

*I'll*  
HAVE  
*it my*  
WAY  
WORKBOOK

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Taking Control of End-of-Life Decisions

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A BOOK ABOUT FREEDOM & PEACE

Hattie Bryant

TIP: “You do not need a lawyer. However, if you have substantial wealth, children who might be prone to argue, or the potential of some estranged person popping back into your life as you are trying to go in peace, you might want to take what you have written here to a lawyer. Hattie’s right that giving out multiple copies of your wishes is a good way to protect yourself and make clear that your single chosen proxy is in charge when you can no longer speak for yourself or if you were to lose decisional capacity.”

– JAMES M. STERN, JD<sup>301</sup>

# MY WAY WORKBOOK

**USER WARNING:** If you apply what you have learned here, you will be ready to die when the time comes. If you have named your proxy on page 211 (surrogate/durable power of attorney/agent/healthcare decision maker) and if you have shared what you've written with every key player in your life, you can breathe easy. If not, every person in your life who will have their own baggage could guilt you into taking treatments you don't want or be more needy as you age and get sick. Please invite your family and friends to handle unfinished business as it comes. Don't let it collect, don't let anyone sabotage your exquisite exit by making you carry their bags.

## NEED TO KNOW #1:

### *Everyone Dies*

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You are living and dying right now. You can't expect to live forever. Before you go on, please personalize and time stamp your workbook.

My name is \_\_\_\_\_

Today's date \_\_\_\_\_ My age is \_\_\_\_\_

The age I feel is \_\_\_\_\_ My current occupation is \_\_\_\_\_

Marital status? \_\_\_\_\_ My household includes \_\_\_\_\_

(If you have children) I have \_\_\_\_\_  
children and they are \_\_\_\_\_ age(s).

*How I would rate my health today?* (CHECK ANY/ALL THAT APPLY)

- I am healthy.
- I have a chronic disability such as congestive heart failure, hypertension, diabetes or COPD that is well managed with medication.
- I have some difficulties with activities of daily living.
- I have a serious disease and I need to get my affairs in order.
- If my doctor is correct, I may die soon.

## NEED TO DO #1:

*Face the inevitability of death and any fears you have about it*

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There might be three good reasons for you to deny the reality of death.

1. *Maybe you deny truth because you have what is called "unfinished business."*<sup>302</sup>

Fritz Perls would say you have things to say to some of the people in your life.

If you died soon, would a person you have been or are currently angry with know that you let it go and you are no longer angry?      **Y**      **N**  
     

If you died soon, would someone you know you have hurt know that you are sorry?      **Y**      **N**  
     

If you died soon, would the people who are so helpful to you in your life have heard you say to them recently, "Thank you for \_\_\_\_\_" ?      **Y**      **N**  
     

If you died soon, would the people you love know that you love them? Have you told them you love them in the last few days or weeks?      **Y**      **N**  
     

Many people hold on to their heart beat in order to complete unfinished business.

The time to complete all unfinished business is *daily*. This way when your body does want to quit, your spirit can make an easy transition out, as you will have zero emotional barriers. You will have no unfinished business. Think of going to sleep every night as your rehearsal for death. (It is, you know.) Settle emotional problems daily, and you'll sleep like a baby.

As he was actively dying, my father asked, "What mistakes did I make with you?" When I told him the answer to his question, he said:

I wanted to do what was best for you and guide you through childhood so that you would become a strong and confident woman. I realize now that I was hard on you and judgmental even to the point of trying to keep certain young people out of your life and out of our home. I was wrong. I should have embraced all of your friends and enjoyed them for their unique qualities. I was wrong and I am sorry for that. I am so proud of the person you have become.

*Write a list of people you need to talk with right away!* These are people you love, people you want to say I'm sorry to, people you want to thank for everything they have done for you, people who occupy both sweet and sour spots in your heart. You want the sour spots to turn sweet and the sweet spots to get sweeter. Even better than talking to the people on this list, write love letters, thank you notes and even a few, "I'm so sorry" notes.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_
10. \_\_\_\_\_

Fritz Perls taught that if you cannot speak to certain people because it would hurt them or because they might hurt you with their response, you should talk to an empty chair. Sit facing the chair as if you are knee to knee and imagine looking into the face of the person, then say what you want to say. If you have a friend or therapist observe you, your relief will be more complete, as observed behavior is more powerful.

