**REPEALING MURPHY’S LAW: THE TRUTH ABOUT ADVANCE DIRECTIVES**

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 Murphy’s Law states that if something *can* go wrong it *will* go wrong. This is particularly frustrating when you or someone you love is facing the end of their lives. You want your wishes respected but it can be difficult even to address the subject much less create an effective Advance Directive.

 This article addresses the problems that can arise, aka Murphy’s Law, and ways you can create solutions that allow *Your Truth* to be heard and respected. (These articles are on http://livingbeyondexpectationsblog.wordpress.com)

**Elephant in the Room**

Did you hear the story about the elephant in the room? No? That may be because nobody talks about it. The elephant may be called Death or Dying but she is in the End of Life family. This article is intended to offer resources and a perspective on the topic that will start or keep the conversation going.

When I started my oncology practice nearly 40 years ago we didn’t talk about *Cancer.* We called it *The Big C,* leaving out the other letters, *ancer*. This is pronounced *answer* and now we do have answers to treat and cure the disease.

Today, we speak of *The Big D* because we don’t think we have answers to this issue. We don’t have a cure for death but we do have many more ways to deal with the inevitable outcome of being born. We are no longer without resources. It is possible to discuss and plan for the End of Life. The issues here, and your responses, can guide you to discover the things you wish for yourself and the persons around you. It may make it more likely your wishes will come true, too.

**Practical preparation for the end of life**

In the nearly 40 years of practicing oncology I have seen many tragedies. One of them comes to mind that might be prevented with some planning.

 *An 85 yo patient comes into the Emergency room with signs of a stroke. He is followed by anxious family. Barely able to talk he says “Let me die.” A daughter tells you he has an advance directive specifying “No Heroics” but she doesn’t know where it is. The patient’s wife breaks down and says “Do something! You must save him!” She has forgotten what they agreed if something like this happened when they filled out their directives years ago when he was still quite competent. She has forgotten also that he has spent the last 4 years in a nursing home as he grew progressively more demented*

*The daughter pleads with her to let him go as he goes into cardiac arrest and resuscitation begins.*

Is there something that could have been done to prevent the patient, family and the medical team from being put in an impossible situation that doesn’t honor the patient’s wishes, doesn’t comfort the family, and thrusts doctors and nurses into the position of rendering complex medical treatment that will not benefit the patient?

The medical teams’ choices are limited. They are vulnerable to being sued if they don’t do something. They can’t point to a legal advance directive that would allow a natural death. However, patients and families can prevent these situations if they do the emotionally difficult work ahead of time. When appropriate I have given patients the following handout and discuss with them these questions and possible answers.

**Question #1 How do I know what I want?**

You may know what you want now, and even think you know when you are in the dying process. When you are confronted with the request to “get your affairs in order” or in a crisis, that may change.

 Your values are less susceptible to change, even when you are in confusion and fear. Write down a *Values Statement*. Answer the question *What makes my life worth* *living? If I lost \_\_\_\_\_\_I would not want to be alive.*

You have to dig deep for your essential truths. You may modify Byron Katie’s Four Questionstechnique for each statement. *Is this belief true? Is it absolutely true under all conditions?* (www.thework.com)

 You need to consider what are the likely things to happen at the end of life. Most people in the US die in a hospital or a nursing facility, not at home. You become dependent on others. You lose control of just about everything. Generally you have various very unpleasant body symptoms. Suffering is nearly universal and Murphy’s Law (if something can go wrong it will go wrong) seems to be the law of the land.

 There are resources available to help you articulate your views. The Coalition for Compassionate Care of California (www.Coalitionccc.org) has information on preparing an Advance Directive and POLST (Physician Orders for Life Support Treatment). They have links to other valuable sites such as Caring Connections <http://www.caringinfo.org>. Five Wishes, provided by Aging With Dignity ([www.agingwithdignity.org/forms/5wishes.pdf](http://www.agingwithdignity.org/forms/5wishes.pdf)), has an excellent form for considering what you want at the end of life (These questions include *The person I want to make care decisions for me when I can’t, The kind of medical treatment I want or don’t want, How comfortable I want to be, How I want people to treat me, What I want my loved ones to know.*

 *Go Wish* cards ([www.gowish.org](http://www.gowish.org)) are another excellent way to consider your end of life options. They are very useful for getting important conversations started, especially with family members. Other websites that can help facilitate conversations include Death Over Dinner (<http://deathoverdinner.org/>) and Death Café (http://deathcafe.com/).

