

Chapter 17: Difficult Situations

*“The measure of wisdom is how calm you are when facing any given situation.”
–Naval Ravikant*

This chapter contains information on how to deal with tough situations with a loved one or a dear friend. There is no script to follow. Each situation is unique and carries with it a different set of circumstances. While some of these issues are complex, there is always a solution and there are many more resources available than we know of when we are confronted with these scenarios. Don't be afraid to ask for help when you need it.

Share end-of-life plans with the entire family

My father died in 2003 at the age of seventy-eight. His death was not complicated. He had a forty-one-year history of diabetes, and he died of debility.

About three months before he died, my mother and I sat down and talked about my father's deteriorating condition with him and had a very frank open discussion after he commented that he was “tired” and did not want to start making hospital stays a part of his normal routine. He decided that he wanted his care to ensure comfort rather than to include corrective measures. Today that is the equivalent to palliative care, which helps people living with chronic serious illnesses and focuses on providing relief from the symptoms and stress of illness. The goal is comfort for the patient and their families. This seemed to be an easy solution that we readily agreed upon. But there was one problem. While my father, my mother, and I were all very clear on his decision, we made one huge mistake. We forgot to share this decision with the rest of my family, and one warm summer day, I was out running errands, and I got a call from my brother Jeff telling me that my father was having a difficult time breathing and he called 911. When they got to the house, my father was in cardiac arrest and my brother called me again to tell me this as they were about to start CPR. I told my brother, “No! No CPR! Dad had decided he doesn't want that, and we support his decision.” But it was too late. As they were about to start CPR, my father's heart began to beat on its own. Due to the “differing of opinions of the family members,” the 911 EMTs had no choice but to transport a patient such as this to the local hospital. Off Dad went to the ER. We raced to the ER and were met by a wonderful doctor who asked what our wishes were, and I

explained the situation and he agreed to a “chemical code,” which means oxygen, intravenous fluids, and medical support but no CPR or heroic measures. This was perfectly reasonable to the doctor as well as our family in conjunction with my father’s wishes, and eight hours later, surrounded by family and a clergy member who had just prayed with my Jewish father, the clergy said “Amen,” and my father took his last breath. No struggles, just a peaceful passing.

Takeaway: Advanced directives should be discussed and, in most cases, posted in the home to avoid confusion like this.

Be aware of a loved one’s limitations

In 1993, I received a phone call from my parents’ neighbor telling me that my father was OK but had been involved in an accident. When my father was backing out of his driveway to go to the store, his foot became stuck on the accelerator pedal of the car due to his peripheral neuropathy (a condition which impairs muscle movement and causes numbness in the feet), so he pressed the gas all the way down while in reverse, traveled over half a football field, and struck the neighbor’s cement front porch and bounced his Buick’s back bumper through the kitchen window. Fortunately, no one was home, but the structural damage was extensive and the house needed to be completely remodeled in the front with structural repairs. My father, while very shaken up, was not hurt. Again, while very grateful, we knew we needed to have some difficult conversations about this event. How could we allow him to drive knowing that this just happened and could happen again at any time?

This accident prompted major discussions around the table that evening. And we found out that my father had had “many near misses” prior to this incident. We told him that while it was just damage to a house and we were so grateful no one was injured, this felt like a warning call we needed to heed. If he could back out of his driveway at sixty plus miles per hour into a neighbor’s home, what if this happened in a busy parking lot and people were standing nearby. He was shaken up enough to listen, and he never drove again after this incident. He willingly gave up the keys.

Takeaway: Discuss with your loved ones any health concerns you may have. My father never revealed to us his prior issues with driving. These concerns can cause embarrassment and lead to a vulnerability that many cannot handle. Subjectively

these incidents appear very different to loved ones looking at them from a different lens. Yes, navigating your loved ones' difficulties with aging is not a perfect science, but we cannot control what we do not know, so it is important to be proactive and try to ensure they aren't hiding information.

When loved ones refuse help

I often see situations where adult children are at their wit's end about what to do with their parent(s) who refuses to accept their advice. I typically get the details of the situation and then weigh in when the safety of their parent(s) is at risk. I have had many meetings with adult children who feel their parents are at risk if they do not bring in help, but the parents refuse to listen, thinking the children are overreacting. Depending on the situation, I advise the children that if parents do not choose to be proactive in certain situations that are not dire, they can wait and see what happens. This is only an option if there is no emergent or dangerous situations going on at the time. If there is potential danger down the road, you can roll the dice and take the time to figure out what the best course of action is if the parents are not open to assistance. While this is not optimal, sometimes it is difficult if one parent remains competent and able to make decisions.

