# THE PRACTICAL ESTATE PLANNER

In practice since 1987, Certified Elder Law Attorney **EVAN FARR** is widely recognized as one of the leading Elder Law, Estate Planning, and Specials Needs attorneys in Virginia, Maryland, and the District of Columbia, and one of foremost experts in the country in the field of Medicaid asset protection and related trusts. He has been quoted or cited as an expert by numerous sources, including: the Washington Post, Newsweek Magazine, Northern Virginia Magazine, Trusts & Estates Magazine, The American Institute of Certified Public Accountants, and The American Bar Association.

Evan has also been featured as a guest speaker on numerous radio shows, including WTOP and Washington Post Radio. Evan has been named by SuperLawyers.com as one of the top five percent of Elder Law and Estate Planning attorneys in Virginia every year since 2007, and in the Washington, D.C. Metro Area every year since 2008. In 2011, Evan was named by Washingtonian Magazine as one of the top attorneys in the DC Metropolitan area, by Northern Virginia Magazine as one of the top attorneys in the Northern Virginia area, and by Newsweek Magazine as one of the top attorneys in the country. Evan is a nationally renowned author and frequent educator of attorneys across the U.S. As an expert to the experts, Evan has educated tens of thousands of attorneys across the country through speaking and writing for numerous national legal organizations such as the National Academy of Elder Law Attorneys, ALI CLE, the National Constitution Center, myLaw CLE, the National Business Institute, the Virginia Academy of Elder Law Attorneys, the Virginia Bar Association, Virginia Continuing Legal Education, and the District of Columbia Bar Association.

## UPDATING YOUR CLIENTS' ADVANCE MEDICAL DIRECTIVES IN LIGHT OF THE COVID-19 PANDEMIC (WITH FORM)

Given the ongoing COVID-19 pandemic, health care providers around the country have been expressing concern that anxious Americans and patients don't really understand what is involved with the various medical interventions needed as a result of this contagion. Further education of the public and attorneys is needed, as are changes to your standard form Advance Medical Directives.

One major issue is the fact that the illness caused by the COVID-19 virus often results in the patient needing to go on and then come off a ventilator. It is common sense that potential ventilator patients need to understand what is actually involved with ventilator use, in order for a potential ventilator patient to decide when and whether he or she would want a ventilator in the event of a serious illness such as that caused by the coronavirus. Ventilators have of course been helpful in saving the lives of many people with COVID-19, but are they worth the discomfort and long-term effects when they don't always work and there may be other less extreme options?

In a recent example, Diana Aguilar, 55, spent 10 days on a ventilator in a New Jersey hospital fighting for her life. When her fever hit 105 degrees and she was delirious, Diana remembers having tough time breathing. The virus had already been ravaging her body and affecting her lungs for weeks. She recalls a doctor sliding a ventilator tube into her mouth and pushing life-saving oxygen deep into her damaged lungs. What Diana was unaware of is the damage ventilators often inflict and the slim odds of survival they afford. Studies suggest more than two-thirds of patients die while on ventilators.

Aguilar, who was sure she was dying, whispered her goodbyes to her husband, son, and daughter, and then she prayed to God. As she was struggling to breathe, every inch of her body ached as she felt it failing. And then came the intubation, a last-resort intervention thousands of patients have undergone in the past few weeks. What many of these people didn't know is that even when patients survive, as Diana did, some of them will continue to be profoundly weak due to muscle atrophy, unable to perform daily activities (such as shaving, taking a bath, or preparing a meal, for example), and some will even be bedridden. "Some people never fully recover," says Michael Rodricks, medical director of

an intensive-care unit in Somerset, New Jersey. "And those who do often must relearn basic skills such as walking, talking and swallowing."

### Ventilators Have Saved Lives

Ventilators, first introduced in 1928, were initially called "iron lungs" and were used to help polio patients breathe. Only recently have researchers learned that the biological responses to the breathing machines that kick in almost immediately often cause lasting harm.

Despite the harm they cause, ventilators have saved many lives, such as Diana Aguilar's in our example, who might not have lived without the help of a ventilator. The mechanical ventilator was what kept her alive, as it breathed for her for 10 days as she lay in a medically induced coma. The reason ventilators work is because they help breathe for the patient when they can no longer do so on their own. The lungs typically deliver inhaled oxygen into the blood supply in seconds. If they aren't working, the damage is swift. A person can go from healthy to dead in less than six minutes. A ventilator helps keep the person alive by keeping them breathing. It can be adjusted to boost oxygen, pressure, and volume, pushing the air forcefully into the lungs, making sure ideal amounts of oxygen and pressure can enrich the blood as efficiently as possible. Aguilar made it through the most harrowing phase of COVID-19 because of the help of the ventilator.

