THE IMPORTANCE OF ADVANCE CARE PLANNING

What Matters encourages everyone to engage in advance care planning and to communicate their health care choices to the important people in their lives, so that their wishes will be known, respected, and honored. It is preferable to share your wishes when you can make thoughtful decisions and have meaningful conversations, rather than waiting until a time of crisis.

What Matters can guide you through the advance care planning steps. A certified facilitator will help you think through and articulate what really matters to you, so you may feel confident that your values, beliefs, and goals will be reflected in any medical decisions that would need to be made on your behalf, should an accident or serious illness render you unable to communicate.

It is important, if possible, to designate a legal health care agent who can speak for you should you become incapacitated and unable to make decisions for yourself. The What Matters Health Care Agent card describes the role of the health care agent and may help you think through some possible choices. We suggest that you then document your selection by completing the New York State Health Care Proxy form. If you spend significant time in another state, you may want to also complete that state’s legal Health Care Proxy form (see state-by-state listing). Be aware that if you do not appoint someone, the NY State Family Health Care Decisions Act lists a hierarchy of individuals to whom the hospital or institution may turn to make decisions on your behalf, and that person may not be who you would want to make these decisions for you.

BUT WHAT IF I THINK I HAVE NO ONE TO APPOINT AS MY HEALTH CARE AGENT?

Many people find that they are not ready or are unable to appoint a health care agent, often because they feel that they have no one to designate or because choosing the right person is difficult for myriad reasons. If this applies to you, here are some suggestions for what you can do under these circumstances:

1. Think creatively about who might be willing to serve as your health care agent (also known as your health care proxy)

2. Determine, document, and communicate your health care wishes in other ways

3. Get your “house in order” by completing other essential documents and directives

4. Organize, store, and share your documents, and communicate your wishes

5. Contact What Matters and have the conversation
1. Think creatively about who might be willing to serve as your health care agent (also known as your health care proxy)

Often people assume that your health care agent must be a spouse/partner, a relative, or someone you are close to, but this is not necessarily the case. Your health care agent may be anyone you trust who is accessible, willing, and able to assume this role.

Do you have a friend, neighbor, or someone you know from communities you are a part of (e.g., your synagogue, gym, volunteer job, etc.) who might serve in this capacity? Perhaps someone who may also need a health care agent, so that you might be able to do this for one another? Who sends you a birthday card each year? Who is someone you are always happy to see and is always happy to see you? Consider widening your net of acquaintances by signing up for classes, memberships, and volunteering. Do not automatically assume no one would want to do this for you or that it is too much to ask of someone; you’ll never know until you pose the question.

Some people are concerned about asking someone to be their agent who does not live locally. In these days of easy communication over distances, as long as the person agrees to serve in this role and has a clear understanding of your wishes, they can serve in this position. You will want to make sure to provide detailed contact information for this person. In this situation, you would also want to consider appointing an alternate, just in case your primary agent is unavailable or unreachable.

2. Determine, document, and communicate your health care wishes in other ways

**Complete a Living Will:** If you are unable to designate an agent, it is still very important that you document your wishes and preferences in what is most often referred to as a “Living Will.”

A Living Will can either be a formal document or something more free-form, like a letter or an audio or video recording. The Living Will is meant to be instructional in nature, offering guidance, not mandates. This form may also serve as a conversation starter should you find someone who is able to serve as your legal agent.

Whatever form you choose, be sure to initial each page and to sign and date the final page if in writing and make sure you state your name and the date clearly if you choose to create a recording. It is very important that you discuss and make a copy of your completed form for your physician to put in your medical folder.

*Note that even though it is not a legal form like the NYS Health Care Proxy form, a Living Will is a way for your voice to be heard if you cannot speak for yourself. There is much evidence to indicate that it will be honored, as the law requires that the hospital respect and make decisions in accordance with your prior stated wishes and preferences.*

There are many templates for Living Wills that can guide you in providing information to help your health care team or decision maker know what you might want under different circumstances. They may ask you to:

- Provide information about who you are as a person and the values and beliefs that could guide someone making decisions on your behalf.
- State your preferences for medical treatment in certain circumstances. Many experts advise that it is best not to be too specific since it is not possible to know in advance all the medical facts, variables, and circumstances that will be in place, and you may want your agent to have the latitude to make the best possible decision at the time.
- Identify any religious or cultural traditions that you would want to be honored.
- Share your fears and concerns about a situation in which you are no longer able to speak for yourself. These fears and concerns can also guide decisions made on your behalf.
The list that follows offers different Living Will forms and templates that you can choose from, or you might want to create your own by adapting different parts of different forms:

- **What Matters Living Will: My Goals, Values, and Preferences**
- **The Conversation Project** (The Conversation Project also has a Conversation Starter Kit and additional resources that address decision-making around Alzheimer’s disease and dementia.)
- **Planning My Way**
- **Five Wishes**
- **Prepare for Your Care**
- **Halakhic Living Will**

**Complete and Carry the What Matters Living Will Wallet Card**

It is recommended that you carry a Living Will Wallet Card in case of emergency or if you forget to take your Living Will with you to a medical facility. This card:

- will help medical providers understand that you have documented your wishes in the absence of the legal Health Care Proxy Form
- ensures that someone who knows you can be reached
- provides space for you to indicate who has copies of your Living Will and where it can be found in your place of residence.

