**Advance Directives: What are they and how doctors actually read them**

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 I think it is fair to say that everything I learned about Palliative Care, Hospice and Advance Directives I learned from a dear friend and career long colleague Jeanie Youngwerth, MD who practices Hospice and Palliative Care at the University of Colorado. (See how young we were when we met!) She so graciously agreed to join me in speaking with our patients about “Advance Directives” back in March before our talk was first cancelled by a snowstorm and then by COVID 19. I appreciate Jeanie for our shared common values around the need to maintain dignity and humanity through aging, advanced illness and the dying process. That is why we take on difficult topics with our patients and are willing to have the hard conversations. We also feel strongly that ***merely having completed an Advanced Directive is not enough.***

Advance Directives is a generic umbrella term that includes various documents and designations that ensure that you get the type of medical care that want when you are not able to speak for yourself. This includes kinds of healthcare that you do and do not want. Types of Advance Directives include:

* A Living Will
* A medical durable power of attorney
* A medical proxy
* Code status document

Let’s take a look at them more closely and discuss how they are used by doctors, patients and families. The Living Will was designed to alert medical professionals and your family to the medical treatments that you would or wouldn’t want to receive. It often includes whether or not you would want treatments such as mechanical ventilation (a breathing machine via a tube in your throat), artificial nutrition, ICU care or blood transfusions. Most living wills tie these treatments to very specific scenarios. For example, “if I was in a vegetative state I would not want to receive artificial nutrition.” They might even state for how long you would want to receive treatment.

Practically speaking, ***doctors don’t use Living Wills.*** Unfortunately, physicians find the Living Will documents to be very unhelpful as the scenarios documented in the Living Wills are so rare, that they almost never apply to the patient’s current medical situation. Therefore, they can’t be used by doctors to guide medical decision making. The other problem is that when a patient is unable to speak for themselves, it is often an emergency. In emergencies, the Living Will is never available and even if it is, the doctor doesn’t have time to read it as s/he needs to be tending to the patient.Instead they ***rely completely on the patient’s medical durable power of attorney or medical proxy*** to make medical decisions.

The medical durable power of attorney is the appointed person chosen to speak on your behalf if you can’t speak for yourself. This can happen to anyone at any age from an accident, a medication, pain, sedation from surgery, etc. If you don’t legally appoint a person to be your medical durable power of attorney to speak on your behalf, you may name someone to be your medical proxy. If you have not designated anyone, the laws in Colorado are complicated and not clear. In some state, the spouse automatically becomes the proxy… not in Colorado. In Colorado, all “interested parties” gather and decide who will be the decision maker for the patient and that person becomes the sole decision maker. “Interested parties” could be family, friends, neighbors, co-workers, or anyone who knows and voices care for the patient. Because the law is so vague, I would encourage you to designate someone and officially appoint them as your health care proxy.

 Who should you pick? Most people pick their spouse. I didn’t. For me, my spouse would have a very hard time letting go… in accordance with my wishes and would be traumatized forever. So, I chose a friend who could be available, cares, but could also be more objective. For me, I actually think this decision is in my family’s and friend’s best interest as well.

It is **crucially important** for the person who you want to make decisions on your behalf to **know you, your beliefs, what is important to you**. The living will won’t have the answers they are seeking and if they know what you want, then that person won’t be burdened by the decisions that they are asked to make.

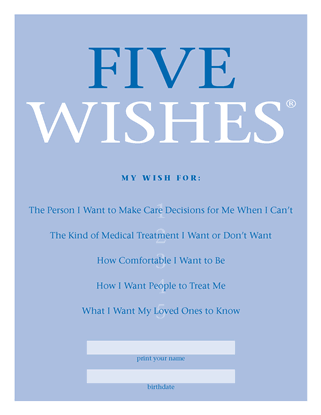
Some people find these conversations very difficult to initiate with family members and with the person they want to be their health care proxy or potential scenarios impossible to imagine.

(For example, you may not want to be on a breathing machine for pneumonia because you have bad lungs and don’t want to have to recover from another severe pneumonia, but what if you got stung on the lip by a bumble bee and only needed to be on the machine for 12 hours until the swelling went down?) There are websites that provide tools to facilitate discussions. They are all different, not one better than the other:

* + [theconversationproject.org](http://www.theconversationproject.org/)
  + [prepareforyourcare.org](http://www.prepareforyourcare.org/)
  + med.stanford.edu/letter.html
  + [getyourshittogether.org](http://www.getyourshittogether.org/)

There is even a card game called Go Wish (available at www.gowish.org) that can facilitate discussions.