### But What Happens After the Ventilator Treatment Is Over?

As the cases of COVID-19 increase, more and more patients are going through the same dreaded treatment as Diana Aguilar. The lucky ones pull through, but their journey back to health can be long and perilous.

The worst-case scenario, besides death, is a condition known as Post-ICU syndrome that can afflict as many as half of COVID-19 patients who survive on a ventilator, says Dr. Hassan Khouli, chair of Cleveland Clinic's department of critical care medicine. "These patients become deconditioned,'' he says. "Some behave like they are really paralyzed, as if they are quadriplegics. They can barely move their muscles.'' The risk of dying also remains higher than average for at least a year after getting off a ventilator, a risk tied to both the number of days spent on the machine and other health conditions the patient had before falling ill.

Hospitals such as SUNY Downstate Medical Center in New York are setting up entire rehabilitation floors to help people coming off ventilators learn how to live again. Others are trying to cut back use of the device, avoiding a rush to ventilators when oxygen may be all that's needed.

### How Do Your Clients Decide Whether They Want a Ventilator?

In nearly all COVID-19 cases, the choice between using a mechanical ventilator or not is the choice between life and death. So, the question becomes, knowing the process, the risk factors, your quality of life and health: if you were to fall extremely ill to COVID-19, would you want to do everything possible to stay alive if it meant going on life support including a mechanical ventilator?

At Cleveland Clinic hospitals, several COVID-19 patients have turned down ventilators once they understood that what was involved was not consistent with their wishes, as indicated in their advance medical directives, according to Dr. Khouli. Some patients prefer the option to be made comfortable for the end of life rather than fight to survive, if their chances are unlikely.

Dr. Kathryn Dreger, an internal medicine doctor in my hometown of Arlington, Virginia, recently outlined what patients should know about ventilators in an opinion piece for The New York Times. She explains that

> [a] healthy lung has almost no substance. Touching it feels like reaching into a bowl of whipped cream. COVID-19 changes all that. It causes a gummy yellow fluid, called exudate, to fill the air sacs, stopping the free flow of oxygen… When more and more alveoli are filled, the lung

> texture changes, beginning to feel more like a marshmallow than whipped cream. This terrible disease is called acute respiratory distress syndrome. COVID-19 can cause an incredibly lethal form of this, in which oxygen levels plunge and breathing becomes impossible without a ventilator…. These machines can't fix the terrible damage the virus is causing, and if the virus erupts, the lungs will get even stiffer, as hard as a stale marshmallow. The heart begins to struggle, begins to fail. Blood pressure readings plummet, a condition called shock. For some, the kidneys fail completely, which means a dialysis machine is also needed to survive. Doctors are left with impossible choices. Too much oxygen poisons the air sacs, worsening the lung damage, but too little damages the brain and kidneys. Too much air pressure damages the lung, but too little means the oxygen can't get in. Doctors try to optimize, to tweak.
>
> Nobody can tolerate being ventilated like this without sedation. COVID-19 patients are put into a medically induced coma before being placed on a ventilator. They do not suffer, but they cannot talk to us and they cannot tell us how much of this care they want.

Patients on ventilators run a higher risk of developing pneumonia because of bacteria that enters through the breathing tube. This is called ventilator-associated pneumonia (VAP). Studies have shown that the incidence of VAP in mechanically ventilated patients is between nine percent and 69 percent, which is four times higher than that in patients admitted to the normal ward. (Wu Ge, et al. "Nasointestinal Tube in Mechanical Ventilation Patients is More Advantageous." https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6555240/. Accessed 13 May 2020.)

Dreger sees her patients in all settings, including the ICU, where she recently cared for a patient who fell ill with COVID-19. "A lot of people are going to die on the vent, which is a lousy way to die," she said in an interview. "A lot of family are going to have to say, 'What did mom or dad, husband or wife want me to do?' And have to make it up because they're not able to be there by their side or not able to ask." This is why Dreger underscores the necessity of an Advance Medical Directive whereby a healthcare agent is appointed to convey your basic wishes regarding the use of invasive life support. Of course all Estate Planning and Elder Law attorneys offer our clients Advance Medical Directives, but are they sufficient in light of the current pandemic, and any future pandemics?