The card states:

*I have not appointed a health care proxy/agent, but have put my values, beliefs, and wishes in a Living Will that will become effective upon my incapacity to speak for myself. I ask/expect/trust that my wishes be honored and my specific instructions followed.*

**Complete a MOLST form with your medical provider**

If you have a serious, life-limiting diagnosis or progressive illness or frailness, you may want to speak to your physician about whether it is appropriate for you to complete a MOLST (Medical Orders for Life-Sustaining Treatment) form. The MOLST form allows you to determine and document your health care choices based upon the medical specifics of your disease and diagnosis. It must be completed with and signed by your physician, nurse practitioner, or physician assistant—it cannot be done on your own. It will become part of your permanent medical record. You can also take your MOLST form with you if you are transferred to another care facility.

Following are some helpful resources:

- **New York State MOLST form**
- **What Matters to Me: A Guide to Serious Illness Conversations** (Workbook prepared by The Conversation Project)
Draw upon Jewish resources that may help guide your decision-making process

- Understanding Advance Care Planning as a Jewish Process
- **Sage Voices:** A diverse group of rabbis and religious leaders speak about end-of-life issues and how they integrate Jewish tradition into their own teaching and care for others. Created by the Center for Pastoral Education at JTS.

Book suggestions on writing a Jewish Ethical Will

- *The Forever Letter: Writing What We Believe for Those We Love* by Rabbi Elana Zaiman

3. Get your “house in order” by completing other essential documents and directives

While planning ahead for your health care wishes is essential for every adult, other types of planning are also important and will help to put your mind at ease. Knowing you have done the best you can may relieve you of burdensome worries and provide peace of mind.

“**After I Am Gone**” Planning

Things to consider include purchasing a cemetery plot, burial vs. cremation, paying for your funeral, and the like. Some suggested steps you might take are:

- Completing a New York State “Appointment of Agent to Control Disposition of Remains” form. In this directive, you can appoint someone who will represent you, take care of your remains, and follow your wishes and any special instructions.

- Engage in funeral pre-planning, which offers the ability to plan for various aspects of your funeral with regard to burial, funeral, religious or other traditions you want to be honored, prepayment of expenses, etc. Our partner, Plaza Jewish Community Chapel, offers this service free of cost and will compassionately walk you through the process.

Legal and financial planning

If you have concerns about material or financial possessions, we suggest you meet with a lawyer and/or financial advisor about creating a Legal Will and financial Power of Attorney (POA). Following are some helpful resources:

City Bar Justice Center: Planning and Estates Law Project

**Aging Alone: What Documents Do I Need & What Happens After My Death:** Provides clear and detailed information about preparing your legal will

**Volunteers of Legal Services (VOLS) Elderly Project** provides free legal services to NYC seniors (age 60+); partners with pro bono lawyers to prepare wills, Powers of Attorney, health care proxies, and other advance directives for free.
4. Organize, store, and share your documents, and communicate your wishes

Organize your documents, accounts, contacts, and other important personal information

In case of an emergency, your vital information should be up to date, including:

- Documents including advance directives, legal wills and forms, and other official papers.
- Contact information for important people, such as your doctors, lawyer, social worker, care manager, caregiver, rabbi or other clergy person, close relative, neighbor, doorman, etc.
- List of current medications and dosages.
- Personal information (financial information, passwords, etc.). Sensitive information of this type should be kept in a private and secure location where a trusted person will know how to access it in case of incapacity or death.

Following are some helpful resources to help you organize your personal information and documents:

- AARP: Organize Documents worksheet
- AARP: What to Keep Where
- File of Life: Vital information cards and magnets for prominent display in your home
- Everplans: Organize, share, and store important documents

Store your documents and Share copies with others

It is important to store your documents in visible, safe, and accessible places. Following are some guidelines:

- Documents should be kept together in a secure but visible place in your home.
- You may wish to keep a copy of your Health Care Proxy and/or Living Will forms and other emergency information on your refrigerator or by your front door, places where emergency personnel will typically check.
- Storing these documents in the cloud or on a secure online app is another option, which allows you to easily access them on your phone or email them as needed.
- Let others know where you keep them.
- Do not put the documents in a locked safe or unit where someone would have difficulty accessing them in case of emergency.
- Sensitive information, such as passwords, should be kept in a private and secure location where a trusted person will know how to access them in case of incapacity or death.
- Share relevant documents with your healthcare agent, physician/health care team and other important professionals in your life such your lawyer, your financial power of attorney, your rabbi or other clergy person, or your caregiver.
Communicate your wishes

Documents are essential but communicating your wishes with important people in your life will make them dynamic rather than just words on a page.

• Have conversations and talk about your goals, preferences and wishes with your healthcare agent and other important people in your life.

• Such conversations can be formal and planned in advance; or they can take place casually and over time—whichever is more comfortable for you.

• To make it easier to start the conversation, you might want to draw upon news articles, current events, or personal experiences to tell others what you would or would not want in similar circumstances (e.g., “I just read an article about what happened to ______________ and it made me realize that I ...”)

• Consider using your completed Living Will form, described above, to guide your conversation and help you express your wishes.

5. Contact What Matters and have the conversation

If you would like to have some support in the Advance Care Planning process, What Matters can help you clarify and communicate your health care choices and goals. Just sign up for a one-on-one or group conversation with our trained facilitators, and we will answer your questions and guide you through this process. You might also make time to speak with your doctor or other members of your health care team, your clergy person or faith leader, your lawyer, or anyone else who might be able to help you think about your values and preferences.

For more information
or to contact What Matters:

website: www.whatmattersny.org
email: info@mmjccm.org
or contact a What Matters site