

My *Heartfelt*
Advance Care Plan



Heartfelt Legacy Foundation

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INTRODUCTION

By Stephen B. Yim

*Among the many gifts my father gave to our family,
one of the greatest of them was the way he handled end of life.*

My father was a physician who specialized in internal medicine and cardiology. He dedicated his life to the care and wellbeing of his patients. I know that my father treated each and every one of his patients tirelessly, with dedication, compassion and kindness. I remember how he would often leave our house in the middle of the night to go to hospital to care for one of his patients. He strived to ensure that each of his patients received the best care possible during the worst possible times.

Soon after retiring from his medicine practice, my father got sick with a rare form of untreatable Leukemia. After investigating the probable progression of this illness, he gathered me, my mom and my three brothers together and explained his illness to us. He told us that he had about four months to live. He said that with this illness, he would eventually slip into a coma, and that when he did, he didn't want to be treated by artificial means. He didn't want to put on a respirator or ventilator to keep him alive. He wanted pain medication to keep him as pain free as possible, and he wanted to stay home.

At the time he told us this, I felt arrogantly confident about what my reaction would be when he did slip into a coma. I nodded yes to his decision, believing that I clearly understood what his wishes were. But I'll never forget when it happened. It's like a photographic snapshot in my mind – my brothers, my mom and I, along with the hospice nurse, surrounded his bedside as he slipped into a coma. My initial and immediate reaction was to tell the hospice nurse to put my dad on a respirator or ventilator, to do anything to keep my dad alive. My reaction startled me and shook me up.

My dad and I used to go to senior facilities to talk about end of life decision-making. Him, from a medical standpoint, and me, from an estate planning perspective. I thought I knew for sure how I would react.

I didn't say anything however. Instead, I stifled my selfish desire to keep my dad alive. I believe that it was because he made an informed decision about his care, that he was able clearly communicate his wishes to us. Because of this, my family and I were able to honor and respect his wishes. While we felt extreme sadness, we didn't struggle with the guilt, anxiety, and depression that many other families suffer when a loved one passes on. Especially when they don't know what their loved ones wanted and had to make those difficult medical decisions on their own.

It is my hope, that one day our Hawaii community will offer to everyone a uniform, systematic, and coordinated process called Advance Care Planning, where we can plan for how we want to be treated during end of life. Much like estate planning, where a trained attorney guides us through the estate planning process, an Advance Health Care Planner will guide us through the end of life process, helping us to (1) clarify illness and treatment options, as well as explore unique beliefs, values and treatment goals; (2) communicate our wishes and intentions clearly to our loved ones and the professionals who are there to assist us; and (3) ensure that these wishes and intentions are honored and respected. And, in doing so, to reduce loved ones' anxiety, depression and stress during the end of life and to preserve precious family relationships.

THE WHY

Why take the time to go through this booklet?

As an estate planning lawyer, I listen to story after story of families who have suffered from anxiety, stress, guilt and depression because they have had to make an end of life decision for their family members. Many family relationships suffer incredible stress when confronted with these issues, especially, if a decision has to be made in an Intensive Care Unit (ICU), where you don't have time to carefully think over decisions as to whether certain medical treatments should be administered or refrained from.

An old saying goes, "You can only test the strength of tea if you put the tea in boiling water." The ICU is not the place we want to test the strength of our understanding of a loved one's wishes with regards to an end of life decision. There is too much at stake.

We now face a crisis as baby boomers continue to age and as medical care continues to advance. Because of the advancement of medical care we are living longer, sometimes beyond what we feel is a good quality of life.

While we plan for and engage in rituals for many of the important events in our life: birth, graduation, marriage, retirement, and death, we do not adequately plan for end of life. The result is that many patients die alone and in pain in an ICU room surrounded by strangers (caring strangers, but strangers nonetheless). While their loved ones needlessly suffer from spiritual, psychological, and relational stress.

There is another way to go through what may well be the worst of time of our life – the end of life. It is a process where a skilled and trained individual guides us through decisions based on our health at the current time to determine what kind of illness we may face in the future and what treatment options are available. Through this planning process we can explore our values, needs and desires about care which include spiritual, relational as well as health care. After making an informed decision about our care, we can communicate these values, beliefs and wishes to our loved ones and our care providers so they can be respected and honored. At the same time, we can leave our loved ones with reduced anxiety, stress and guilt.

I refer to this as a process, because everything changes as time goes on. We get older, we face different types of ailments and medical care changes. Our ideas, values, and beliefs, often change as we get older. Because one goal is to honor and respect our wishes, we must keep our Advance Health Care plan current to mirror and reflect our intentions.

To have this become a ritual, we must normalize this as a uniform and systematic process which encompasses our entire community. From the first stage, where the process can be introduced by an estate planning attorney, a financial advisor, a spiritual leader, or even a primary care physician, well before any chronic or serious illness exists. This is the beginning. This is where we each can start a baseline to work off from, to normalize this process, to make the communication process easier, looking forward to a more difficult time.

Then, through the next phase, where we may begin to experience a decline in our physical and mental abilities due to a chronic and progressive illness. When hospitalization and additional illness may become more frequent.

And then, through the last stage, which is intended for the frail elderly or those whose death will fall within the next 12 months. Many of these individuals are living in long-term care facilities and are at risk for complication and are losing their decision-making capacity.

These are the stages when it is most important to establish and continually update our Advance Health Care plan. So that our wishes and intents are followed through and honored by the ones we love.