Dreger suggests that people consider the questions such as:

- If you're on a ventilator and require a feeding tube through a hole in your stomach, would you want to continue on the ventilator?
- If you're on a ventilator and your kidneys shut down, would you want dialysis?

## Feeding Tube Issues

A ventilator prevents the patient from eating normally, so a different tube that provides nutrients is typically inserted into the patient's vein. But patients who are on long-term ventilation will eventually require a feeding tube directly inserted into the nose or mouth, or through a hole made in the stomach. Other conditions can of course also cause the need for a feeding tube.

A feeding tube can be uncomfortable and even painful sometimes. People on feeding tubes need to adjust their sleeping position and have their tubes properly maintained to avoid infections and other complications.

## Types of Feeding Tubes

There are multiple types of feeding tubes, and they are used for a variety of conditions. The nature of the problem will usually determine the type of tube that is used. Some are intended to be temporary, and others are meant to be long-term or even permanent.

A nasogastric (NG) tube is a flexible tube of rubber or plastic that is passed through the nose, down through the esophagus, and into the stomach; a

variation of this is called a nasointestinal tube, as it's inserted through the stomach and down into the middle portion of the small intestine. The procedure is uncomfortable, but it shouldn't be painful. A nasointestinal tube typically requires the use of abdominal and chest X-ray examination to ensure proper placement. The outside of the tube will be taped down in place on the skin so that it doesn't become dislodged accidentally. NG tubes and J-Tubes can only stay in place safely for about 14 days. Placement via the throat longer than two weeks increases the risk of erosion of the throat and esophagus, which can lead to permanent issues such as damage to the voice box and throat.

A long-term or permanent feeding tube is one that is intended for use for months, years, or even permanent placement. These tubes move food directly into the stomach through an incision cut into the stomach or jejunum. Most common is the Gastric tube (G-Tube), which allows for direct access to the stomach through an incision in the left upper side of the abdomen. A variation of this is called a Jejunostomy Tube (J-tube), as it's inserted through an incision into the middle portion of the small intestine, called the jejunum. The incision is lower than G-tube placement, and the J-tube tends to be smaller than the G-tube, which can limit what can be infused to thin liquids and finely ground powdered medications.



### The Argument Against Feeding Tubes

COVID-19 is affecting people of all ages and with any number of underlying health conditions. One of these underlying health conditions is of course dementia. The use of feeding tubes has gone down substantially in the past few years for advanced dementia patients, for many reasons:

- Eating food is not just for nourishment, but also a source of both pleasure; a feeding tube completely eliminates the pleasure part of eating.
- Feeding tubes are often traumatic. A person with dementia may not be able to understand why a gastroenterologist is cutting open his or her belly, and may find the inserted tube confusing and traumatic, often on a repeated basis since short-term memory is often missing in these patients.
- Food is a source of social interaction. The mush or liquid that flows through feeding tubes eliminates the taste of food and the social interaction of hand feeding.
- Future medical problems can be caused by gastric tubes. Almost 20 percent of the time, the tube becomes blocked or dislodged within a year, requiring hospitalization. Patients may also try to pull it out, leading to physical or chemical restraints or, if they are successful, leading to potentially significant medical complications such as infections. G-tubes are also associated with an increased risk of pressure ulcers or bedsores, perhaps because they encourage inactivity or cause diarrhea; and these ulcers heal more slowly than in people without tubes.
- Future medical problems with nasogastric tubes. NG tubes can be very effective at treating some conditions and in administering medications, but they're not without the potential for some less-than-desirable effects. People with an NG tube might experience some symptoms such as diarrhea, nausea, vomiting, or abdominal cramps or swelling. One of the things that can happen while the tube is being inserted is an injury to the esophagus, throat, sinuses, or stomach. It's possible that if an NG tube gets blocked or torn, or if it comes out of place, there can be further problems. There's also a possibility for any food or medicine being put through the tube to be regurgitated or to go into the lungs (aspirated).
- Feeding tubes don't prolong life. As it turns out, feeding tubes don't keep advanced dementia patients alive longer. Several studies led by Dr. Joan Teno, a geriatrician at the University of Washington show that they make no significant difference. After receiving a feeding tube, patients with advanced debilitating diseases lived a median of 165 days, and two-thirds died within a year.

