

END-OF-LIFE

DECISION-MAKING TOOLKIT

for Guardians



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ACKNOWLEDGMENTS

Our Law Office, a group of fifteen first-year law students at Northeastern University School of Law, partnered with Greater Boston Legal Services and Guardian Community Trust to conduct research regarding end-of-life decision making for incapacitated people under guardianship. Our research culminated in a white paper that provides an overview of guardianship law in each state, an explanation of the perspectives of various stakeholders in the guardianship process, and recommendations for best practices to be adopted in Massachusetts.

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GUARDIANSHIP

In Massachusetts

As a guardian in Massachusetts, you are responsible for making decisions on behalf of an incapacitated person. Eventually, you may need to make end-of-life decisions on their behalf, which may include executing a Do-Not-Resuscitate Order, withdrawing life-sustaining care, or transitioning the incapacitated person to hospice or palliative care. In Massachusetts, you will need to seek court approval before you make these decisions.

Because Massachusetts law requires guardians to employ a substituted judgment standard when making decisions on behalf of an incapacitated person, it is important for you as guardian to engage in meaningful conversations with the incapacitated person in your care. These conversations will guide you as you work to determine the goal, values, and wishes of the incapacitated person. These conversations, however, can be difficult. This toolkit is designed to make them easier for both guardians and incapacitated persons.

Within this toolkit is a guide to using the substituted judgment standard and several tools to facilitate conversations about treatment preferences, religious and cultural values, and goals and values regarding healthcare. Because some people are unable to speak as they approach the end of their lives, we have also included a tool to help communicate with non-verbal patients.

These tools are meant to serve as starting points. You should modify them and build off of them as is helpful and appropriate for you and the incapacitated person in your care.

Making care decisions for another person can be difficult and emotionally draining. Because the health and well-being of guardians is also important, we have included a tool to help identify when you may be dealing with grief, as well as resources to help you manage it.

At the end of this toolkit, you will find a list of community organizations for guardians. These organizations provide tools, resources, and training for guardians in their states.

Becoming a Guardian

Navigating the Court System

WHO NEEDS A GUARDIAN?

In Massachusetts, the court may appoint a guardian for:

- An incapacitated person - Someone who lacks the legal capacity to make their own decisions.
- An intellectually disabled person - Someone with significantly below average intellectual functioning.
- A person with mental illness - Someone who, due to mental illness, has a lowered ability to cope with the ordinary demands of life.
- Other special circumstances - For example, someone who suffers a traumatic brain injury or a disabled child reaching adulthood.

CAN I BECOME A GUARDIAN OF AN INCAPACITATED PERSON?

In Massachusetts, the court will **NOT** appoint anyone as a guardian who:

- Is currently being investigated for a crime.
- Has assault and battery charges pending for causing injury to the incapacitated person.
- Is being investigated for neglect of the incapacitated person.

HOW CAN I BECOME A GUARDIAN?

To become the guardian of an incapacitated person, you must file a petition with the Probate and Family Court. You can file to become either a complete or a limited guardian. At the court hearing, you will be called the petitioner and the incapacitated person will be called the respondent. To begin the process, you will need to file the following forms:

- **Petition for Appointment of Guardian for an Incapacitated Person (MPC 120)**
You will be able to indicate on the petition whether you are filing for complete or limited guardianship.
- **Medical Certificate (MPC 400)**
A registered physician, licensed psychologist, or certified psychiatric nurse clinician specialist must examine the incapacitated person within thirty days of filing the petition and sign the medical certificate.
- **Bond (MPC 801)**
You will file a bond that includes the estimated value of the incapacitated person's real estate and personal estate. The bond confirms that you submit to the jurisdiction of the court where you are filing to become a guardian. The surety on the bond can be waived.

IN SPECIAL CIRCUMSTANCES A GUARDIAN MAY ALSO NEED:

□ **Clinical Team Report (MPC 402)**

This form is required when the incapacitated person has an intellectual disability. The incapacitated person must have been examined by a physician, licensed psychologist, and a social worker within 180 days of when the petition is filed. This report must be completed by this clinical team.

□ **Rogers Authority**

If the incapacitated person is treated with antipsychotic medications, you will need to request Rogers authority. If you request this authority:

1. The court will appoint a lawyer to represent the incapacitated person.
2. You will need to submit findings and a treatment plan that the court must approve.
3. The treatment plan will be subject to an annual review on a date set by the court.