**Question #2 How do I get my doctor and the medical system follow my wishes?**

Getting the medical system to do what you wish is complicated. Some times it is like an old car that doesn’t always work. You have to know which part to tap and how hard to tap to get it working. The good news is that it does still run and if you do a little work it will get you where you want to go.

Doctors and nurses are human, just like you. They don’t have enough time to do all the things they need to do and hence not be able to do all the things you wish. Be compassionate with them. Everyone becomes more understanding when they feel understood.

Doctors have to obey certain laws both for your safety and theirs. If you come to the Emergency Department and there is no **legal** document instructing them not to start treatments, they must respond to the medical situation as the patient arrives. Too often Advance Directives are not available or not signed and they have to at least temporarily do what is medically necessary. If a patient arrives in crisis, unable to breathe they can be intubated, even if the tube is removed when more information is available.

If you find out what they need from you and make it easy for them to have it they will pay more attention. Gather your thoughts, write down succinctly questions or information you wish to give them and get it to them in the way that is easiest for them: email, fax, or perhaps letter. They can read much faster than you can speak.

Doctors’ and nurses’ first priority is to take care of your body not your soul. Don’t expect to buy jewelry at an auto repair shop. They also have to obey the onerous and often irrational rules of the system in which they work even if there is no law on the books. There is no logic to driving on the right side in the US and on the left side in England but we do it because it’s safer that way.

Even with advanced electronic medical records systems important information is not always readily available. Keep your own set of important medical documents with you if possible. These might include an Advance Directive detailing your wishes for life support or a POLST if your life expectancy is less than a year. Put a note on your insurance card letting them know you have such information as we have a dot on drivers’ licenses if you wish to be an organ donor.

Have an advocate with you. Friends or family work well if they know your values and specific wishes. Advocates should be able to be aware of the immediate situation as well as all the circumstances surrounding it. They need to be clear but not aggressive or angry. Hostility and confusion invites chaos.

**Question #3 How do I get my family to follow my wishes?**

 You may think your family knows what you want, but have you asked them to repeat back what they think you said? When they are confused or frightened will they remember it?

 All too frequently a patient will have a legal document describing what care they wish or don’t wish and they are brought to the hospital after someone calls 911 without it. The ER doctor doesn’t have that piece of paper. A family member appears and panics, telling the ER staff to “do everything!” The doctor generally follows the loudest voice and/or does something that keeps the person alive until things can get sorted out.

 Preventing this scenario takes planning because you have to imagine what can go wrong. Even if you have a document saying *Do Not Resuscitate* with you, a family member can trump that by demanding more care. Doctors don’t always have time to explain why they should not do something. Having the DNR statement helps a lot but you may also need to have family agreement and prepare them for ultimate crises.

 Having difficult discussions with your parents, partner, sibs or children takes time. The whole conversation doesn’t happen all at once. The other person has to understand what they feel and you both have to find a way to honor the other person’s feelings. Keeping an attitude of compassion for everyone concerned makes getting to *yes* easier. The payoff is that everyone becomes more accepting of what can happen and may even understand that it might happen.

The difficulty of such discussions can be a measure of their value. Facing end of life issues together can bring cohesiveness to a family that been separated by distance, personalities or prior conflicts. Even an agreement to disagree regarding possible courses of action, as long as the individual whose life is at risk makes the ultimate decision, prevents conflicts. The ripples of such discussions travel generations by the example that is set. That can be a great gift to families.

There is no guarantee that if you do all these things you will have your wishes respected and avoid the suffering that ambiguous situations create. Patients must share some of the responsibility for the mishaps that occur during end of life care. Regardless of what created the problems, we can all be involved in finding solutions. This elephant in the room is not going away by herself.

**Decisions, decisions, decisions**

Making decisions for ourselves and for family and loved ones is complex. What we want changes either from changing circumstances or changing your mind. There are many pathways to the end of life. Some are sudden like a stroke or an accident. Some are the result of a chronic disease with a more or less predictable outcome like metastatic cancer or ALS (Lou Gehrig’s Disease). Still other paths involve aging, especially if dementia occurs.