## Why Some Might Think Feeding Tubes Are a Good Idea

Older adults nearing death still do receive feeding tubes, sometimes because families insist, sometimes because health care providers don't offer enough information to help them decide.

Feeding tubes remain more popular in certain kinds of nursing homes, too. For-profit nursing homes use them more than nonprofits. In New England, fewer than two percent of residents are tube-fed. In parts of the South, the rate can run up to 10 times higher.

Higher Medicare reimbursement for tube-fed patients (and the labor costs of hand feeding) make some nursing homes more apt to recommend tubes.

In addition, many families can find it difficult to refuse a fairly minor surgical procedure that provides nutrition.

NG tubes can help prevent surgery in some cases, such as with an intestinal blockage. An NG tube is temporary, so it will only be in place for as long as it's needed.

## Updating Your Outdated Advance Medical Directive

The question for your clients to consider is whether quality of life is more important than being kept alive at all costs. And it's up to you to record their wishes in their Advance Medical Directives. But it's likely that your standard Advance Medical Directive does not include important issues related to this pandemic and possible future pandemics. The COVID-19 pandemic has raised tremendous awareness about ventilator use. What if the next pandemic attacks the kidneys and causes the need for dialysis?

At my law firm, we have updated our 4 Needs Advance Medical Directive® (which we license to Attorneys around the country) to address some of the unique issues that have arisen as a result of this COVID-19 pandemic, and that may arise as a result of future pandemics. I do not claim to have thought of all possible scenarios, but at least this may provide you with a starting point for updating your own Advance Medical Directive template.

This section was already in our Advance Medical Directive:

### ADDITIONAL INFORMATION TO ASSIST MY AGENT

I understand that it is my responsibility to communicate any information about my religious beliefs, basic values, and health care preferences to my Agent in advance, to the extent that I wish them to be followed. To that end, I make certain wishes known below and I may attach to this document a separate writing giving additional information to my Agent which I request my Agent to honor.

1. **During a Pandemic:** During any such time as there exists an unusual widespread contagious illness or pandemic (for example, the coronavirus / COVID-19 pandemic of 2020), I direct that the actions taken by my Agent, family, physicians, health care providers, and all those concerned with my care be controlled by the following declarations that I have initialed:

_____ If there is a chance for me to recover from the illness, I want all available health care treatment in accordance with accepted health care standards, including experimental and untested treatments if deemed appropriate under the circumstances.

_____ Evaluation of my future quality of life shall not be taken into consideration.

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_____ If there is a chance for me to recover from the illness, I want all reasonably available health care treatments in accordance with accepted health care standards, but I do not want experimental and untested treatments.

_____ Evaluation of my future quality of life shall not be taken into consideration.

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## Exceptions in the Event of a Pandemic

_____ Even if there is a chance for me to recover from the illness, I would not want to be intubated and placed on a ventilator under any circumstances.

_____ If there is a chance for me to recover from the illness, I would want to be placed on a ventilator, but I would want the ventilator discontinued if I reach the point where I also need a feeding tube inserted through a hole into my stomach.

_____ If there is a chance for me to recover from the illness, I would want to be placed on a ventilator, but I would want the ventilator discontinued if I reach the point where I also need kidney dialysis.

_____ Even if there is a chance for me to recover from the illness, I would not want to be intubated and placed on a ventilator if there is a limited supply of ventilators and that limited supply can be used to treat other people.

_____ Even if there is a chance for me to recover from the illness, I would not want to be placed on kidney dialysis if there is a limited supply of dialysis machines and that limited supply can be used to treat other people.

_____ Even if there is a chance for me to recover from the illness, I would not want to be placed on kidney dialysis.

_____ Even if there is a chance for me to recover from the illness, I would not want to be resuscitated by having electric shock applied to my chest.

_____ Even if there is a chance for me to recover from the illness, I would not want to be resuscitated by having chest compressions that could break my ribs.

_____ Even if there is a chance for me to recover from the illness, I would not want be placed on a feeding tube of any type for hydration or nutrition.

_____ Even if there is a chance for me to recover from the illness, I would not want be placed on a feeding tube inserted through a hole into my stomach.

_____ Even if there is a chance for me to recover from the illness, I would not want blood, plasma, or platelet transfusions.

_____ Even if there is a chance for me to recover from the illness, I want to be permitted to die naturally, and I do not want life-prolonging procedures. If life-prolonging procedures are started, I want them stopped, with the exception only of any procedure necessary to provide me with comfort care or to alleviate pain.