WHAT HAPPENS AFTER I'VE SUBMITTED MY PETITION FOR GUARDIANSHIP?

Once you file to become a guardian of an incapacitated person, a hearing will be scheduled with the court. Fourteen days before the hearing, you must have someone without a stake in the case give notice to the incapacitated person by delivering a copy of the petition for guardianship in person.

WHAT DO I DO ONCE I'M APPOINTED?

If you are appointed as a guardian, you will have to file a **Guardian's Care Plan/Report (MPC 821)** within 60 days of being appointed. You will need to file this form annually.

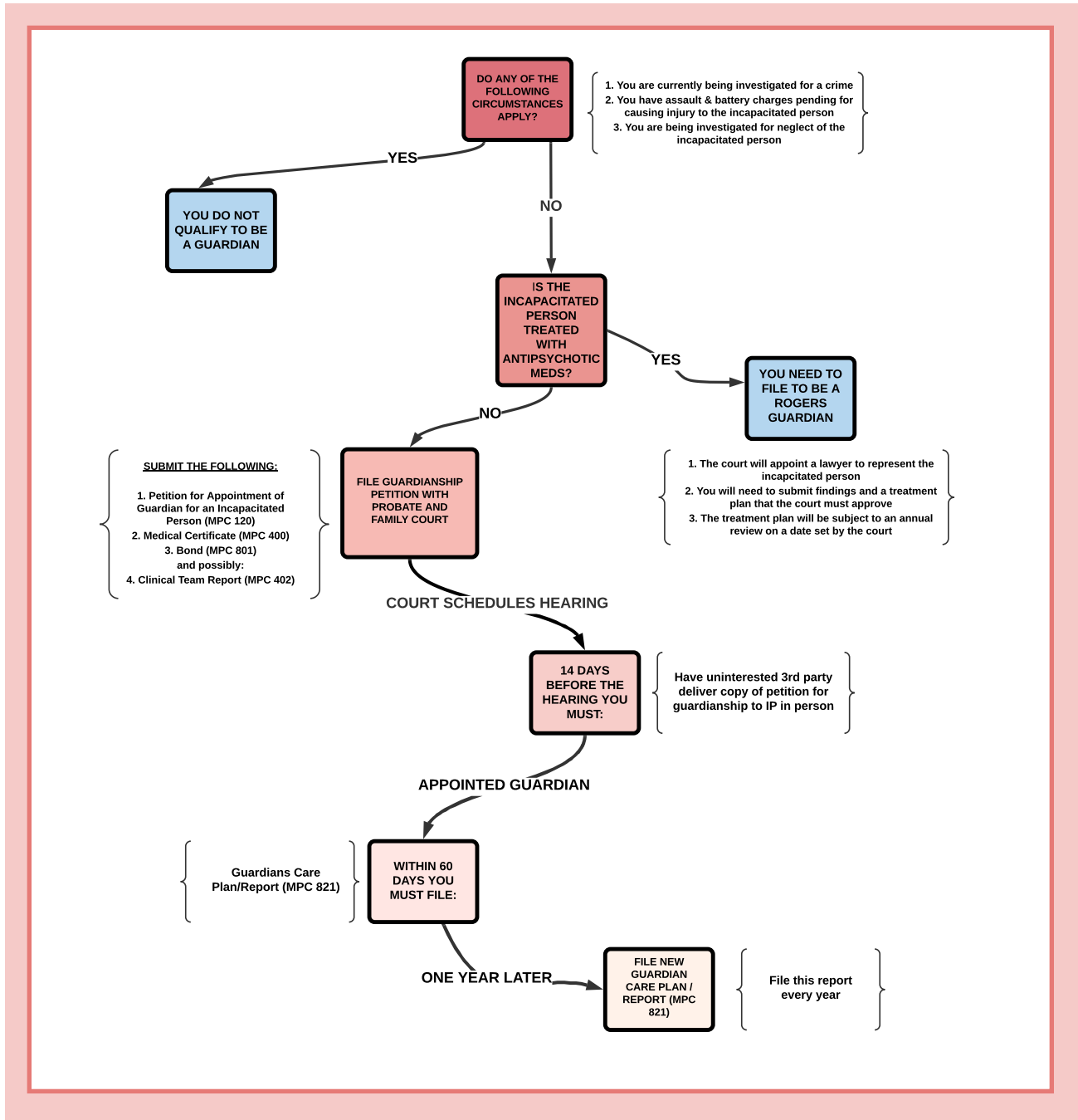
*All forms required for becoming a guardian can be located on the Massachusetts government website:
<https://www.mass.gov/how-to/file-for-guardianship-of-an-incapacitated-person>*

HOW WILL I KNOW WHAT I CAN DO AS A GUARDIAN?