Once the parent(s) is at risk of harm to themselves or others, something needs to be done to protect them. There is a risk associated with stepping in when they have refused help, but most often their insight and judgement and reasoning skills are no longer intact, so what they see subjectively is quite skewed. I get at least one call a week regarding this very topic.

This situation happened with William, who was in the beginning stages of cognitive impairment but insisting that he didn't need help. "I can live by myself; I am perfectly capable," he used to tell his children. Since he kept insisting, the children continued to hesitantly agree that he could stay by himself. But in September, he was in his walk-in closet and somehow got locked in with no cell phone or means of communicating with the outside world for three days. His three children all lived out of state, and while they could not reach him, they did not raise any concern for three days until someone actually checked on him for a wellness check. There he was in his closet, hungry, thirsty, and in need of a good shower but not "injured" per se, except for the ramifications of dehydration and lack of nutrition for three days. He was hospitalized, and as hospitals will often do,

the social worker indicated that the patient “was not safe to go home without oversight.” This can mean that the loved one goes home with a family member who will provide this oversight, they go to a facility that will provide oversight, or they go home with caregivers who will provide this service. The hospitals are often the first to step in and dictate that a loved one can no longer live on their own safely.

If the patient refuses to have the oversight once they get home, they will actually send a caseworker out to the home and make sure someone is there, or they will send the patient back to the hospital and mandate that they get put into a facility.

Navigating situations where a loved one refuses help can be very difficult, especially if their spouse covers up for them, as they want to be the partner that helps in “sickness and in health.” They want to protect their spouse and protect the children from worry or concern. Typically, I get a call before any major issue has occurred, but such issues are oftentimes right around the corner. It is usually about their loved one’s memory failing along with their inability to remember to take their medications on time, or how to take them. It can be more serious like Mom took the car and was lost for hours and could not find her way back. Again, the spouse will try and rationalize why this occurred, like she didn’t sleep well last night or she had a headache this morning. These little issues typically go on for a while before it is brought to the attention of the adult children. At this point, the children can then process this information in many different ways: they can minimize what they’ve heard, they can rationalize away what they have heard, they can step in and try to make big changes only to have them backfire, or they can put their parent’s safety first and implement small, needed changes. Often when the children identify an issue and request professional help for assistance in the home, the caregiver many times will be turned away at the door. The loved one will say, “Why is she here? I don’t need help!” For this reason, the children are so concerned that they will be accused of not loving their parent or, worst-case scenario, be cut out of any future gatherings or turned away forever. These are fears adult children have, but concern for a loved one who is having cognitive issues needs to be addressed, especially when their safety may be compromised. It also explains how a trip to the ER or hospital can help families determine when an individual needs urgent intervention as identified by the medical community and

not the adult children. It helps to have a neutral third party weigh in on these difficult decisions to help prevent the children from carrying all the burden.

Get advice on these difficult subjects to provide direction and professional guidance on the small, needed changes you can make to ensure your parent's safety without changing so much that it backfires. Many wonderful geriatric case managers and companies do this every day and know exactly how to guide you. Unfortunately, aging parents, especially those with cognitive impairment, lack the insight and judgement to be able to understand subjectively what is happening in their life that is causing them to be unsafe.

Because of this, there are resources, like APS, to help. APS can intercede in urgent or dire situations to investigate the safety and well-being of older adults. I have had to call them in on several cases in my career when I could not get a patient or their family to intercede in dangerous circumstances for whatever reason. APS is not adversarial and typically families will come back and thank me for getting them the help they needed. These situations are VERY DIFFICULT!!

Takeaway: When you face parents who do not want to listen to what you have to say, sometimes a third party is needed to listen to what you are seeing and make suggestions. There are more and more people utilizing LCSWs and RN case managers who can be very helpful in these situations.

When you can't be proactive, you need to be OK with being reactive. Aging is difficult for the individual as well as the family, especially if dangerous circumstances are emerging. Therapy can be very good for the adult children but not always feasible for someone with cognitive decline. Many unexpected challenges can surface, but fortunately, there are many resources available to help you.

Fear of upsetting your parents, or of losing their love and support are valid feelings, but if there is imminent danger, you must do the right thing to protect your loved ones.

When a loved one puts their vanity above their safety

Linda had repeated falls. I had worked with her spouse for several years, but now she was starting to have some balance issues. We discussed options including physical therapy and even using a cane or a walker. She told me "I would never be

seen dead with a walker or rollator.” Eventually, she fell right in front of her children at the mall and actually knocked her front teeth out. She spent several thousand dollars to fix them, and soon after that, she fell again. The second repair on her teeth made her stop and think. She was finally open to a change in her thought process, and we got her a rollator with the help of a physical therapist. After one week, she said to me, “Why didn’t you make me do this earlier?” This actually increased her independence, as she can now safely exit the apartment building where she lives without the fear of falling. It has been several years now since she has fallen. She has so much more confidence and freedom, not to mention independence, back in her life. It is hard to impart wisdom, but eventually, we learn that vanity cannot replace safety.

