

## **The Horse on the Dining Room Table**

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Imagine you've been invited to a dinner party. The table is set beautifully with china, crystal, and silver. The hosts have provided a sumptuous meal and good music, and the guests are engaged in stimulating conversation. But wait. On the middle of the dining room table spreads a real, live horse. Everyone sees the horse, but no one says a word about it. Everyone knows that everyone else has seen the horse. According to Glaser and Strauss (1965), this is what is called mutual pretense, a "*communal drama in which everyone involved acts out a role*" denying the obvious (*Corr & Corr, 2013, p. 151*). What if one of the guests says, "Oh, look at the horse on the table!?" Total buzzkill. Guests gasp, someone spills their drink, another faints.

"What did I do wrong?" demands the offending guest, as he is being escorted out. "I simply said there was a horse on the dining room table!" And therein lies the problem. No one wants to be reminded of the horse. I teach a Death, Dying and Bereavement course at York College. During the first lecture, I ask my students to come up with slang idioms for the word death. They offer kick the bucket, croaked, snuffed it, bought the farm, passed away, and pushing up daisies to name a few; the list is endless, really. I tell my students that in this class

we will use the word “death” in all of its conjugated forms. I believe that in order to **know** something we must call it by its proper name. The euphemisms are rather like calling Voldemort from Harry Potter “*He who must not be named*”.

Voldemort by any other name is still Voldemort, and the same goes for death. And the horse remains in the middle of the table, even if we do not acknowledge it. By not calling death by its name, we attempt to distance ourselves from it, make it less real, and perhaps even try to deny it. Guess what. It doesn’t work.

How do I know this? I’ve extensively reviewed the research. And in so doing, I’ve learned that there is a 100% chance that any given person will someday die. During the 20<sup>th</sup> century the average life expectancy increased dramatically from fewer than 50 years in the early part of the 20<sup>th</sup> century to our current life expectancy of nearly 79 years (Corr, Corr, & Doka, 2019).

Given that researchers have established that a person will die at some point, and will likely die within a century of their birth, one would expect that we would be more comfortable with the subject of death. But we’re not. In fact, as life expectancy has increased, so has our unwillingness to confront death. Advances in science and technology have informed contemporary western attitudes about death. These advances are a double edged sword. On the up side, medical and technological advances, along with public health initiatives, have reduced the number of deaths from accidents and communicable or infectious diseases. This

means that, for better or worse, we're living longer and having fewer encounters with death. But then there are downsides. The use of extraordinary measures has, in some cases, prolonged dying. Please note that I said these measures have prolonged **dying**, not **living**. And, moreover, medicine has moved dying from the home to the hospital.

In by-gone days, the family tended to the sick and dying. They didn't shy away from death. They sat with the corpse, washed it, made the coffin, and dug the grave. Community members and friends would come and sit with the family and the body, sharing stories and food. After the funeral, the bereaved were nurtured and cared for by extended family and the community. Death was not hidden away. It was viewed as an unhappy, but natural part of life. Philippe Aries (1985) a French cultural historian describes this as "Tame Death". He contrasts "Tame Death" with "Death Denied", a set of values which views death as something unnatural, basically a medical failure. Death-denying individuals go to extraordinary measures to stave off death, often prolonging, rather than postponing, their dying. Their funerals, if they have one, are typically for close friends and family only. There is no mourning period, and expressions of grief are suppressed. Indeed, to death-denying people, mourning is considered unhealthy (Aries, 1985). Western Culture's attitude toward death, dying, and bereavement is one of death denial. In the words of Virginia Safford, "... suffering and death of

living things is part of a grand and natural cycle, tragic only because we alone among the animals are so aware of mortality and time. Death is not a part of happiness at all, but it makes clear the urgency of joy.”

It has occurred to me that people prepare for major milestones like marriage, having a baby, or going to college, through internet searches, reading books about it, talking to professionals, and comparing notes with friends. We micro-manage, obsess about, and sometimes spend a lot of money and time on these things. But most of us don't do this sort of thing for the dying process. Dying is a major milestone for each of us, and something our families will experience as well. We should prepare for dying, just as we prepare for the other milestones of our lives.

I ask my students, “How would you like to die?” And they look at me with astonishment. How dare I ask them such a question! After all, they're only 20 years old. I tweak the question a bit: OK, then, how would you like to live until you die? Is that better? One student said, “live hard, die easy”. I bet no one here thinks “geez, I think I'd like to die after being in a coma for 15 years.” I imagine that for many of you, the ideal death would be to die in your sleep after spending a lovely evening with family and friends. Here's another buzz kill: few of us will die that way.