2. *You may deny that you are going to die because people depend on you and you have bills to pay. The obligations keep you on a fast track and you simply don't have time to die.*

*Make a list of people who depend upon you.* This would include children under 18 or physically/mentally disabled and unable to care for themselves, parents, a spouse, employees who work directly for you, students in a class you teach, etc. (Skip this section if this does not apply to you.)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Do you worry that some of these people will fall apart without you?

Y	N
<input type="checkbox"/>	<input type="checkbox"/>

If you died soon, would you leave financial burdens behind?

Y	N
<input type="checkbox"/>	<input type="checkbox"/>

What steps can you take to be at peace over these concerns?

3. *You may deny that you are going to die because you have places to go and people to see. These are dreams. So go ahead now and take action on the dreams.*

*Make a "Bucket List" of things you want to do before you die.* There are two parts: one is the list of things you want to do every day, and the other is the special experience list.

Things I want to do every day.

1. *Be grateful.*
2. *Be kind.*
3. *Enjoy friends and family.*
4. *Notice the beauty around me.*
5. *Express love.*
6. *Give and receive forgiveness.*
7. \_\_\_\_\_
8. \_\_\_\_\_

9. \_\_\_\_\_

10. \_\_\_\_\_

I have already had a very full life, and if health permits, I still want to:

1. Travel to \_\_\_\_\_

2. See \_\_\_\_\_

3. Learn how to \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

“Mental health is dedicated to seeing reality at every cost. Denial is what keeps us from emotional growth. It is the deepest problem my clients face as they cannot get better if they don’t face truth with radical honesty. Even with truth staring them in the face, they can stay in their denial and remain stuck in situations that will eventually cause them to lose their minds or stunt their growth. For a person to die peacefully I would say that a person will need to let go of the mythological fantasy that he/she is not human and that the myth he/she refuses to release is very real.” - DR. LYDIA NAVARRO



## NEED TO KNOW #2:

### *Medicine Has Its Limits*

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*“We look for medicine to be an orderly field of knowledge and procedure. But it is not. It is an imperfect science, an enterprise of constantly changing knowledge, uncertain information, fallible individuals, and at the same time lives on the line. There is science in what we do, yes, but also habit, intuition, and sometimes plain old guessing. The gap between what we know and what we aim for persists. And this gap complicates everything we do.”<sup>303</sup> – Dr. Atul Gawande*

## NEED TO DO #2:

*Think hard and make hard choices for yourself*

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No family member, no doctor, no psychologist can do this for you. It's too personal.

The following are several true/false statements designed to help clarify your thinking regarding end-of-life decisions. Read the following statements and check the answer that most agrees with your thinking. You'll notice throughout this workbook that there are statements marked with a +. We'll explain what that means later, but for right now just answer the questions based on your feelings at this time. There is no "right" or "wrong" answer. There are only answers that reflect your opinion/view.

	TRUE	FALSE
I am afraid to die.		
I am afraid of the dying process.		
I am afraid my family will fall apart if I am not here to hold everyone together.		
I am afraid my spouse will not be able to live without me.		
I am afraid I will be dependent on others in the last few years of my life.		
+ In the case of trauma such as a car accident or severe life-threatening medical events such as a stroke or heart attack, I am OK with intubation for a few days if I can walk out of the hospital in the condition I was in OR if there is high certainty that I can return to the condition I was in before the trauma.		
+ I want an incision/cut in my stomach to attach a feeding tube if I can't swallow.		
+ I want an incision/cut in my throat to attach a breathing machine if I cannot breathe on my own.		
+ I understand that it is legal for me to refuse medical treatment.		

The American Bar Association Commission on Law and Aging toolkit helps us think about how we want our end-of-days preparation to go. This exercise is used with permission.<sup>304</sup> All answers marked with a “+” are especially useful to your healthcare proxy (more about that in Chapter 4).

It is important to know that many treatments can keep us alive even when there is no chance that the treatment will reverse or improve our condition. Ask yourself what you would want in each situation described if the treatment would not reverse or improve your condition. We give you these five ways to describe your wishes:

1. Definitely want curative care.
2. Probably would want curative care that might keep you alive.
3. Unsure of what you want.
4. Probably want only care to keep you comfortable.
5. Definitely want only care to keep you comfortable.

