a peaceful passage.

The millions of members of the [Compassion and Choices](#) organization have spearheaded this movement. Twenty more states have bills in their legislatures right now. The entire country of [Canada](#), our closest neighbor, legalized the practice last year.

In addition, there's extensive discussion going on all around the world answering the question of how to help people mortally wounded by dementia to prepare advance directives so they can protect themselves from a protracted dying process.

As a society, we are looking at death with new eyes.

Sharing the end of life with a person—or even a faithful pet—is a rare opportunity for each of us to serve one another, to love one another, to enjoy a sense of personal fulfillment and growth, and to ultimately find serenity and peace being present for a person who's living the end of life.

Gwendolyn London wrote, “Dying is a spiritual process with medical implications.” It is a privilege and a life changing experience that teaches us how to live more fully and be compassionate to each other—and toward ourselves.

I’m on this journey with my beautiful big sister now. A few months ago she was diagnosed with pancreatic cancer. We have no idea how close she is to the end of this journey. I’m spending more time with her and we are having a love fest. I’m learning to let her do things her way in her own time, and not the way I want her to. I’m letting go of expectations.

She’s doing a fine job of preparing herself and her loved ones. She downsized last year and kept only her favorite things. Things which she is sorting for distribution.

She changed her Power of Attorney from her son to her daughter, deciding that she would be better able for the responsibility than he would. She’s taking care of her legal and financial business to ease her children’s lives after her death. She’s already met with a palliative and hospice care provider to stay ahead. She is learning how to receive care from others, instead of always giving it. I describe my sister as a person who if she had one nickel she would figure a way to give you half of it.

She is teaching all of us who know her how to live the end of a life with courage and grace.

As she nears death, she will enter what I believe is a Chrysalis stage in the process of transforming. It’s a quiet state of being but there’s a tremendous amount of activity going on.

Hospice patients have told me about visits from loved ones who have already died. I’ve been asked to open the door or a window so someone could go out, or go “home.” I’ve been asked to peel the potatoes for a banquet because the family was coming soon and she’d need to feed a lot of people.

Some talk of travel. In fact, ten days before my mother had the stroke finally took her life and made her a hospice patient the third time that year, she told me she in great detail that was taking a trip on cloud. “I’m going to New York first and then I’ll come back to Chicago, then I’m going to go to California because Chicago’s too cold.” I paid attention.

She said there were 3 rooms on her cloud because we have a large family and she would have many visitors. When I asked her, “What color cloud is it, Mom?” she said, “It’s a big, fat, fluffy, white cloud,” with joy I had not seen in her face for years.

It’s this time near the end of life when loved ones want to keep vigil that I see the need for Chrysalis Rooms in nursing homes and hospitals: the places where we die. Dying rooms like birthing rooms, or those welcoming spaces at hospice houses; sacred spaces where loved ones can gather in peace and comfort, and be supported by skillful care. A safe place to bear witness to love and loss.

It is no mystery that every death breaks hearts. Grieving is as natural as breathing. It’s through those broken hearts that we are opened up and transformed by our grief.

Grief moves a person to create art and music, literature. Charitable organizations like the [Susan G Komen](#) Foundation or [Alex’s Lemonade Stand](#) whose father started this foundation in honor of his eight-year-old daughter who died of a brain tumor.

Your community has people in need. Every donation of time and money, or money, every act of service in someone’s name is grief turned to love.

The best medicine for grief is gratitude. Gratitude will prepare you for the practice of letting go.

Letting go and giving up are two very different things. Not giving up is when you hold on to something tightly because you’re afraid of what will happen to you if you let go of it.

Letting go is surrendering to what is.

Start practicing letting go with your drawers and your closets and your garages and your basements. If you cannot let go of the things in life that are meaningless or useless, how will you be able to let go of the things you value, like your hearing or your eyesight, your car, or your ability to walk or hold a fork steadily, or your loved ones standing around you as you lay dying--or your body?

Start practicing.

If you start this weekend, consider the Monarchs who are returning to Mexico, some from as far as 3,000 miles away in Canada. None of them has ever made this journey before, yet they know how to find the high mountain forests where their ancestors wintered four generations before.

Practice letting go a little bit every day because one day you will emerge from your chrysalis and soar with the Monarchs.

Make younger friends—and older friends. We need each other.

Have *a lot* of hugs and a *little* dessert every single day.