Glaser and Strauss (remember them?) described four different patterns of dying, called trajectories: The first is sudden death, in which there is one abrupt, fatal event, such as an aneurysm or accident; the second is terminal illness, such as cancer, which has a more or less predictable point of resolution; the third is chronic disease, such as kidney failure or COPD, which generally follows a slow, steady decline, also with a predictable time of death; and the fourth is frailty, more commonly known as “old age”, in which the body gradually shuts down, and the time of death is unpredictable. Unfortunately, we don’t get a choice about our dying trajectory. We can’t predict when we will die.

No matter your age, 18 or 122, you need to give some thought to your end of life wishes. You young people might think this doesn’t apply to you. But it does.

In 1990 Terri Schiavo was 26 years old when her heart stopped beating, depriving her brain of oxygen, resulting in a catastrophic brain injury which left her in a vegetative state. Ms. Schiavo could not think, eat, or move. She hadn’t formally documented her end-of-life wishes. Her husband could recall a conversation they had, but there was nothing in writing. For eight years Ms. Schiavo was given rehabilitative treatment, but she didn’t improve any. Then for another seven years her husband, her parents, and the courts fought with each other about Ms. Schiavo’s care. Feeding tube out, feeding tube in, feeding tube out.

After fifteen years of heartache, and legal battles, and expenses, Ms. Schiavo finally died. Would she have wanted this for herself?

We all pass our death date every year that we live, but we don't know what that date is; neither do we know how we will die. But we can decide how we live until we die and we can decide what sort of care we want or do not want at the end of our life. Control freaks rejoice! We can write the last chapter of our life, acknowledge the horse on the dining room table. There are four things that you can do to make the end of your life less trying for your loved ones. The first is to prepare an advance directive, sometimes called a living will. An advance directive is a legal document that outlines what medical interventions you would like to have, and by implication, what you don't want to have, in case you are incapacitated (that is you cannot speak for yourself). For example, let's say you were in a vegetative state, or rapidly declining because of illness. Would you want a feeding tube or a breathing tube? If your heart stops, would you want to be resuscitated? Or would you prefer to have comfort care instead? Comfort care means that you will be kept comfortable until you die: your pain will be managed, you will be kept clean and warm. In other words, no extraordinary medical measures will be perpetrated upon you.

Once you have tackled your fear of thinking and talking about death (calling out the horse on the dining room table), it's easy to prepare an advance directive.

Just as you would if you were planning a wedding or researching college choices, you can go to the internet, visit a bookstore or library, or talk to a lawyer, doctor, or funeral director to learn about advance directives.

The second thing that you can and should do is to designate someone as your healthcare power of attorney. This person will make health care decisions for you if you are too sick to make them for yourself. Choose someone you feel confident will be able to fulfill this role: that is, someone you know will have your best interest at heart and will not panic in the moment. This may or may not be your spouse. A friend of mine shared that her husband is not her health care power of attorney because she knows (and they have discussed) that he would be too emotional. Instead, her best girlfriend has agreed to take on this role. Your HCPoA should also be accessible. Many families are spread out geographically. It may not be in your best interest to have a loved one who lives in Hawaii serve as your HCPoA if you live on the east coast of the United States.

Think of your health care power of attorney as an orchestral conductor. A good conductor knows how the music is supposed to sound and he or she has the authority to direct all of the members of the orchestra in their parts. By having a health care power of attorney, you ensure that your final wishes will be honored; your POA will get your family and your medical care team to work together to give you the sort of death you really want.

The third way to make your end of life less traumatic is to discuss your final wishes with your family. Make it perfectly clear to them what you value, what makes life meaningful to you. Be very specific about what sorts of care you will and won't accept. Then threaten them with hauntings if they do not comply with your wishes.

Finally, do not put your advance directive in a safety deposit box. It cannot be retrieved easily! Remember, you do not get to choose when you are going to have a health crisis. Banks are not open after a certain time of the day, nor are they open on weekends or holidays. Make several copies, and give one to your doctor, one to your health care power of attorney, and keep a copy at home for yourself. Be sure to tell your family where you have put this document along with all your other important papers. I suppose you could go to the extreme and tattoo DNR on your chest as one gentleman I know did. He wanted to cover all of his bases. I am not necessarily advocating this, but it serves to illustrate an important point.

So, the horse on the dining room table is not going away. In spite of the hosts' best efforts to shoo the horse out of the room, it remains. Wouldn't it be better to acknowledge the horse, call it death, accept it, and live with it so that we can get on with the task of living fully, gratefully, and joyfully?

If you wish to learn more about advance directives, or how to have the conversation about advance care planning, Deb Gogniat and I will be facilitating a program at UUCY about this topic. It is scheduled for Sunday, January 6, 2019