There is no one correct way to make decisions but some basic principles exist.

* You need information you can rely on. Rarely do we have all the information we need or want. There are resources available online and in the community. Your friends may have gone thru this process and can share how they did it. Your doctor can be an important source of information, answer many questions, and support you as you consider what you wish to do.
* Sometimes free advice from friends is worth exactly what you paid for it. What they did may have been just right for them. They may be emphatic about their advice because they lovingly want good things for you, too. Sometimes, however, they want someone else to do as they did to confirm that their decisions were right.
* Decisions involve both analytic/intellectual and emotional/psychological processing. Both head and heart are involved. Some persons are more comfortable with one part than the other yet the wisest decisions include both aspects of our wisdom. It pays to cultivate listening to both heart and head.
* Many decisions require time to ripen. We may have to “sleep on it” or let the process reveal itself. There isn’t time to do this in crisis so some decisions have to be made in advance. You can make decisions in steps, absorbing information slowly and working with it like you eat an elephant, one bite at a time.
* Decisions often consider the wishes of persons other than yourself. Sometimes individuals may give up their needs to satisfy another’s. I have had patients receive chemotherapy and go thru the side effects because someone told them they *had to.* Unfortunately the necessity was theirs and not the patient who was treated.
* There is often no *right* decision and we are left with either compromises or avoiding a *wrong* one. Some *best* decisions require considering information rather than letting emotions—especially fear—get in the way. Other *best* decisions require insight and subjective values. At that time over thinking and an endless search for more information gets in the way.
* There are no *perfect* decisions, only ones that are appropriate and the best you can do at the moment. Maybe things don’t turn out the way you wanted or expected. Take it easy on yourself, don’t judge yourself harshly. Just make another the-best-I-can-do-now decision and see how that turns out. Go back and look at your values statement that would be part of your Advance Directive package. Maybe your values have changed and your decisions should reflect that.
* Decisions often can be changed when new information is available. When faced with an acute event some decisions must be made before information is available. Understand that the decision will be revisited when more information is available or when you can calm yourself and let wisdom rather than crisis prevail.
* Some decisions are provisional and not final. They are taken in steps and as things change, the decision changes. It may be useful to have a *stop time* as the default option when dramatic interventions are required such as intubation in the Emergency Department. This way the initial decision is recognized to be temporary.
* It is important to review your document annually. Things change over time. The person you chose as your surrogate may no longer be the right choice. Your values may change as you gain more experience. Because you have actually created a document its memory remains at least in your subconscious. When someone you know goes thru an unpleasant dying process you may think of new things you want or don’t want. Set up a review date on your calendar that you can remember. Let your surrogate or other important person know about it. They can remind you and help hold you accountable for what you promised. The “second look” experience is *much* easier than the initial one!

**Family Matters**

A necessary part of planning for end of life care, especially advance directives, is communication with persons who might be involved at that time. Communication can get sticky when difficult topics or individuals are involved. Even communicating with yourself—how shall I confront my own death—can be difficult. We try to avoid painful or fear provoking conversations and it doesn’t get much harder than dealing with the reality that we, too, will die.

Naming a surrogate to represent your wishes if you cannot do so yourself may be easier than describing your wishes. An Advance Directive is not in effect when you are able to speak for yourself. Putting yourself mentally in the position of someone who is at the end of life is not easy. Imagining this brings up multiple considerations. *I don’t want to burden anyone. I don’t’ want to cause pain or conflict. This isn’t the right time and I’ll put it off for another day. I don’t want to be judged or face argument and I just don’t know what to say.*

Conversely the listeners in the conversation may become sad or frightened. They may become embarrassed by what you say, as if it is some teen-age talk about sex and the facts of life. Really, you are talking about the ultimate fact of life.

There are valuable consequences of overcoming these concerns, however. You take a huge burden off your family and friends if you explain to them what you want. You can avoid having things *done to you* that are really not what you want *done for you.* Subconsciously, beneath our desire to avoid the subject of death, we understand that the subject of death will not avoid us. Like going to the dentist with a bad tooth-ache, it’s better to get it over with. You don’t really know how far the ripples of such conversations may spread. Your children may so respect your actions that you serve as a model for them, and they will tell their friends, thus influencing many people, not just the ones in earshot.

