

graceful exit

HOW TO ADVOCATE EFFECTIVELY,
TAKE CARE OF YOURSELF,
AND BE PRESENT FOR THE
DEATH OF A LOVED ONE

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Getting Everyone on the Same Page

Rallying around a loved one in failing health can bring out the best in everyone involved. All too often, however, it brings out the worst.

In fact, one of the hardest things about a family illness is family. Heightened emotions, lack of sleep, and long hours of bedside vigil tend to magnify personality traits (for better or worse) and expose long-buried grudges. I've witnessed adults argue across the bed of a comatose patient, and I've seen otherwise sensible human beings practically come to blows over everything from who would receive certain items of clothing or china dishes all the way up to selling the family farm. It can happen with the sanest of families. Recently, my own family underwent a rocky experience over an elderly aunt's illness when people who were close turned against each other over a disagreement about how to manage her care.

I empathize with how easy it is to let ingrained dynamics and run-away feelings take over a situation. Yet when a family doesn't, can't, or won't come together in a crisis, the bickering or silence overshadows the critically ill patient's needs. Distracting disagreements occur at critical moments. It's draining and stressful—and almost always avoidable.

Relationships can be difficult in good times. Under stressful times, buried emotions such as guilt and resentment can emerge and clash, and we end up at wit's end, frustrated at everyone's behavior, overwhelmed with our own feelings, and lost in terms of how to handle it. That's why I chose to begin this book by exploring what's behind

the family drama that surfaces when a loved one is ill and offering some ideas on how to manage it so everyone can concentrate on what matters most.

Understanding Family Roles in a Crisis

To better explain what can happen in the family dynamic during an emotionally challenging time, I'm going to use the example of the Rodríguezes. Angela Rodríguez was a widow whom I cared for over many years. She had four children—three daughters and a son. Toward the end, when Angela was diagnosed with advanced dementia and late-stage lung cancer, she was no longer able to speak for herself and couldn't participate in her own medical-care decisions. Finally, she was admitted to the hospital for what was clearly the last time. Her family gathered.

The youngest daughter, Maria, lived in New York, far from her mother's home in Florida. She hadn't seen Mom in several years and rarely checked in with other family members about Angela's health. Maria wasn't up-to-date on her mother's condition before she arrived, nor was she entirely clear about what was going on with her care. But that didn't stop Maria from swooping in and attempting to take control.

Maria harassed her siblings, barked orders at the nurses, and argued with me and the rest of Angela's medical team. She strenuously disagreed with every decision we made and was anything but shy about voicing her opinion. When the medical team recommended palliative care and hospice, Maria demanded her mother undergo a battery of what the rest of us knew were unnecessary tests. She insisted on ordering procedures Angela wouldn't likely survive and, according to her siblings, their mother wouldn't want. The rest of the family members were trying to hasten their mother's death so that they could inherit her money, Maria asserted. As for the doctors and hospital, she threatened to sue us for incompetence.

Experts have a name for Maria's behavior. They call it the "Daughter from California" syndrome. Compared to the rest of her family, the Daughter from California usually has the least understanding about

what is happening to a loved one and carries the greatest burden of guilt. Unraveling everything that's already in place is her way of taking charge and channeling her difficult emotions.

The Daughter from California isn't always the youngest daughter, like Maria. For that matter, she isn't always female. She can be a mother, a son, a cousin, an aunt, an uncle, or a longtime friend. And she doesn't literally have to be from California. If we place this scenario in California, she can be the Daughter from New York, the Daughter from Kentucky, the Daughter from Ohio, or the Daughter from Australia. In my experience, the farther away she lives from the patient and the longer she's been out of touch, the heavier her conscience and the louder and more irrational she becomes.

The Daughter from California syndrome was first documented in 1991 by Dr. David Molloy in an article published with some colleagues in the *Journal of the American Geriatrics Society*.¹ The person described in this piece was the daughter of an incapacitated patient, and she did indeed hail from the Golden State. The descriptions of her tirades and tantrums are classic to any medical professional who has spent time counseling families at the bedside of a critically ill patient.