When you are appointed the guardian of the incapacitated person, the court will issue a decree that details your specific authority and responsibilities in documents called the **Decree and Order and Letters of Appointment**. If you wish to exercise a power is not listed in the court's Decree and Order, you must petition the court for approval. To do so, you must file a **Petition to Expand/Modify/Limit the Powers of a Guardian (MPC 220)**.

Becoming a Guardian

Steps to Follow



WHAT ARE MY RESPONSIBILITIES AS A GUARDIAN?

The scope of your responsibility as a guardian will first depend on which type of guardian you become. There are two general types of guardians in Massachusetts:

1. **Plenary (complete) guardianship**

You may be appointed as a plenary guardian if the incapacitated person is incapable of making any decisions for themselves.

2. **Limited guardianship**

You may be appointed to make decisions only in specific areas where the incapacitated person needs help. For example, you may be responsible for medical treatment decisions but no other decisions.

You may be responsible for:

- Making decisions for the incapacitated person in accordance with their wishes and values.
- Filing the Guardian's Care Plan/Report (MPC 821) annually.
- Notifying the court if your address changes or the incapacitated person's address changes.
- Notifying the court if the incapacitated person dies.
- Petitioning the court to end guardianship if it is no longer needed (MPC 203).
- Filing a Petition to Expand/Modify/Limit the Powers of a Guardian (MPC 220) if you must.

You are NOT able to:

- Revoke a Health Care Proxy or any advance care directive.
- Spend or distribute the incapacitated person's assets.

CAN I MAKE END-OF-LIFE DECISIONS AS A GUARDIAN?

End-of-life decisions for incapacitated people under guardianship require court approval in Massachusetts.

You will be required to attend a hearing in court where the court will determine whether or not to approve a particular end-of-life treatment decision. The court will appoint a lawyer to represent the incapacitated person who will attend the hearing. Generally, the court will not schedule this hearing until the incapacitated person is actively dying and will need an end-of-life decision to be made in the near future.

Recall that if the incapacitated person dies, you are required to notify the court. You must file a copy of the death certificate with the court.

MASSACHUSETTS LAW

The Substituted Judgment Standard

In Massachusetts, as the guardian of an incapacitated person, your duties may include making medical decisions on their behalf. State law requires application of the substituted judgment standard when making extraordinary medical decisions for an incapacitated person under guardianship. You will do this by applying information you know about the incapacitated person and the treatment to a set of factors in order to determine what you believe the incapacitated person would choose to do in this situation if they were competent.

The Massachusetts courts have set forth six factors that you, as their guardian, would need to consider with the court to determine what health care choice the incapacitated person would have made. These factors are: (1) their expressed preferences; (2) their religious beliefs; (3) the impact on their family; (4) the probability of adverse side effects; (5) the consequences if treatment is refused; and (6) the prognosis with treatment.

First, you must look to any wishes or preferences the incapacitated person may have expressed while they were able to. These could include statements about conditions the person would find intolerable or their thoughts about specific medical treatments. Second, you must consider if there are any religious beliefs the incapacitated person may have held that would impact their decision about medical treatment. Third, you must take into account the impact the proposed treatment would have on the incapacitated person's family, usually

with an eye towards minimizing the potential burden on the family or allowing the family to be nearby. Fourth, any potential adverse side effects of the procedure on the incapacitated person must be taken into consideration, including the possibility they will occur and their potential severity. Fifth, you must look to the consequences for the incapacitated person if the treatment is refused. Finally, you must consider the incapacitated person's prognosis with the treatment.

Once these factors are taken into account, they are then weighed by the court against the four potential interests the state might have in the outcome of the medical treatment decision. The state interests are: (1) the preservation of life; (2) the protection of innocent third parties; (3) the prevention of suicide; and (4) maintaining the ethical integrity of the medical profession.

The first of these, the state's interest in preserving life, is also the most important. Next is an interest in the protection of innocent third parties from the consequences of the decision, which usually refers to any children that might be impacted by the refusal of medical treatment by the incapacitated person. The state also has an interest in the prevention of suicide, which is fairly straightforward. There is also a state interest in upholding medical integrity. However, a patient's right to make their own medical treatment decisions does not undermine medical integrity.