Conversations with family are necessary to avoid the all-too-common event of a relative bursting into the picture demanding “do something!” when you and perhaps the rest of the family want to allow a natural end to life, without a lot of fuss. Depending on family dynamics, the conversation can get stuck in various ways. Even as you have to get over your avoidance to think about the topic, your family has to get over their personal reluctance to hear about it. It’s painful to consider that your father, mother, sibling or child will not be with you some time in the future. Unless prepared, that thought stirs up a lot of strong emotions.

Common thoughts and expressions include *I’m not ready for that; Don’t worry, things will get better; What will I do without you?* Let family know they are giving you a great gift. Let them know that even if they don’t like it, or disagree with what you wish, you want them to at least listen and understand that this is what you *do* wish.

Families are complex these days. There may be previous husbands and wives from other marriages and children may be step-brothers and step-sisters. Similarly there may be parents’ sibs involved. Any of these persons may have a point of view different from yours and show up later demanding that they be heard. It is better to hear them before a crisis. In most states there are lists of who has decision priority if no one is otherwise listed. Typically the current spouse is at the top for married persons but you may want a different person to be your surrogate.

Long-married couples are attached to each other, that’s probably why they have remained married a long time. That same attachment can make it hard to let go of the person they have loved for the last 50 years. Understandably, in crisis, they may not be ready to have the “no CPR” clause in your Advance Directive honored. Similarly, the daughter or son may not feel they are ready for you to die, regardless of what they agreed upon in the family discussion. Repeated conversations determining if that person is actually willing to go thru with what you’ve indicated will be needed. That’s why an annual review of your Directive is a good idea.

Many families are not close and there are persons who are estranged or at least not connected with the rest of the family. This may be because of distance, old disagreements, or differing views. Being heard by some persons may not be possible, much less having agreement. It is possible, if you foresee conflict, that your Advance Directive may specifically exclude someone from making health care decisions for you. If this is so, it is probably prudent to let them know that you’ve chosen only certain persons to make decisions and give whatever face saving reason you can offer.

Sometimes there are persons in your life who simply cannot or will not engage in discussions about end of life and dying. You may not be able to change this. If they are not going to be involved directly in your end of life decisions then you may have to honor their silence. If they are to participate in helping your wishes be observed, you may have to use other means to express your intentions. If you send a letter telling them what you wish write it compassionately, showing your understanding that the situation inherently has conflict. You do not want to create more distance but simply acknowledge that there are differences and you respect them. Since only you understand the nature of your situation you may have to be creative in “getting to yes.”

Your family will be different in some ways than these examples. The bottom line is that you must consider the context that surrounds your life. There are other persons who will be affected by your decisions. They may have strong feelings brought up by your discussing your wishes. They are only human. Your job, however, is to let them know what *you* want, not necessarily to do what they want or even to make them happy.

 **Repealing Murphy’s Law:**

“If something can go wrong it will go wrong.”

*Can you do that? Really?*

Well, no you can’t completely eliminate things going wrong but you can increase the chances of things going right. This is particularly true when dealing with end of life wishes and advance directives. Keeping Murphy out of it does take work, sometimes a lot of work. It’s frustrating. If only other people would do their job…

The fact is that if you want your Advance Directive actually to work the way *you* want you’ll have to do a lot of work yourself. If you can’t do everything yourself at least verify that someone you trust has done everything. I’ve outlined some of the places where problems can arise and suggested strategies to work around them.

**The directive isn’t legal.**

If the paramedics come or you arrive at the emergency department, the medical personnel have to follow the law or the “standard of care” that applies to your situation. If you’re unconscious or really in trouble they will try to save your life; that is their job. They don’t have a choice *unless* there is a *legal* document instructing them to do otherwise. In most states there are specific documents that allow treatment to be withheld. These include Advance Directives; these may differ from state to state. In California there is also a document called POLST—Physician Orders for Life Sustaining Treatment. A medical bracelet indicating no resuscitation may not be legal but it can at least slow down some interventions.