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*On pages 195 and 196 circle the number  
that corresponds to your desires.*

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WHAT IF YOU...	WANT CURATIVE CARE		→	WANT COMFORT CARE	
No longer can recognize or interact with family or friends.	1	2	3	4	5
Comment _____					
No longer can talk clearly.	1	2	3	4	5
Comment _____					
No longer can respond to commands or requests.	1	2	3	4	5
Comment _____					
No longer can walk but can get around in a wheel chair.	1	2	3	4	5
Comment _____					
Are in severe pain most of the time.	1	2	3	4	5
Comment _____					
Are in severe discomfort (such as nausea, diarrhea) most of the time.	1	2	3	4	5
Comment _____					
Are on a feeding tube to keep you alive.	1	2	3	4	5
Comment _____					
Are on kidney dialysis machine to keep you alive.	1	2	3	4	5
Comment _____					
Are on a breathing machine to keep you alive.	1	2	3	4	5
Comment _____					
Need someone to care for you 24 hours a day.	1	2	3	4	5
Comment _____					

No longer can control your bladder.                      **1**        **2**        **3**        **4**        **5**

Comment \_\_\_\_\_

No longer can control your bowels.                      **1**        **2**        **3**        **4**        **5**

Comment \_\_\_\_\_

Live in a nursing home permanently.                      **1**        **2**        **3**        **4**        **5**

Comment \_\_\_\_\_

Other    **1**        **2**        **3**        **4**        **5**

Explain \_\_\_\_\_

*Now, read the following questions and check the box that best reflects your response.*

	<b>STOP CURATIVE TREATMENT AND PROVIDE COMFORT CARE/PALLIATIVE CARE TO ALLOW NATURAL DEATH</b>	<b>PROCEED WITH AGGRESSIVE TREATMENTS</b>
What would you tell your doctor to do if you had a disease that is incurable and you will become dependent on others for your care?		
What would you tell your doctor to do if you have a disease with no hope of improvement and you are suffering with severe pain?		

### NEED TO KNOW #3:

*Doctors do not expect as much from medicine as the rest of us do. Doctors know about and use palliative care. Doctors know what their colleague, Dr. Tracy Balboni says, "Medicine cannot give us what we need for a peaceful death."*

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### NEED TO DO #3:

*Think and decide for yourself if you want to allow nature to take its course.*

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Joseph Gallo, MD, professor at John Hopkins Bloomberg School of Public Health, and a group of his colleagues collected responses from 765 older physicians to learn how they felt about using life-sustaining treatments for *themselves* under the following scenario:

*“If you had brain damage or some brain disease that cannot be reversed and makes you unable to recognize people or to speak understandably, but you have no terminal illness, and you live in this condition for a long time, indicate your wishes regarding the use of each of the following medical procedures by placing a check mark in the appropriate column.”<sup>305</sup>*

*Now, it's your turn. Please check the boxes on the following page that fit your response.*

PROCEDURE	YES, I WOULD WANT	NO, I WOULD NOT WANT	UNDECIDED	I WOULD WANT A TRIAL TREATMENT, BUT STOP IF NO CLEAR IMPROVEMENT
Cardiopulmonary resuscitation (CPR)				
Mechanical ventilation				
Intravenous hydration				
Feeding tube (via mouth, trachea or into stomach) to provide nutrition				
Major surgery				
Dialysis				
Chemotherapy for cancer				
Invasive diagnostic testing such as endoscopy (equipment inserted in the body to examine an area)				
Blood or blood products				
Antibiotics				
Pain medications, even if they dull consciousness and indirectly shorten my life				



Specifically regarding CPR, how do you feel about its use vs. allowing natural death? Remember that the older we get, the greater the chance that CPR can lead to complications that can mean we're technically alive—but only by machine. Knowing that, if my heart stops (CHECK ONE):

	I want CPR.
	Do not attempt CPR, allow natural death.
	I will have CPR, if and only if, the doctor thinks I will be as good as I was before my heart stopped.

If your health ever deteriorates due to a serious illness and your doctors believe you will not be able to interact meaningfully with your family, friends or surroundings.

*Check which of the following statements best describes what you'd like to tell them.*

	I prefer that they stop all life-sustaining treatments and allow natural death to come as gently as possible.
	I would like them to keep trying life-sustaining treatments.

WHAT ABOUT PALLIATIVE CARE?	YES	NO
+ If you are in great pain as you become more ill or more frail, would you want your doctors to bring in a palliative care team which provides pain management, symptom management, plus emotional and spiritual support for you and your family and helps promote quality of life?		

If the following will not bring me back to the life I had before I arrived at a hospital...