Takeaway: Advice is not always heeded in a timely fashion. You cannot force change; you need to be patient and understand that your loved one is not ready, and in the interim, they may experience a fall or injury. While it is hard to accept, it is the way it is. Oftentimes, in retrospect, your loved one will do what Linda did and say, “Why did I wait to do this?”

When someone isn’t capable of taking care of their loved one

One day I went to see one of my patients in her daughter’s home for her first visit. It was not a clean house, and I had to step over lots of trash to get to the stairs, but I did not want to judge this patient’s care by my initial impression of the home. When I ascended the stairs and entered the room of the patient, I found an elderly woman who would not speak to me. She looked terrified, but I was also a stranger so it was hard to know why this lady seemed so scared.

At that point, I began asking the daughter questions, and she seemed to be a caring, concerned daughter until I asked why her mother had a bruise under her eye. “I hit her,” she told me. I asked her to repeat what she said, and again she stated, “I hit her. I had had a really bad day, and she was not cooperative, and I just hit her.” I asked the daughter if she had told anyone besides me, and she said that she had told APS and they were working with her. I was completely appalled by her response and also somewhat skeptical of whether she had actually reported this incident. I called my boss as I left the house, since this was my first elder abuse case as an NP. We contacted APS, and they were aware of the situation and the daughter promised not to do it again. Unfortunately, two weeks later she did it

again, and we were able to have the mother removed from this abusive home. The vulnerability of a nonverbal patient is multifaceted.

Takeaway: APS is a helpful agency. They look out for our vulnerable patients and will intercede when needed. Do not be afraid to contact them.

It's OK to change your mind

My friend Lisa's father, Mike, chose not to treat his invasive colon cancer after it was explained how extensive the surgery would be to remove part of his colon, his bladder, and his prostate. He was eighty years old at the time. Not only would he need a colostomy, but he would need a urostomy (procedure to allow urine to be collected outside the body) as well. He was so fearful of the complexity of this surgery that he opted to try chemotherapy and radiation and stop after that. When he finished his five weeks of chemotherapy and radiation, he was wiped out. He had mouth ulcers, no appetite, had lost forty pounds, and didn't recognize the skeleton in the mirror. It was hard, it was painful, it felt draining, and he was unsure he could go on. He was told by his doctors that this was normal after an arduous course of treatment like he had just been through and that he *would* get better; he just needed to be patient. Eventually, he started feeling better from this draining experience, just like his oncologist said. He began to eat, he slowly put on weight, and he threw himself a "celebration of life" party because he said he couldn't "make his own funeral" so he wanted to be alive to celebrate with his family and friends. It was an amazing party. Mike's plan was now to enjoy the life he had to the best of his ability, and when the time came, he would sign up for hospice services.

Then four months into feeling better, Mike had sudden abdominal pain, constipation, and vomiting; it sounded like an obstruction to me. Off to the ER he went, as the pain was unbearable. A scan was done and a large blockage from tumor growth was diagnosed. The doctor explained that the only option was surgery; the tumor had grown and was blocking his bowel. The man who never wanted a colostomy suddenly changed his mind. Maybe he could live with a colostomy? When facing the option of imminent death or a colostomy, the colostomy suddenly did not look so ominous. He chose surgery. He reversed his hospice mindset and instead opted for a colostomy bag. It was a hard adjustment for sure, and again, he was told to be patient. He did not want to look at it, touch it,

or have anything to do with it. I told his daughter to support him and just give him time. Now nine months into it, Mike has adjusted to his colostomy, and he is glad he chose to do the surgery.

Takeaway: Mike is an inspiration to me and taught me to be open minded because it is OK to change your mind. He also taught me that one day I also want to throw a celebration of life while I am still alive and breathing. Thanks for the lessons, Mike! Hard decisions need support, and this family definitely provided support to their parents as they have both aged into their eighties, and they have adjusted their support as their parents' needs changed. Mike's daughter and my friend, Lisa, and her sisters have done a great job caring for both of their parents, adjusting to the constant turning tide of elderly parents and the challenges their illnesses present.

Ask for a copy of your labs or studies

Because you can get erroneous information, like what was conveyed to Delores in chapter 7, get a copy of your test results before you throw in the towel and give up. Remember the doctor recalled that Delores's CT scan in 2008 showed terminal bone cancer and was advised to "go home and get her affairs in order." Medical providers are busy people, and the best way to deal with a difficult situation is with the facts. I am at fault here too, because I did not question the results from the doctor. Fortunately, the radiology tech intervened and helped us figure out what was truly going on with Delores.