 The document isn’t *legal* unless it is on a 1) recognized form, 2) filled out, 3) signed, and 4) properly witnessed or notarized. It isn’t useful, however, if the instructions on it are ambiguous or not specific enough. Read it over. Are all the appropriate boxes checked, all the signatures—by the specified persons—there in all the right places? Ask someone to read it as if they were going to follow the instructions. Then ask them to explain back to you what they understand. It may not be exactly what you wanted. If not, make the corrections.

**The directive isn’t where it needs to be.**

One of the most common problems in the Emergency Department is a patient transferred from a nursing home without all the necessary paperwork. If you or someone you love is in a nursing home or assisted living facility, verify the directive is in the chart. See if there is a notation on the medical information sheet (where insurance information, etc. is kept) stating what the instructions are; i.e. DNR do not resuscitate or No Code. Ask the director of nursing or the administration what procedure they follow if patients are to be transferred to a hospital. If enough families do this the facility may be able to identify and correct problems.

If you are at home and the paramedics come they are trained to check the refrigerator door to see if there is a “Vial of Life” in the freezer. This is a container where appropriate medical information such as Advance Directives, medication and drug allergy lists, or other relevant documents are kept. It could be as simple as a zip-lock baggie that is brightly colored and easily found. (Don’t hide it under the containers of left over lasagna where it can’t be found.) Tape a note to the freezer stating that there are medical instructions inside.

There should be copies of the directive in your hospital chart, doctor’s office chart and perhaps even in the glove box in your car. You can make a small card for your wallet or purse that at least tells people where the directive is kept. Attach this card to your insurance card because whenever you encounter a health institution the first thing they ask for is your insurance card. When you are at your doctor’s office or the hospital, ask to see the chart (often electronic) and identify where they record your life support wishes. Give a copy of your directive to relevant persons who might be they ones you call to take you to the doctor or hospital. If you have regular appointments with doctors take a copy with you and show it to the doctor and staff: they are more likely to remember that you have a directive.

**Doctors don’t follow the directive.**

Sometimes, even though the Advance Directive is clear and legal, physicians may not observe the requests. There can be various reasons. The doctor may interpret the circumstances differently from the way the patient or family does. She or he may feel the situation is temporary and that their primary responsibility is to maintain life until “nature heals.” In some situations the physician may have religious or ethical beliefs that conflict with requests. In some traditions the obligation is to preserve life since “life belongs to God.” If there is a fundamental conflict between the physician and the patient, and it can’t be resolved with an honest conversation, it may be appropriate to get a “second opinion” and change doctors.

More often there are rapid medical changes and the medical team responds to these events, forgetting in the midst of a crisis that there is a conflict in this choice. In critical care units there are often multiple specialists involved in treating the patient. Not all of them may be aware there is an Advance Directive. The designated surrogate or family member who acts as the conduit for information to be shared with other members can verify that the DNR order is visible in the chart.

It may be difficult to prevent some interventions from being initiated. You can, however, request they be discontinued automatically after a specified duration.

Hospitals are required to make an ethics consultation available to resolve conflicts. Ask the nurses about how this can be arranged.

**Somebody challenges your wishes.**

Family members may speak up and request—even demand—care that is in conflict with the patient’s wishes. If the advance directive specifies a certain person, that is the person who is legally in charge if the patient cannot speak for him- or herself. If there are certain family members whom you know may contest your wishes, the advance directive may specify who may or may not make decisions. This takes the conflict out of personal choices and keeps it a matter of legal responsibility.

Most of the time a family member may challenge the directive because they are not prepared for your death and strong emotions create strong responses. This is a most human response and dilemma. There are many motivations for such responses. The strongest is love and the wish to be with you “a little bit longer.” There may also be personal “unfinished business.” Sometimes the death of one person puts a lot of responsibility on those who are left behind and they are not prepared for a life without you.

Lives and relationships are complex and many of these issues cannot be avoided. The best preparation is communicating your wishes and answering family members questions if possible. They may not agree with you but at least you can ask that they respect that these are your wishes. If you can anticipate conflict perhaps you can explore their feelings and wishes. Just as you want to be heard, they may also need to be heard.

**Amending your Advance Directive**

Recently my wife and I completed our Advance Directive using the Five Wishes form [www.agingwithdignity.org/forms/5wishes.pdf](http://www.agingwithdignity.org/forms/5wishes.pdf). This is an excellent form and is legal in many states including where we live in California. However, I wanted to be more specific in my wishes and wrote this appendix to reflect my personal values and the ways I want decisions to be made if I can’t. As a physician I understand the inner working of hospitals and doctor’s thinking. Hence, I chose language both my surrogate and my doctor would understand.