- |  |                          |                          |
|--|--------------------------|--------------------------|
| 1. Do you want to be attached to a mechanical breathing machine?         | <b>Y</b>                 | <b>N</b>                 |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Do you want antibiotics?  | <b>Y</b>                 | <b>N</b>                 |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Do you want hydration with intravenous lines?                         | <b>Y</b>                 | <b>N</b>                 |
|  | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Do you want tube or intravenous feeding if you can't eat on your own? | <b>Y</b>                 | <b>N</b>                 |
|  | <input type="checkbox"/> | <input type="checkbox"/> |

#### **NEED TO KNOW #4:**

*Your doctor cannot decide alone what to do for you when you can no longer speak for yourself. You cannot depend upon professionals only or family and friends only — you need a circle of care.*

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## NEED TO DO #4:

*Choose a person who will speak to doctors for you.*

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If you only do one thing in this workbook, this is the one thing I hope you do. Before you choose your proxy though, I want you to consider the fact that...

A medicalized life can make you and your family poor financially and emotionally.

“Care at the end of life is expensive and too often has no affect on function, independence, duration or quality of life. Furthermore it can cause more pain and suffering with no chance of improving anything. The fact that costs are insulated makes the technology and ineffective care even more alluring.” - DR. RICHARD DELLA PENNA

My dad was good at facing the truth about money because he never had much of it. He grew up poor and wouldn't tolerate waste in our house. He was a conservationist and today we might call him an environmentalist. At seventy-eight he had cancer, and the chemotherapy was a drag. He could see that it was a short-term fix and he considered the time and money being spent on him to be a bad investment. He announced to us, "Save the healthcare for the grandchildren." He invited hospice in and slipped away peacefully taking time to have some nice conversations.

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Patients and families often pay a high price—psychologically and economically—for difficult and unscripted deaths. The Dartmouth Atlas Project, which gathers and analyzes healthcare data, found that 17% of Medicare's \$550 billion annual budget is spent on a patients' last six months of life.<sup>306</sup>

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*Need to Do:* **Decide how much your own healthcare costs should impact the healthy friends and family in your circle of care. These are *your* thoughts; not what you believe others would expect you to answer.**

BASED UPON WHAT I KNOW, MY HEALTHCARE COSTS TODAY ARE:	TRUE	FALSE
My healthcare costs are minimal.		
My only healthcare expenses are for insurance premiums and occasional doctor visits.		
I have noticed my health insurance premiums rising as I age.		
I am guessing my health insurance premiums will continue to rise.		
I am ready for the cost to increase.		
I avoid going to the doctor because I can't afford it.		
+ I am willing to spend my savings on my healthcare even if it means I will have nothing left to leave my children.		
+ I am willing to leave my children with unpaid medical bills.		
+ Money is not an issue to me if I can add weeks, months or years to my life.		
+ I am willing to spend my savings on my healthcare.		
+ I am willing to be sick from treatments if it means I can live another year or two.		
+ I am willing to live a medicalized life. (This means I am dependent upon drugs, devices, monitoring by doctors, etc.)		
+ I am willing to ask my friends and family to support me in my decision to pursue all treatment options that will require their time and energy.		
It would be easy for me to live in my house even if I was in a wheelchair.		

*Check the statement that fits you best:*

- It's OK with me if keeping me alive requires unlimited resources paid for by insurance (private/Medicaid/Medicare), my own savings/the savings of family, and makes heavy demands on the time and emotions of family and friends.
- It's OK with me if keeping me alive requires unlimited resources paid for by insurance (private/Medicaid/Medicare) and my own savings. However, I do not want my care to be a financial or emotional burden on my family. So, when my money runs out, let me go naturally. I realize that this choice means I might have nothing left to leave to my children and grandchildren.
- It's OK to keep me alive so long as it's paid for by insurance (private/Medicaid/Medicare). So, when my benefits run out, let me go naturally. That way I can leave any assets to my family.
- I am beginning to understand that keeping me alive at all costs (money and the efforts required of so many others) is not what I want for my life. I want to leave gently with people sorry to see me go rather than hoping I will go.



*Quantity or Quality?*

Given the research provided and how you've answered the previous questions, do you want your doctor and others in your circle of care to be focused on maximizing the length of your life or the quality of your life?<sup>307</sup>

*Please circle one:*

**Quantity**                      **Quality**  
(number of days)              (the stuff of your day)

Regarding quality, physician and financial planner, Dr. Carolyn McClanahan, has a company called Life Planning Partners. The company tagline is "Financial Health for Life." She requires her clients to complete her checklist called Quality of Life Requirements, and wants you to know that her checklist found on the next page is not a standalone document. Rather it is one to be used in addition to other documents related to your life planning.



