## **Table of Contents**

Introduction	1
Why is This So Hard to Talk About?	2
Birth and Death – Death and Birth	5
Dying in the United States	6
The Cost of Dying	9
A "Good Death"	10
Planning Death?	12
If You Choose Not to Make a Plan	14
Making Tough Decisions	16
Difficult Choices: Quantity vs. Quality	18
Waiting for the Doctor to Say "It's Time"	20
"Allow Natural Death"	21
Summary So Far	23
Tools for Planning	23
Which Tool is Right for You?	26
Choosing Your Health Care Representatives	29
What is Life Support?	30
Artificial Administration of Nutrition and Hydration	36
Making Advance Directive Decisions: The Scenarios	39
Completing a KEY <i>Conversations</i> Individual Worksheet	41
Making POLST Decisions	42
Making Decisions When Faced with Dementia/Alzheimers	45
How to Fill Out the Advance Planning Forms	46
What to do With Your Completed Forms	46
Having the Difficult Discussion with Family and Loved Ones	48
Your Healthcare Goals at the End of Life: Moving From Cure to Comfort	53
Learning Assertiveness in the Health Care System	56
In Conclusion	60
Resources	62
APPENDIX A - Oregon Advance Directive and Helpful Hints for Filling It Out	65
APPENDIX B - Oregon POLST and Helpful Hints for Filling It Out	72
APPENDIX C – Ethics, Religion, and the End of Life	75
APPENDIX D – Natural Death – What is it and What Does It Look Like	82

## Introduction

This workbook is designed to assist you in making decisions about the kind of health care you hope for at the end of your life. It will cover a lot of ground in helping you to think about, decide, document, and finally discuss your wishes for care when you are no longer able to speak for yourself.

From exploring why this is so hard to talk about in the first place to looking at the ethical considerations of available options, from learning about the real benefits and burdens of aggressive medical treatment at the end of life to planning for a conversation with your family and health-care providers, this workbook will move you toward the ability to clarify your own thoughts and focus your actions so that you will be able to travel toward the end of your life knowing that your

Nothing in life is to be feared. It is only to be understood.

Marie Curie

wishes are clearly known by your loved ones and health care providers.

Whether you are a healthy younger adult who is likely still far from natural death or are elderly and/or facing life-limiting illness right now, there will be something here for you to learn and act upon.

The goal is for you to be able to plan, <u>in advance</u>, what level of care you prefer at the end of your life, whether that care becomes needed because of an unexpected accident/health crisis or because you find yourself slowly growing increasingly frail and dependent over time.

While you are still competent to make decisions and can speak for yourself, you can remain actively involved in making those decisions – hopefully this workbook will help you anticipate more clearly what choices you may face along the way. Just as important, though, is making sure that your wishes are known so that they are followed even in cases when you are not able to speak for yourself.

Creating a solid advance plan for end-of-life health decisions involves a number of steps:

- Discern your own value and wishes what is most important to you in the last chapter of your life?
- **Delve** into new information that would be helpful to you as you consider your options.
- **Decide** which documents are most appropriate for you, who your best choice for Health Care Representative might be, and how you'll respond to the questions presented in the documents.

- **Document** your wishes in the Advance Directive (and POLST, Worksheet, Five Wishes, or whatever is appropriate for you).
- **Distribute** copies of your documents to important people, especially your close family and loved ones and your health care provider.
- **Discuss** with those important to you *why* you made the choices that you did, and ask for them to respect your decisions, following through for you when you no longer can.

These steps form a logical path toward a goal of a peaceful, dignified death that is as free as possible from confusion, stress, misunderstandings, misinterpretations, and conflict.

Well over half of deaths in the U.S. involve someone else making decisions for patients who are no longer able to communicate their own wishes directly.