A similar situation happened with Roselle when she was told by her primary medical provider that her "blood work was fine." I asked twice for a copy and eventually was given a copy, which actually showed a significant anemia that required a blood transfusion. Do not be afraid to ask for important lab work and other medical studies when they are completed. They can be life savers.

Takeaway: Asking questions pays off. You don't want to harass anyone, but you want to have the facts. The same goes for emergency room visits and getting copies of all tests that were done. I feel like in recent years the hospitals have done a good job of sending patients home with their studies—blood work, X-rays, and scans—which is very helpful. Follow through is better when you have the facts in your hand and you aren't waiting for a fax or a phone call.

Helping loved ones with cognitive impairment

I work with a very well-respected geriatric psychiatrist who is adept at working with dementia patients with difficult behaviors. He has been making house calls to these underserved patients for fifteen years and is very good at understanding the disease and how to treat it. There are many neurologists, psychiatrists, and geriatricians who come in contact with these difficult-to-treat dementia patients and do not know where to turn. It takes a highly skilled medical practitioner to work with these patients and their families. Oftentimes, we will come into a home, and a family member will tell us that their loved one thinks it is December, and no matter what they tell them, they refuse to accept that it is, in fact, June and not December. These arguments escalate and become very frustrating for both parties. I strongly urge all adult children or spouses to *not* engage in arguing with your loved one. It is pointless, it is shaming, and it gets you nowhere.

When we are with a family and an argument ensues, Dr. S tells the family, “It is more important to be kind than it is to be right.” How true this statement is and how many families have benefitted from this statement.

There is no doubt that dealing with loved ones who have any type of cognitive decline is very difficult—perhaps one of the most difficult, as patients who have cognitive decline do not subjectively have any awareness of their decline and will challenge you on every single issue that is raised. They tell their family the same stories over and over, but the family members have to bite their tongues because admonishing them that they already told this story is shameful to them and makes them feel bad when they have no recollection of what they told their loved ones. On top of all the day-to-day struggles with cognitive impairment, they often won’t accept help. If they will not allow you to bring in an advocate for them, such as a nurse, a geriatric case manager, or even their doctor, then you need to solicit help on your own.

Understanding dementia is frustrating for families of loved ones who suffer from it. Grasping a disease that is destroying your loved one’s cognition, insight, independence, and life is difficult. Families need training or therapy with geriatric case managers or LCSWs to help them through this process. I have families that try everything they can to get their loved one to “accept or embrace” their diagnoses to no avail. It is irrational to think that an individual with cognitive impairment can rationalize and accept what is happening to them. Some turn to a therapist, thinking it will help their loved one understand, but it doesn’t. Not even a professional can

help them understand due to the patient's lack of memory and retention caused by their illness.

Takeaway: This is a very difficult medical journey to navigate. Caregivers need to step in and give families a break. Caregiver stress in a family member is real.

Remember to implement distraction with your cognitively impaired loved one; it may be the only way to break the cycle of their perseveration. Get them involved in exercise and socializing with kind, understanding people.

Remaining kind, patient and loving to your loved one with dementia is imperative. Do not shame them, bully them, or admonish them for something they have no control over. Many individuals with this disease were highly intelligent, productive members of society so treating them respectfully is a necessity.

If a loved one has dementia or any type of cognitive decline, education is the best tool for you. Sign up for a course or a support group and educate yourself. Accept that your loved one is not willfully trying to upset you with their repetition, but rather the disease is causing this behavior; they have NO control over it.

Implement a system that prompts your loved one to use the talents and abilities that they still possess. Encourage music, dancing, or art projects. We have artists that have continued to draw through their entire journey with dementia and we marvel at their masterpieces. Be kind to all patients no matter what their disease process is. They need your love and support, not your criticism and correction; it feels shameful and confusing to them and can contribute to their depression and frustration.

When they are done with their life

My patient, who was struggling with horrific hallucinations and chronic intractable back pain that could not be medically managed, told me several years ago that he “no longer want[ed] to eat. [He was] done with [his] life.” The patient clearly told his family that his life was too arduous to continue at seventy-eight years old. He stopped eating and called his children to let them know. They all gathered around him to discuss his decision.

After listening to him, they all came to understand his very personal suffering and his lack of interest in taking multiple medications that did not seem to help. The process, of course, did not take long and hospice came on board within forty-eight

hours to be a part of the care team. Ronald was made comfortable, his family stayed with him, and they laughed, cried, and shared with the time they did have. Once Ronald's life was over his family shared how special his last ten days were, and while they were deeply saddened by his death, they were comforted by his peaceful departure and that his desires were honored.

Takeaway: Sometimes it is just best to let your loved one go out on their own terms.