Many Advance Directives are based upon the assumption that we will die of a chronic illness or with dementia. These circumstances allow persons to anticipate problems before a crisis occurs. Sometimes, however, there are sudden events like accidents or strokes which leave us incapacitated. If there is a person designated as surrogate they may not fully understand your wishes. If there is no surrogate named there is even more confusion.

I want to emphasize this Appendix is personal to me and is offered only to stimulate you to make your own document. Attorneys can help you prepare a similar personalized statement and will probably offer something more complete than what I wrote. Though I have a personal physician who understands my wishes I don’t know if he will be available when I need him. Giving doctors guidelines in the language they recognize makes my wishes less ambiguous and easier to follow. They understand “a <5% chance of recovery” (less than 5 chances out of 100 cases) though it may not mean much to non-medical persons.

**Appendix 1 to Five Wishes**

**Instructions for my surrogate and family**

I wish treatments that make my life worth living according to the following values listed below. If treatment has little chance (less than 5%) of returning me to a life I deem worth living I do not wish life sustaining treatment started. If it has been started then I ask that it be stopped if there is a less than 5% chance of recovery.

 The outcome of serious illness is always ambiguous. I wish decisions made based upon the prudent opinions of my doctors at the time, which should be offered as if they were making the decision for themselves if they were in my circumstances.

**The values that make life worth living.**

I wish to be comfortable physically. Unpleasant symptoms should be treated to allow comfort. If side effects of treatment cause their own problems then I wish my sensorium maintained clear enough to communicate meaningfully with those I love UNLESS I indicate pain levels of 7 or more out of a 10 point scale. In that case make pain control the highest priority.

The most important value is to be able to communicate with those I love. I wish no impediment to that and request my environment support this communication. If I am unable to think or communicate—and have <5% chance of regaining this capacity—life is not worth prolonging.

The next most important value is to be cognizant of my environment and aware of my thoughts and feelings. I have always been a thinker and wish to remain so. If there are illnesses or injuries or anticipated treatments that would prevent me from thinking clearly be aware that if I cross the point where I can no longer understand myself or environment (e.g., dementia, CVA, brain injury, etc.), life becomes much less worth living. I do not wish life prolonged under these circumstances if they are irrecoverable.

I would prefer to remain active but would accept a life limited in physical movement if it could not be avoided.

I do not wish to avoid death but be alive as long as I find life worth living. The problem with death is the saying goodbye to those I love, and their sadness at losing me. I hope to prepare all of us for my death which “will come when it will come.” (Julius Caesar, Shakespeare) I have additional instructions for the different ways I may become incapacitated.

**Sudden event such as accident or stroke that leaves me unable to communicate what I want.**

 If the event is so severe that even if I regain consciousness I will be so impaired that I would not regain awareness of my environment, of other persons, or self-awareness I would not wish life sustaining treatment.

It may take some time to determine this and life support may be initiated. If it is the opinion of at least 2 physicians (including a neurologist) that the chances of my recovery to a satisfactory state are <5%, life support may be withdrawn. If they cannot make this determination within 30 days I wish life support withdrawn. If in my surrogate’s opinion and there is family consensus that I am suffering **and** they, too, are in distress at my status, at 30 days from the initial event life support should be withdrawn A satisfactory state is one in which I am able to communicate so that I am understood and I can understand the persons around me.

**Progression of a chronic disease such as malignancy, heart failure, etc. so that I am unable to communicate, that state is not likely to change, and death is likely to occur in </= 6 months.**

I would request to be on comfort care, whether Hospice or not, and symptoms managed well. Symptoms of infection, shortness of breath, pain, and any other distress should be treated but not with antibiotics, transfusion if actively bleeding or other treatments which would prolong my dying.

**Development of dementia so that I am unable to communicate, or recognize family, or not able to improve with whatever current treatments are available.**

I would find this state unsatisfactory and wish life support withdrawn. Life support interventions such as tube feeding, ventilatory support should not be done though oral feeding and oxygen are acceptable.