If your healthcare providers state you will never regain these functions, you are to be provided care that will keep you comfortable and pain free until you die.

*In order to live the life you desire, it is important for you to retain the ability to:*  
(INITIAL ALL THAT APPLY TO YOU)

- Share your thoughts through words, gestures, or assistive devices.
- Understand what people are saying to you.
- Know that you are hungry. You are able to eat and swallow if someone feeds you.
- Chew and swallow food. Losing this ability results in the need of a feeding tube.
- Take care of your own toileting needs.
- Take a bath or shower with or without assistance.
- Interact in social settings.

*List other functions that are important to you:*

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TIP: “The Supreme Court has determined you have the right to make you own healthcare decisions, and no one can interfere with that right. All you need is a simple statement of your preferences, such as a POLST. You do not need a twenty-page Advance Directive and Living Will.”

– JEANNE FITZPATRICK, MD AND EILEEN M. FITZPATRICK, JD<sup>308</sup>

**\*Family and friends are important to your care.** Just like I was my mother’s champion, you will probably need someone like me to speak for you when you cannot speak for yourself. The person you choose is called your durable power of attorney or surrogate or proxy. It is a legal relationship, so it is very important that you choose this person carefully and once they have accepted, communicate (possibly over several or many conversations) what you believe deep in your heart is best for you.

You can change your proxy choice at any time. You simply have to ask for all of your first instructions to be returned to you and provide a second set of instructions.

You *cannot* choose your physician or any person who works for an institution from which you purchase healthcare service unless that person is your spouse or close relative and the person must be over eighteen years old now.

As you think about the importance of this person in your healthcare decision-making, certain characteristics are desirable.

\*If you are already so seriously ill that you may not get to leave the hospital and if you have not chosen a proxy, it might be easier for your family, friends and physicians if you answer the questions most especially about how you want to live your life. The simplest questions for you to answer are on pages 206, 207 and 208.

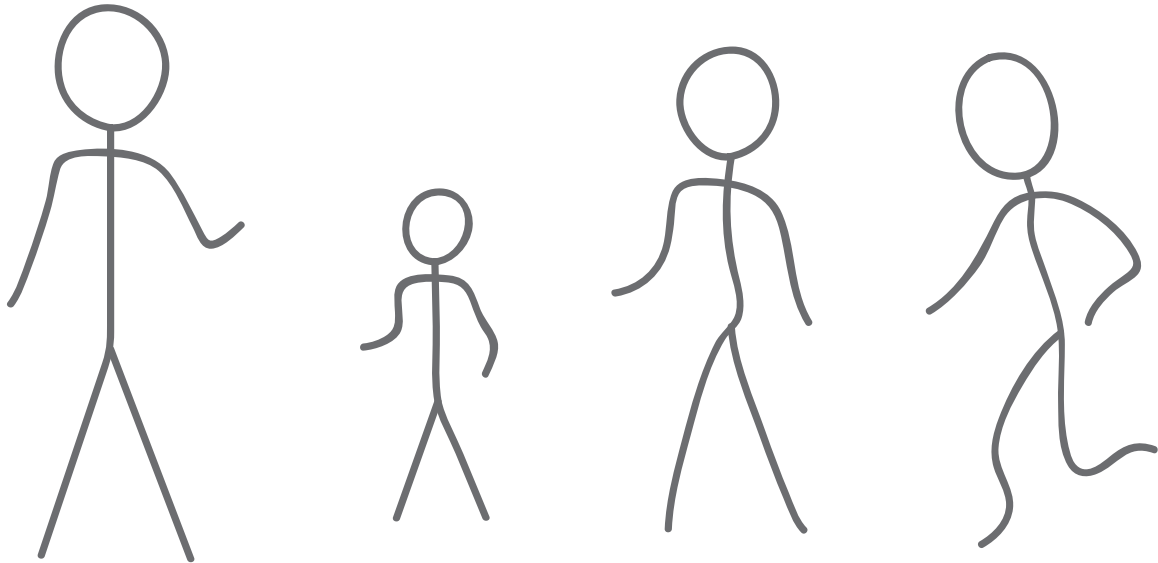
Think about people you know who...