Janet, Angela's oldest daughter, had stepped in several years earlier to manage her mother's care when Angela first needed assistance. Janet lived only a few miles away from her mother. She was always the "responsible one," so she flowed naturally into the role of the "Leader" as Angela's health worsened. While it's admirable that Janet had done the heavy lifting of shuttling their mother to and from appointments, paying the bills, keeping the paperwork up-to-date, and otherwise maintaining a semblance of order in her mother's life, she sometimes got bossy with her siblings in a way they didn't appreciate. She took offense when they questioned her about her understanding of the clinical situation or Angela's finances, as if they were suggesting she didn't know what she was doing. This led to quite a bit of squabbling among the group. As Angela's condition worsened, clashes between Maria and Janet escalated.

Leader is a tough role to play in a family crisis. I have a lot of respect for anyone thrust into this position. Because they carry so much of the

load, Leaders can sometimes resent the rest of the family for not doing more, yet they frequently feel entitled to make all the decisions, often without input from the rest of the family. In my twenty-plus years of practice, I have often witnessed leadership manifest positively. At other times, like in this case, the Leader is most effective at stirring up strife.

Jonathan, the second oldest and only son, found himself cast in the role of the “Mediator.” Growing up with three sisters taught him a lot about conflict resolution, and it really came into play now that his mother was dying. Increasingly, he became the family go-between. As Maria and Janet’s relationship deteriorated, he frequently stepped in to break up their arguments. For a period, the two sisters would only speak through him. It was very trying for everyone—including Angela’s medical team.

Mediators like Jonathan soak up the emotional angst for the entire family. The effort to keep the outer peace roils their inner peace. Many Mediators I’ve known suffer from insomnia, anxiety, dramatic weight changes, and a host of other serious mental and physical side effects that result from the stress of constantly placating the family. In their efforts to keep the peace, Mediators often suffer more than any other family member, usually for naught. No matter how hard the Mediator works, the underlying family dysfunction doesn’t change.

Finally, there was Samantha, the middle daughter. When Janet informed her that their mother’s illness had taken a turn for the worse, Samantha booked a plane ticket to Mexico and didn’t check in with the family. After about a week, a Facebook friend helped track her down, but even then she was reluctant to face the situation. Only after a brutal text and phone exchange with Janet did she agree to come to Florida and participate in their mother’s care.

“Runaways” like Samantha can’t cope with tough situations such as a terminally ill family member. I sometimes refer to this sort of person as an “Undecided” because of his or her inability to confront feelings or play any meaningful part in the decision-making process. Rather than pitching in, they are no-shows. Even when they are in the room, they are often reluctant to contribute in a significant way. They usually find it difficult to even sit with the dying patient. The idea of it horrifies them.

In many families, the Runaway is the most infuriating archetype of all, perhaps even more so than the demanding Daughter from California, the domineering Leader, or the martyred Mediator, who are, in their own way, at least trying their best. The Runaway's habit of checking out, especially when the going gets tough, can be difficult to comprehend. Others find it childish and irresponsible.

These types of family dynamics can surface at any time and place during the caregiving process, even in seemingly tight-knit families. End-stage caregiving can exacerbate them, however, especially if the patient is the last surviving parent or a child.

You might think that the Rodríguezes are at the extreme end of family dysfunction, but I've seen similar scenarios more times than I can count. But why does it happen? These siblings might not have been the best of friends, but they certainly tolerated each other, even enjoyed each other's company in other situations. Why would Maria make such a scene when it was so obviously detrimental? Why did Janet have to be so bossy? Why was Jonathan so weak and ineffective? And why did Samantha disappear? Did they not all love their mother and want to do what was best for *her*?

I believe that much of the conflict comes from a lack of empathy and understanding.

We can't always name our emotions or understand our behaviors, much less those of our siblings. Usually, we don't even realize we're misbehaving, and when another family member, in turn, reacts irrationally, we tend to focus on the unhealthy reaction, and the conflict escalates. We begin to treat one another with more and more suspicion, distance, hostility, and fear. The aggressive actions each takes toward the other are returned in kind but increased in intensity. Thus, in each round of exchanges, the parties become more belligerent, more hostile, and less cooperative. We speak of this dynamic as upward spiraling. Escalation, by its very nature, moves participants toward more and more painful conflict.