PURPOSE OF THIS BOOKLET

The purpose of this booklet is to guide you through questions about what quality of life means to you, to ferret out your intentions, values and beliefs. These questions are designed to encourage you to reflect on your ideas about your healthcare and how you wish to be treated. This booklet is also intended to help you communicate those intentions, values, and beliefs to your loved ones and care providers either in writing, or by discussion so that they will be honored and respected. The goal is to communicate now so that your wishes are clear when you can no longer speak.

Because change is a guarantee in life, I encourage you to revisit the questions in this booklet from time to time, to ensure that your wishes clearly reflect what you presently desire.

ARE SOME CONDITIONS WORSE THAN DEATH?

On the following pages you will find a series of questions intended to help you think about situations in which you would not want medical treatment administered to keep you alive. These days, many treatments can keep people alive even if it will not reverse or improve their condition. Ask yourself what you want in the situations described below if the treatment would not reverse or improve your condition. Treatment might include surgery, medication, resuscitation, ventilator, respirator, hydration, or nutrition.

Directions: Check the boxes numbered from 1 to 5, which best indicates the strength and direction of your desire. You are encouraged to add additional thoughts in the comment boxes.

1. *Definitely want* treatments that might keep you alive.
2. *Probably would* want treatments that might keep you alive.
3. *Unsure* of what you want.
4. *Probably would NOT* want treatments that might keep you alive.
5. *Definitely do NOT* want treatments that might keep you alive.

	Definitely Want Treatment				Definitely Do Not Want Treatment
What If You ...	1	2	3	4	5
Were no longer able to recognize or interact with family or friends					
Comments:					
	1	2	3	4	5
Were no longer able to think or speak clearly					
Comments:					
	1	2	3	4	5
Were no longer able to respond to commands or requests					
Comments:					
	1	2	3	4	5
Were no longer able to walk but were able get around in a wheel chair					
Comments:					
	1	2	3	4	5
Were no longer able to go outside and must remain at home all day					
Comments:					

What if You...	Definitely want Treatment				Definitely Do Not Want Treatment
	1	2	3	4	5
Are in severe untreatable pain most of the time					
Comments:					
	1	2	3	4	5
Are in severe discomfort most of the time (such as nausea or diarrhea)					
Comments:					
	1	2	3	4	5
Are on a feeding tube to keep you alive					
Comments:					
	1	2	3	4	5
Must use kidney dialysis machine to keep you alive					
Comments:					
	1	2	3	4	5
Must use a breathing machine to keep you alive					
Comments:					

What If You...	Definitely want Treatment				Definitely Do Not Want Treatment
	1	2	3	4	5
Need someone to take care of you 24 hours a day					
Comments:					
	1	2	3	4	5
Were no longer able to control your bladder					
Comments:					
	1	2	3	4	5
Were no longer able to control your bowels					
Comments:					
	1	2	3	4	5
Were living in a nursing home permanently					
Comments:					
	1	2	3	4	5
Other					
Explain:					

Additional Comments:

HOW DO YOU WEIGH ODDS OF SURVIVAL

People evaluate the pros and cons of medical treatment in very personal ways. This explains why some people may choose a treatment and others reject it. The big question is, how much would you be willing to endure if the chances of regaining your current health were high? What if chances were low?

Answer the questions below to assess your willingness to take such risks.

Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatments have very serious side effects, such as severe pain, nausea, vomiting, or weakness that could last for months.

Would you be willing to endure such severe side effects if the chance to regain your current health was:

(Circle one answer for each)

High (Over 80%)	Yes	Not Sure	No
Moderate (Over 50%)	Yes	Not Sure	No
Low (20%)	Yes	Not Sure	No
Very Low (less than 2%)	Yes	Not Sure	No
Very, Very Low (less than 1 in 1000)	Yes	Not Sure	No

Additional Comments:

PERSONAL PRIORITIES & SPIRITUAL VALUES IMPORTANT TO YOUR MEDICAL DECISIONS

People have personal priorities and spiritual beliefs that may have an effect on their medical decisions. This is especially true at the end of life with regard to the use of life-sustaining treatments. To make your values and beliefs clearer, consider answering the questions below. Use more paper if you need more space.

1. What do you most value about your physical or mental wellbeing? For example, do you love most to be outdoors? To be able to read or listen to music? To be aware of your surroundings and who is with you? What about seeing, tasting, or touching?
2. What are your feelings regarding the end of life?
3. Would you want to be sedated if it were necessary to control your pain, even if it makes you drowsy or puts you to sleep much of the time?
4. Would you want to have a hospice team or other palliative care (i.e. comfort care) available to you?

5. If you could plan it today, what would the last day or week of your life be like? For example, where would you be? What would you eat if you could eat? What would your environment be like? What would be your final words or last acts? What would you be doing?

6. Are there people to whom you want to write a letter to or for whom you want to prepare a taped message? Perhaps marked for opening at a future time.

7. How do you want to be remembered? (If you were to write your own epitaph or obituary, what would you say?)

8. What are your wishes for a memorial service – for example, the songs or readings you want, or the people you hope will participate?

9. How would you describe your spiritual or religious life?

10. What gives your life its purpose and meaning?

11. What is important for others to know about the spiritual or religious part of your life?

12. What do you need for comfort and support as you journey near death? For example, to pray with a member of the clergy? To have others pray for you? To be read to from spiritual or religious texts? To have music playing in your room? To be held?

13. What are other priorities/values you would like others to know?

BURIAL AND FUNERAL ARRANGEMENTS

Where do you want to be when you die?

Would you prefer to be in a hospital, at home, or in a special place?

I would prefer to be: *(circle one)*

Buried

Cremated

No Preference

I would like my remains to be placed:

What are your thoughts about your memorial service – such as songs or readings you want, or the people you hope will participate?

Other Preferences:

Additional Comments: