

End-of-Life /Legacy Planning Resources Binder United Parish in Brookline January 2023

Overview

In October 2022, the United Parish Legacy Planning and Adult Deepening ministry teams offered a 3-session program called "Wills & Wishes". The intent was to start a UP community conversation about end-of-life planning -- the emotional and spiritual considerations as well as medical, financial, and legal issues. It was aimed at adults of all ages.

We designed the program to complement the launch of the United Parish Legacy Giving Program, which invites us all to name United Parish as a beneficiary of a will or trust, providing a legacy of giving to our church family.

This sampler of resources is a "starter kit" of information that the Wills & Wishes team gathered and found useful in developing the workshop series. It is a compilation of:

- Key Content from Workshop Sessions
- "End-of-life *Questions To Discuss With Your Family & Other Loved Ones*" These conversation starters are good for opening this difficult topic with loved ones.
- · Web Resources key organizations, information, and worksheets
- Book Suggestions

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1. Talking About Death with Loved Ones

A starting point in articulating your end of life "wishes" is to use some of the excellent tools that exist to help you understand, ponder, and prioritize all your choices. The next important step is to engage your loved ones with your deliberation process and priorities.

An easy way to get started is to review the 4-page "*End-of-Life Questions To Discuss With Your Family & Other Loved Ones*" in Appendix A at the back of this document. It is a randomly arranged set of questions, and you will find some have more emotional impact than others.

The *Five Wishes* is also a popular questionnaire and planning document that families can use as a conversation starter, since it is written in everyday language, making it easy to understand and complete. It covers personal, spiritual, medical, and legal wishes all in one document. <u>https://www.fivewishes.org/for-myself/</u> (Five Wishes will also be discussed later in the next section. If it is filled out and properly signed, it can serve as a living will in many states.)

The Conversation Project associated with the Institute for Healthcare Improvement also has a Conversation Starter Kit to help people discuss end-of-life care at <u>https://theconversationproject.org</u>.

2. Health Care Proxy & Personal Directive/Living Will

The **Health Care Proxy** is a legal document that designates a trusted person to be your Health Care Agent. Your Agent makes health care decisions for you when you are unable to make health care decisions yourself – if even for a short time while you recover. You may already have designated a Health Care Agent (primary and secondary) if you had a medical procedure. Importantly, this is necessary for anyone <u>age 18 and older</u>, because the medical privacy regulations (HIPAA) will not automatically allow next-of-kin to make medical decisions.

Before completing a Health Care Proxy, you should discuss your plans with the two people you would like to designate as your primary and secondary Health Care Agent. The Health Care Proxy document should be shared with your primary doctor so that the Proxy can be uploaded to the medical records system. It should be reviewed every few years to see if the designated Agents are still available and appropriate, and should be kept on file in an accessible place.

The **Personal Directive/ Living Will** is a written, legal document that spells out medical treatments you would and would not want to be used to keep you alive, as well as your preferences for other medical decisions, such as pain management or organ donation.

You should address a number of possible end-of-life care decisions in your living will or personal (also called advance) directive. Talk to your doctor if you have questions about any of the following medical decisions:

- **Cardiopulmonary resuscitation (CPR)** restarts the heart when it has stopped beating. Determine if and when you would want to be resuscitated by CPR or by a device that delivers an electric shock to stimulate the heart.
- **Mechanical ventilation** takes over your breathing if you're unable to breathe on your own. Consider if, when and for how long you would want to be placed on a mechanical ventilator.
- **Tube feeding** supplies the body with nutrients and fluids intravenously or via a tube in the stomach. Decide if, when and for how long you would want to be fed in this manner.
- **Dialysis** removes waste from your blood and manages fluid levels if your kidneys no longer function. Determine if, when and for how long you would want to receive this treatment.
- **Comfort care (palliative care)** includes any number of interventions that may be used to keep you comfortable and manage pain while abiding by your other treatment wishes. This may include being allowed to die at home, getting pain medications, being fed ice chips to soothe mouth dryness, and avoiding invasive tests or treatments.
- **Organ and tissue donations** for transplantation can be specified in your living will. If your organs are removed for donation, you will be kept on life-sustaining treatment temporarily until the procedure is complete. To help your health care

agent avoid any confusion, you may want to state in your living will that you understand the need for this temporary intervention.

• **Donating your body** for scientific study also can be specified. Contact a local medical school, university or donation program for information on how to register for a planned donation for research.

In our Wills & Wishes workshop, we had a presentation from an expert at Honoring Choices Massachusetts. Their online "Getting Started Toolkit" for both health care proxies and personal directives can be found at <u>www.honoringchoicesmass.org</u>.

How health care proxies, personal directives and living wills address dementia has some unique issues. Compassion & Choices (compassionandchoices.org) is an organization working to transform the way people live and die with dementia by helping them assert their care preferences early in their dementia journey, to choose what health care they want to receive and which care they may forgo when their dementia reaches an advanced stage. They offer a Dementia Values and Priorities Tool to help individuals identify their personal values and care wishes, provide clear care instructions to their loved ones and take the burden off of others to make difficult decisions when the person with dementia can no longer make those decisions themselves.

The Conversation Project's *Conversation Starter Kit* also addresses health care proxies and personal directives at <u>https://theconversationproject.org</u>

Two UP members who are physicians told workshop attendees about MOLST – "Medical Orders for Life-Sustaining Treatment" that are used in Massachusetts. MOLST is a standardized medical order for use by clinicians caring for patients with seriously advancing illness.

MOLST forms are also relevant when a patient is at home with serious medical issues and/or a Do Not Resuscitate (DNR) order. MOLST forms are usually printed on a bright color paper and posted-in an obvious place like a refrigerator. Senior housing developments may have other specified locations.

They have basic information Emergency Medical Providers need to know if called to your home due to a medical emergency. The form has basic information as to how much intervention you would like given: resuscitation, intubation, etc. These forms can be found at https://www.molst-ma.org

POLST is a similar national program for "portable medical orders", that may eventually supplant the state-by-state programs like MOLST, which is used in Massachusetts. <u>https://polst.org</u>

3. Durable Power of Attorney

A Durable Power of Attorney is a legal document in which you appoint a trusted person to manage and protect your financial interests - when you are not able to manage your financial matters yourself. You can appoint a trusted person as your agent, called an 'Attorney-in-fact', to pay your bills, sign a contract to pay for short or long-term care, and make financial decisions on your behalf. Your Attorney-in-fact can act even if you become incapacitated.

Although it is not required, it is generally recommended that you ask an attorney to draft a Durable Power of Attorney for you. Two people should be named, a primary and secondary agent. If there is a capable spouse, they are usually chosen as the primary agent. This document is often notarized at an attorney's office or a bank. It can also be revoked or changed as long as you are deemed a competent adult. It is nullified at your death.

It is important to choose this person carefully, whether spouse, family member, or friend, since they will oversee your finances should you be incapacitated. This person will pay the mortgage/rent, sign checks on your behalf, and receive income in your name. If you own property jointly with another, for example a house, be sure that you have Power of Attorney for each other. No disposition of jointly owned property can be made unless the incapacitated partner has given Power of Attorney to the other.

4. Wills/ Choosing an Executor/ Probate Process

A will is a legal document that coordinates the distribution of your assets (estate) after death and can appoint guardians for minor children. A will allows you to communicate your wishes clearly and precisely.

A will generally includes:

- Designation of an executor, who carries out the provisions of the will, and is usually in charge of settling any debts, taxes, and funeral expenses before distributing the remaining assets as the will designates.
- Beneficiaries—those who are inheriting the assets.
- Designation of guardians for any minor children.

It is advisable to work closely with an attorney to create and update your will, but there are many good resources and templates online that can help you get organized, to reduce legal costs. The United Methodist Foundation of New England has a helpful workbook available online called *"Provide & Protect: A Guide To Planning Your Will And Trust"*, which can be found at https://umfnelegacy.org/?pageID=19

Before naming an executor or assigning guardianship to minor children, be sure to get permission from the people involved. Be sure <u>everyone</u> in the family knows who and why these people were chosen.

Without a will, the state decides how to distribute your assets to your beneficiaries according to its laws. This is known as dying intestate, and the resulting settlement process may be expensive and not produce the results that you would prefer for your loved ones.

Probate is the court-supervised legal process of transferring property and ownership after someone has died, governed by state law. Whether an estate must be probated depends on how the decedent's (the person who has died) property is owned when they die. Typically, the probate process involves:

- Deciding whether the decedent's will is valid
- Changing the title (ownership) of real estate or personal property, such as bank accounts, stocks, or bonds, that is only in the decedent's name
- Paying the decedent's creditors
- Getting the decedent's medical records
- Filing the decedent's tax returns and paying taxes

In Massachusetts, it can usually take a year or so, because creditors have up to a year after a death to come forward with claims. Probate is simplest when someone dies with a valid will with a designated executor and/or has a surviving spouse that jointly holds most of the assets.

https://www.mass.gov/info-details/find-out-when-its-necessary-to-probate-an-estate https://www.investopedia.com/articles/pf/08/what-is-a-will.asp#toc-what-does-a-will-cost

5. UP Legacy Giving/ Designating Beneficiaries

When you are preparing a will, we hope you will consider naming United Parish as a beneficiary of your will, with a statement:

I give to United Parish in Brookline, MA, (Tax ID# 042-458-504) or its successor thereto, _______% of my residuary estate [or the sum of \$___] for its unrestricted use and purpose.

Another effective way to create a legacy gift, instead of through the will, is to name United Parish as a beneficiary for all or a percentage of an IRA, 401(k), 403(b), Pension, Profit Sharing Plan, or life insurance policy. This enables a direct transfer of the asset to a beneficiary. These types of asset transfers outside the will usually avoid probate and the associated fees.

It is very important to let the Pastor and Treasurer of United Parish know of your designation <u>in writing</u>, as not all plan administrators feel an obligation to inform the beneficiaries.

For more information contact legacygiving@upbrookline.org.

6. Hospice and Palliative Care

While this topic was not addressed in the workshops, here are two overview resources from two of the organizations already mentioned:

Palliative Care

https://www.honoringchoicesmass.com/wp-content/uploads/2017/10/Palliative-Care-for-Consumers.pdf

Hospice - How to Interview a Hospice

https://compassionandchoices.org/docs/default-source/default-document-library/fs-how-to-interview-a-hospice.pdf?sfvrsn=90d9d0b7_1

7. End-of-Life Plan for the Body

Most people decide before death about the preferred method for disposition of their body at end-of-life; others leave it to loved ones to decide. Some people also plan and pay for funeral home services while they are alive, making the time immediately after death easier on the family.

Your choices for the disposition of the body may include:

- Donating organs
- Donating the whole body for medical training or research
- Cremation of remains followed by burial of ashes at a cemetery, storage in a columbarium, or disposition of ashes at a beloved outdoor site by family member
- Burial in a casket in a cemetery.
- Green/ecological burial of a body wrapped in a biodegradable shroud (at this time that is done only at Mt. Auburn Cemetery in Cambridge, but more cemeteries will likely be offering this in the future.)

The United Parish pastors can also advise on these issues.

8. Funerals and Memorials

United Parish pastors are available to work with members to plan their own funerals and memorial services while they are still alive. They are also available to work with families to plan funerals and memorial services once the loved one has died.

Funeral services can be provided at United Parish, with further liturgy provided at a burial site at the wishes of the family.

Memorial services can also be provided at United Parish and scheduled at a convenient time to convene the loved ones of the deceased. United Parish staff and members are available to assist a family in hosting a "collation" or reception after a service.

United Parish waives building usage fees and the pastors' honoraria for contributing members. The pastors deposit any honoraria received into their discretionary funds, often used to help people in need and for special staff events. The church does charge fees for the services of part-time staff involved in the service (i.e., Music Minister, sextons, Media Producer).

United Parish pastors typically offers these templates when they work with church members or their families involved in planning funeral or memorial services.

Funeral Scripture Readings and Hymns

Funeral or Memorial Service Information Sheet

9. The End-of-Life File

These items – plus other documents that are unique to you and your family - should be gathered and put in one easily accessible location that the executor and other family members know about. Making a copy and sharing it with your attorney or a family member is also a good idea.

Health Care Proxy/ Personal directive (signed by 2 witnesses) Lawyer and accountant information Copy of birth certificate Copy of Marriage / Divorce certificate Will (and Trust) Power of Attorney Life Insurance Policy (the last bill is sufficient to show its existence) Military Service documents Investment and banking information Contact info for person/business with access to stored valuables/ safe deposit keys Real Estate documents and where to find the deed Debtor information (Credit cards, mortgage, etc.) Copy of Driver's License and S.S. card Tax info (Hard copy or password to online tax preparation software) Passwords (use of a password manager app is recommended) Letters to loved ones Burial/ cremation/ research /organ donation arrangements or instructions for the body Funeral or memorial instructions (this should also be on file at United Parish)

10. Last But Not Least: Communicate With Loved Ones!

Tell stories. Clean out the emotional attic. Share and discuss any long-held secrets or disappointments. Apologize for lies or hurtful words. Communicate/ clarify/ explain.

Most important words when life is ending:

Please forgive me.

I forgive you.

Thank you.

l love you.

I'm proud to be your mother/father.

I'm proud to have you for a mother/father.

Appendix

- A. End-of-Life Questions To Discuss With Your Family & Other Loved Ones
- **B. Web Resources**
- C. Book Suggestions

Appendix A

End-of-Life Questions To Discuss With Your Family & Other Loved Ones

- 1. If you needed help going to the bathroom today, who was the first person you would ask to help you. Who would you never be able to ask?
- 2. What would you like done with your body after you die?
 - a. embalmed and buried
 - b. natural burial
 - c. donate to science
 - d. cremated
 - e. other

Do you intend to be an organ donor?

- 3. What is the first memory that comes to mind when you think about physical pain?
- 4. In order to provide you with the best care possible, what three non-medical facts should your doctor know about you?
- 5. What is your earliest memory of a difficult decision?
- 6. If you had one day to say you were sorry to anyone who you wanted before you died, who would be the first?
- 7. If your doctor believed you had six months to live, who would you want them to tell?
- 8. Which is more frightening to imagine: suffering the worst physical pain of your life or not getting a chance to say goodbye to your family?
- 9. If only one story is told that your memorial service, who should tell it?
- 10. If you could control only one thing about the place where you spend your last hours of life, what would it be?

- 11. Think of someone you have loved who has died. What could you keep in your pocket to remember them by?
- 12. If you were diagnosed with a terminal disease, who would you turn to for advice?
- 13. In the movie The Princess Bride, Buttercup realizes that every time Wesley says "As you wish", what he really means is "I love you". What is a similar code phrase that someone you know uses to say I love you?
- 14. What do you think happens to you after you leave this life?
- 15. What is your earliest memory of attending a funeral or memorial service?
- 16. If you had three months to live, what 3 things would you give yourself permission to do? Choose one per month.
- 17. How old were you when you first realized you would eventually die?
- 18. If you could pick anyone to sing at your memorial service, who would it be and what would they sing?
- 19. When you think about care at the end of your life, do you worry more about:
 - a. not getting enough care
 - b. getting overly aggressive care
 - c. other
- 20. Your will is a list of things you will give away after you die. What gift would you be better off giving today rather than after your death?
- 21. Who should your healthcare proxy get advice from if they need to make a decision about your care? A health care proxy or agent is the person who makes decisions for you if you are unable to communicate for yourself.
- 22. If someone wanted to make a donation in your memory after you died, where would you like their donation to go and why?

- 23. Think about the most important decision you have made in the past two years. What did you give up when you made that decision?
- 24. What is the last meal you want to eat and who would you like to join you?
- 25. What is one of your personality characteristics that you that you would like to pass on to a loved one?
- 26. Which of your personality characteristics do you hope will NOT be passed on to your dear ones?
- 27. What are three virtues or values that were passed down to you, that you feel are significant and would like to pass on to your next generation?
- 28. What is a learning that you had during a difficult time that you would like to share with a loved one that you have not shared?
- 29. Do your loved ones know what you would like to do with your pets when you die?

Credits: Some of these questions were adapted from the Hello game from CommonPractice.com

Appendix B Web Resources

https://www.fivewishes.org/for-myself/

The *Five Wishes* is a popular questionnaire and planning document that families can use as a conversation starter, since it is written in everyday language, making it easy to understand and complete. It covers personal, spiritual, medical, and legal wishes all in one document.

https://www.honoringchoicesmass.com

Honoring Choices developed the *Who's Your Agent? Program*, a structured approach to health care planning and establishing a Health Care Proxy.

https://theconversationproject.org

The Conversation Project was co-founded by journalist Ellen Goodman to help people share their wishes for care through the end of life. The web site has lots of guides and resources for those who want to:

- Start a Conversation
- Choose a Health Care Proxy
- Be a Health Care Proxy
- Talk to my Health Care Team about my End of Life Care
- Talk about the Care I want for my Serious Illness
- Help the person I Care for with Alzheimer's or Dementia
- Talk with my Child Living with Serious Illness

https://www.molst-ma.org

Medical Orders for Life-Sustaining Treatment (MOLST) in Massachusetts MOLST is a standardized medical order form for use by clinicians caring for patients with serious advancing illnesses.

- Basic MOLST information
- MOLST Implementation Tools

POLST is a similar national program for "portable medical orders", that may eventually supplant the state-by-state programs like MOLST. <u>https://polst.org</u>

https://compassionandchoices.org

Compassion and Choices seeks to empower everyone to understand and chart their own end-of-life journey. They have more resources than some other sites on the issue of dementia care and a health care agent's role over time for someone with dementia.

https://umfnelegacy.org/?pageID=19

The United Methodist Foundation of New England has a helpful workbook available online called *"Provide & Protect: A Guide To Planning Your Will And Trust"*, which helps you organize the information needed to prepare a will.

https://www.aarp.org/home-family/friends-family/info-2020/when-loved-one-dieschecklist.html

AARP's website has a helpful article titled "What to Do When a Loved One Dies" that provides practical steps you need to take in the first few weeks:

To Do Immediately After Someone Dies

- Get a legal pronouncement of death
- Tell friends and family
- Find out about existing funeral and burial plans

Within a Few Days of Death

- Make funeral, burial or cremation arrangements
- Secure the property of the deceased
- Provide care for pets
- Forward mail
- Notify your family member's employer

Two Weeks After Death

- Secure certified copies of death certificates
- Find the will and the executor
- Meet with a trusts and estates attorney
- Contact a CPA
- Take the will to probate
- Make an inventory of all assets
- Track down assets
- Make a list of bills
- Cancel services no longer needed
- Decide what to do with the passport
- Notify the following of your loved one's death:
 - the Social Security Administration
 - o life insurance companies
 - o banks, financial institutions
 - o financial advisers, stockbrokers
 - o credit agencies
- Cancel driver's license
- Close credit card accounts
- Terminate insurance policies
- Delete or memorialize social media accounts
- Close email accounts
- Update voter registration

https://www.mass.gov/doc/em-board-consumer-fact-sheet/download

The Massachusetts Board of Registration in Embalming and Funeral Directing has published a *Consumer Fact Sheet for Funeral Planning*. This guide summarizes key funeral consumer rights protected by state and federal laws and other resources, in recognition that "making funeral arrangements is often an emotionally challenging experience. With preparation, consumers can make choices that meet their needs and budget."

Appendix C Books

These books were recommended by members of the Wills & Wishes team but are just a sample of the many available. If you have others to recommend adding to this list, please send your suggestions to legacygiving@upbrookline.org

Being Mortal: Medicine and What Matters in the End by Atul Gawande

American surgeon Atul Gawande addresses facts and personal stories about end-of-life care, hospice care, and suggests that medical care should focus on well-being rather than survival.

Talking About Death Won't Kill You: The Essential Guide to End-of-Life Conversations

by Kathy Kortes-Miller

This practical handbook will equip readers with the tools to reconnect with the idea that death is part of life, and help readers have meaningful conversations about death and dying.

A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death by Dr. BJ Miller and Shoshana Berger

A practical, compassionate, and comprehensive **guide** to dying--and living fully until you do. This is a great reference book for everything from how to let people know I'm dying to how to write an obituary.

I'm Dead, Now What? ~ Important Information About My Belongings, Business Affairs and Wishes

published by Peter Pauper Press

This planner /workbook can be used to organize key information in one place and should be kept in a secure location once complete.