The last piece of the Advance Directive is the CPR Directive and that is state specific. The Colorado CPR directive refers only to your Code status. Code status refers to what you want a medical professional to do when you die – would you like them to attempt to bring you back to life (Full Code) or would you like them to allow you to have a natural death (DNR or DNAR)? DNAR stands for do not attempt resuscitation, and has replaced the term DNR (Do not resuscitate). If you are a Full Code, health care professionals will proceed with CPR - chest compressions, place a tube in your throat and if you regain a pulse, connect you to a ventilator or breathing machine. The overall survival to hospital discharge after CPR is about 15% (and not all 15% go home, many end up in a nursing homes and with brain damage). When deciding on Code status, it is important for patients over 80 years old and those with metastatic cancer to know that, if they were to die and receive CPR, the chance of returning home is close to 0%. I tell you this, because I think most people are not adequately informed when they are deciding on their code status, and having information helps one feel most secure in their decisions.

My Favorite Documents:

The Five Wishes is a Living Will that is the most patient, family and physician friendly version of a will that I have ever found. I particularly like it, because it is written in simple, practical language and extends beyond medical procedures. It is also valid in most states in the United States. We have these documents in the office free for patients or they can be purchased online for $5. If you go to my website, [www.jeannetteguerrasiomd.com](http://www.jeannetteguerrasiomd.com), click on patient education, click on upcoming events, and scroll down to Advance Directives. You will see free forms that you can download and print that may be helpful including:

* An MDPOA form
* Colorado CPR Directive, that a physician needs to co-sign

Completing these documents can be overwhelming and we are happy to help you. There is one more document that you may see called the MOST form, which I personally tend to use for sicker patients. The MOST form should always be filled out with a physician and with a thorough discussion. [Www.coloradocareplanning.org](http://Www.coloradocareplanning.org) also has a lot of great information as it pertains to the laws of Colorado.



Your homework:

* Identify someone to make medical decisions on your behalf if you are unable
* Pick one or two tools listed above to talk with them about what is important to you (i.e. having everything done and living as long as possible, only living if you can communicate, not dying in the hospital, etc.)
* Decide on a code status with that medical decision maker

Q+A

1. **What happens if the ambulance takes you to a hospital you know will not honor your wishes due to their religious dicta and/or if you are just not comfortable with the level of care at that hospital?**

While this is a scary prospect, it does happen. There are some religious hospitals (usually Catholic) that will have hospital policies that supersede your wishes. For example, say you wish to be removed from a breathing machine or to have artificial nutrition stopped if you haven’t shown signs of improvement. Some religious hospitals may continue treatment based on their doctrine regardless of your wishes. Fortunately, I have never had that experience with Rose Medical Center Hospital. If you did end up in such a hospital you can request a transfer of hospitals, more easily done from the emergency room prior to admission, but it is possible. Be persistent if your wishes or the wishes of the person you represent are not being honored. A medical durable power of attorney is much more effective in these situations than a medical proxy. The hospital you are leaving is responsible for accommodating travel and transfer to the new hospital. The patient however, must be clinical stable… meaning they won’t die during the transportation from one hospital to another.

1. **Is there a difference between a health care proxy and a medical proxy? Or a medical durable power of attorney and a health care power of attorney?**

No and no. The words medical and health care are interchangeable and vary by state.

1. **Do DNR tattoos work?**

Unfortunately not. Patients need to have capacity to make their own healthcare decisions, meaning they must be able to communicate at a basic level their understanding of the medical situation, consider the risks and benefits of treatment options, weigh it against their values, and communicate their wishes, while not suffering from a debilitating mental health problem, like depression that could cloud their judgment. There is no way to assess the patient’s capacity when they got the tattoo. Also, patients are allowed to change their mind and sometimes do based on the situation that arises. So, no, tattoos do not work.

1. **What questions do a patient or medical durable power of attorney have to ask to understand how continuation of treatment is different than comfort care? Aggressive CPR versus a natural death? Withdrawing versus withholding treatment?**

I would ask: “What will happen if we pursue {plan A} versus {plan B}? What should I expect from each option.” Ask the hard questions: ask about pain, quality of life, length of life, cost, housing, nursing care, independence. If a doctor avoids answering, ask another doctor. This should be matched with what is important to the patient, i.e. being alive, or being able to spend as many days as possible sitting on the porch in the sun, or reaching a birthday or family celebration. Pick the option most aligned with what is important to the patient.

1. **What is the difference between withdrawing and withholding treatment?**

Withdrawing treatment refers to stopping IV fluids or stopping artificial nutrition, while withholding treatment means never starting it in the first place. Let me just say, withdrawing treatment is infinitely more difficult for family members and medical decision makers then to never have started in the first place.