Naming the archetypes your family members are enacting can be useful in helping to interpret behavior, emotions, and reactions, all of which are personal but not always easily understood. They help put

family dynamics into much-needed perspective. Having context can lead us toward acceptance—and from there to forgiveness and conflict resolution. Ultimately, everyone wants what's best for the entire family, most of all for the ailing loved one who may no longer be able to voice her wishes. To get there, we sometimes need to lay down our arms and follow our moral compass.

Moral Compass

When everyone's screaming, no one hears anyone. Instead, everyone's focus is on their own needs, pain, and confusion. In truth, it doesn't really matter what others say, how they behave, or how they communicate. A family member's irrational behavior only hurts our ego. It doesn't touch the authentic part of us, the grounded part that knows, regardless of the surrounding chaos, what is right and what is wrong. When the Leader is screaming over the phone at the Runaway for not taking her shift at the hospital, the Runaway's programmed reaction is to hang up and drive in the opposite direction of the hospital. But if the Runaway stops to consider what she knows is right—*that everyone in the family needs to pitch in with caregiving at this critical time and that it's important to spend as much time with Mom as possible*—she can take a huge leap and choose to overlook the Leader's behavior and do the right thing. In other words, the Leader's behavior doesn't change what's right or wrong. When we pause to consider our values, regardless of how others behave or what our initial reaction is, a peace settles over us. We know what we need to do.

Families that make an effort to engage everyone in the process—to ensure every family member's wishes, struggles, and concerns are at least heard—seem to get through the experience more easily. I see this over and over again. They are more present and better able to give their dying loved one the most meaningful care and attention. Achieving this sometimes requires distancing ourselves from other family members' emotional roller coasters and owning our own behaviors.

Changing someone's personality and behaviors is not an option, but we can change how we react to them and, in the process, take the

relationship to a higher level. When overlooking difficult behavior is far beyond our ability at the moment, when forgiveness isn't even on the radar, and when personalities interfere with caregiving to the point of gridlock and exhaustion, talk to a counselor. Engage the entire family, if possible. A professional, third-party perspective is sometimes the best medicine.

End-of-Life Documents and Roles: A Glossary of Terms

Each state has its own rules and regulations regarding each of the documents listed below. To learn how your state interprets these forms, visit the National Hospice and Palliative Care Organization website at caringinfo.org, click on “Advance Care Planning,” and select your state. All of the documents listed can be found online or via your doctor or lawyer and should be filled out when you are of sound mind and body. In all cases, the doctor in charge indicates when you are unable to make your own medical decisions.

Advance Directives. A set of legal documents used to state end-of-life wishes in the event you can no longer communicate. Advance directives may include a *living will* and a *health care proxy* (sometimes referred to as a *medical or health care power of attorney*).

Health-Care Agent/Surrogate/Attorney-in-Fact. The person you select to make decisions about your medical care on your behalf. A health-care agent may base his or her decisions on your living will. If the living will is outdated, the health-care agent, along with the medical team, may choose not to honor your wishes.

Health-Care Proxy/Medical Health-Care Power of Attorney.
A document that indicates your choice of a *health-care agent*.

Living Will. A document that expresses the general extent of medical treatment you wish to receive if you are unable to communicate your wishes. A living will guides your family, health-care team, or

health-care agent in making decisions about whether to administer life-sustaining treatments such as CPR, resuscitation, intubation, and artificial nutrition and hydration. You can request to receive these treatments if they will lead to recovery and normal function. You can request not to receive these treatments if they will prolong life with no sign of a return to normal function.