- Would be willing to speak for you.
- Can separate their personal desires for you from your desires for you.
- Would take some time soon to review with you what you are writing in this document.
- Lives close to you or can travel to you quickly or work via phone, email and text with a physician.
- Is young enough and healthy enough to be around in the future.
- Is someone you trust with your life.
- Can calmly manage any conflicts.
- Can stand up to family members who may not agree with you.
- Can negotiate with physicians to achieve your stated goals and be willing to fire a physician who doesn't listen.
- Can listen to facts presented and make a rational decision.

*Write your list of possibilities...* (minister, adult children of your friends, nieces, nephews, neighbors, one of your own children—the one who is feisty, outspoken, strong, persistent and maybe even considered obnoxious—a godchild, a cousin, a sibling—much younger one—the spouse of a niece, nephew or your own spouse—if much younger but probably not a good choice)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_

Remember we discussed that it's best to name one person, not a committee. There are plenty of reasons that this person might not be your child or your spouse but at the same time, it is your choice.



+ *The person I choose to speak for me if and when I cannot speak for myself.*

1. \_\_\_\_\_

+ *If the first person I named is not available, this person will step in.*

2. \_\_\_\_\_

Please turn to page 213 and add your proxy choices to line one and two. Fill in the rest of the form and before you sign, find a couple of neighbors or friends to witness for you.



## FOR MY HEALTHCARE PROXY, FAMILY, FRIENDS AND HEALTHCARE PROVIDERS

### *Durable Power of Attorney for Healthcare Decisions*

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Based upon the work you see I have done on the preceding pages, I want you to know that if and when I can no longer speak for myself,

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Address: \_\_\_\_\_

City/State: \_\_\_\_\_ Phone No: \_\_\_\_\_

will be in charge of making sure that my wishes are respected. If this person is not available, the alternate proxy/surrogate

is \_\_\_\_\_

Address: \_\_\_\_\_

City/State: \_\_\_\_\_ Phone No: \_\_\_\_\_

I, \_\_\_\_\_ being of sound mind, do hereby designate the above to serve as my Attorney-in-Fact, for the purpose of making medical treatment decisions for me (including the withholding or withdrawal of life-sustaining procedures, nutrition, hydration) should I be diagnosed and certified as having an irreversible condition and be comatose, incompetent, or otherwise mentally or physically unable to make such decisions for myself.

My named proxies are strong people who know me well and need only to refer to my answers to the questions in this plan which I have written in my own hand or have dictated to a caregiver.

The key information my proxy needs comes from the sections of these pages that bear this sign: + My answers to these questions constitute my advance directive in case I do not take the time to create a separate document.

I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

My Name (In Print): \_\_\_\_\_

My Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Address: \_\_\_\_\_

In our joint presence, \_\_\_\_\_ who is of sound mind and eighteen (18) years of age, or older, voluntarily dated and signed this writing or directed it to be dated and signed for the grantor.

Witness 1 Name: \_\_\_\_\_

Address: \_\_\_\_\_

Witness Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Witness 2 Name: \_\_\_\_\_

Address: \_\_\_\_\_

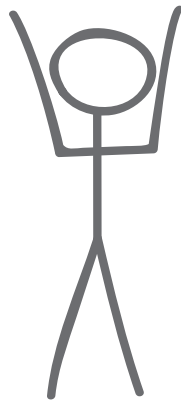
Witness Signature: \_\_\_\_\_ Date: \_\_\_\_\_

# Congratulations!

**Now that you have completed your MY WAY WORKBOOK, PLEASE MAKE MANY COPIES.** Make copies of the MY WAY WORKBOOK for your proxy, spouse, doctors, children, siblings, friends, neighbors and any person in your circle who could argue with your proxy over your wishes. You can retrieve free PDF files of these MY WAY WORKBOOK pages from **IllHaveItMyWay.com**.

There is documented evidence that doctors don't even need to see what you have written if others have heard you speak clearly about your wishes, so sharing your wishes is especially powerful, and talking about them even more so. Be open to answering questions and encourage those close to you to do the same kind of thinking you have just done, documented and shared. Then, go have some fun with the rest of your life!

**Write me when you've finished this. I would love to hear from you. You can reach me at [Hattie@IllHaveItMyWay.com](mailto:Hattie@IllHaveItMyWay.com)**



This workbook is excerpted from the book, *I'll Have It My Way*.

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