Durable Power of Attorney. A document stating whom you wish to manage your affairs if you are unable to do so. This person, called an *attorney-in-fact*, makes financial decisions but may not have the authority to make health-care decisions. ☹

A Designated Spokesperson

On a more practical level, one thing that might have helped the Rodríguez family avoid acrimony is a document known as a health-care proxy. This legally binding document allows for the appointment of a health-care agent. If Angela had signed one of these in advance of her illness, she could have assigned one or more of her children the authority to make health-care decisions on her behalf as soon as she was no longer able to speak for herself. Besides giving someone else the power to make choices about her care, the document entitles that person to speak to her doctors and gather medical records without breaking any privacy laws. (The Health Insurance Portability and Accountability Act of 1996, also known as the HIPAA Privacy Rule, limits the amount of information doctors can give to patient families without a signed consent.) Ideally, a health-care proxy is part and parcel of a living will, which states preferences for life-sustaining treatments, such as CPR, mechanical ventilator, dialysis, invasive procedures, tube feeds, and others.

Filling out a proxy isn't difficult or time consuming. That's why it's so frustrating to me that so few people have them. A 2014 study published in the *American Journal of Preventive Medicine* found that only 26.3 percent of people have any sort of living will or health-care proxy in place. Respondents cited lack of knowledge as the most

common reason for not having an advance directive.² It is possible that all the medical and legal terms confuse people. Worse, most people think they have to wait until they fully understand their wishes before assigning a health-care agent. The truth is that we all have uncertainties about what we want when facing the crossroads of a critical illness. Even with the best technology, we can't predict the final outcomes. And as technology advances, decisions about end-of-life treatment will likely become even more complicated, adding to the confusion. The more confusing the system becomes, the more we need help. We all need a trustworthy person to help make decisions for us when we can't do it for ourselves. Appointing a proxy you trust could be among the best decisions you ever make.

Life is finite, yet we celebrate the beginnings and run away from the endings. Filling out a proxy is an excellent antiprocrastination exercise, and it is extremely easy. It is not a perfect document, but it is the best first step. You don't need a lawyer. Most doctor's offices and hospitals have a standardized form they can give you, or you can download one from the Internet and file it anywhere you might receive care. (Keep a copy for yourself.) As long as it complies with your state's legal requirements, it is considered binding. Moreover, it only goes into effect when you are unable to participate in care decisions; if you regain that ability, the proxy gets tabled.

Obviously, the best course of action would have been for Angela to have signed a health-care proxy while she was still cognizant. Once she was incapacitated and without a proxy on file, none of her children had the legal right to make health-care decisions on her behalf, setting the stage for the ongoing sibling battles. When a situation like this escalates, it often winds up in court, where a judge appoints a conservator, giving that person the legal authority to sign documents, checks, and forms—legal, medical, or otherwise—on the sick person's behalf. (More about conservatorships and durable power of attorney in just a moment.)

Having a family member appointed conservator is a best-case scenario. In some instances, the court gives proxy and power of attorney to a legal representative or hospital administrator. It's safe to say that

most of us would not want a court-appointed stranger making life-or-death decisions on our behalf.

It's important to tell the health-care agent you have chosen that he or she will make decisions on your behalf in case of incapacitation—and to update the proxy as your situation changes. One of my patients, Betsy, suddenly developed a debilitating disease. She became very weak and was not able to talk. She lived alone prior to the hospitalization and did not have children. A close friend, Toni, had been helping her for years, but Betsy had designated her only sister, Eleanor, as her health-care agent. The problem was that, following a nasty family dispute, the two sisters had not spoken for more than twenty years. Now Eleanor, the estranged sister, was in charge of making important decisions that were best suited for someone who knew Betsy better—someone like Toni.

I had a very emotional conversation with Eleanor, trying to get her to understand the position she was in. Nonetheless, she ended up authorizing unnecessary procedures driven by guilt, even though my patient had clearly stated that she didn't want to spend the last days of her life on machines. Unfortunately, she did, and all because of an outdated document.

Perhaps people don't talk about death and debilitation because in many cultures these are taboo subjects. But talk about them you must. You must believe me when I tell you that no family plan is complete without a clear statement about death and dying. If you have a family member whose health is seriously failing, make it a priority to get a proxy in place. Doing so helps avoid some very difficult arguments and disagreements.

Power of Attorney

Had Angela been lucid, she could have also assigned a durable power of attorney (POA) to one of her children or another party. This is a common procedure when a very sick person, often an older adult such as Angela who suffers from dementia or some other debilitating disease, begins moving toward a time when he or she will no longer be