DECISION-MAKING TOOL

Applying the Substituted Judgment Standard

As explained previously, the substituted judgment standard must be used by a guardian to make decisions on behalf of an incapacitated person, based on the incapacitated person's wishes. The tools provided are designed to help guardians discuss an incapacitated person's medical and end-of-life care preferences, in order to use the substituted judgment standard. *The following tool is designed to help guardians weigh the six factors of the substituted judgment standard.*

- 1 EXPRESSED WISHES REGARDING TREATMENT**
 - Using the *Discussing Medical Treatments* and *Discussing Values* tools provided, what do you believe are the expressed wishes of the incapacitated person? What are their main goals and wishes for care? What would the incapacitated person choose, if they were able to make the choice for themselves?
 - If the incapacitated person has not expressed views about this specific treatment, based on their other expressed wishes and preferences, what do you think they would want?
- 2 RELIGIOUS BELIEFS**
 - Using the *Religious and Cultural Considerations for End-of-Life Decisions* tool provided, how does the incapacitated person's religious beliefs impact their wishes and preferences about this treatment?
- 3 IMPACT ON FAMILY**
 - How does the decision to receive or not to receive treatment impact the person's family?
 - Does the incapacitated person want you to heavily consider the impact on the family?
 - Does the decision put an undue burden onto the family of the incapacitated person?
 - Does the incapacitated person have children, and if so, how does the decision impact them?
 - Are there any other family concerns that need to be taken into account while making this decision on behalf of the incapacitated person?
- 4 PROBABILITY OF NEGATIVE SIDE EFFECTS FROM TREATMENT**
 - What are the possible negative side effects of the treatment? What is the probability of negative side effects occurring?
 - Using the *Discussing Medical Treatments* tool, how does the incapacitated person feel about these side effects and how does that impact their feelings about the treatment?
- 5 POSSIBLE CONSEQUENCES IF TREATMENT IS REFUSED**
 - What are the possible consequences without treatment? How likely is it that they may occur?
 - Using the *Discussing Medical Treatments* tool, how does the incapacitated person feel about the possibility of those consequences and how does that impact their feelings about the treatment?
- 6 PROGNOSIS, OR LIKELIHOOD OF SUCCESS, WITH TREATMENT**
 - What is the likelihood of success?
 - Using the *Discussing Medical Treatments* tool, how does this align with the overall healthcare goals of the incapacitated person? How does it impact their feelings toward the treatment?

DECISION-MAKING TOOL

Discussing Medical Treatment

Discussing medical treatment decisions, particularly end-of-life decisions, can be incredibly difficult. However, it is crucial that you understand the wishes and values of the incapacitated person in order to make medical decisions for them that they would make themselves.

If the incapacitated person you serve is capable of verbal communication, you can engage them in the following dialogue in order to assess their treatment preferences. This guide should help you to understand the wishes and values of the incapacitated person.* (Note about adaptation)

***Read the incapacitated person the following statements regarding medical treatment and ask them to answer YES or NO based on whether or not they agree with the statement.
Check off any YES answer.***

GENERAL TREATMENT & COMFORT PREFERENCES

- I DO NOT WANT TO BE IN PAIN.
- I WANT MY DOCTOR TO GIVE ME ENOUGH MEDICINE TO RELIEVE MY PAIN.
- I DO NOT WANT MY DOCTORS OR NURSES TO DO ANYTHING OR OMIT ANY TREATMENT THAT IS INTENDED TO END MY LIFE.
- I WANT TO BE OFFERED FOOD AND FLUIDS BY MOUTH.
- I WANT TO BE KEPT CLEAN AND WARM.
- IF I SHOW SIGNS OF DEPRESSION, NAUSEA, SHORTNESS OF BREATH, OR OTHER FORMS OF DISCOMFORT, I WANT MY DOCTOR TO DO WHATEVER THEY CAN TO HELP ME.
- I WANT TO HAVE PERSONAL CARE LIKE SHAVING, HAIR BRUSHING, AND TEETH BRUSHING, AS LONG AS IT DOES NOT CAUSE ME PAIN OR DISCOMFORT.
- IF I HAVE A FEVER, I WANT TO HAVE A COOL CLOTH PLACED ON MY HEAD.

If possible, ask them to indicate anything else they would like their care-givers to do to make them comfortable.

DECISION-MAKING TOOL

Discussing Medical Treatment

WHAT IS LIFE-SUSTAINING TREATMENT TO THE INCAPACITATED PERSON?

- MEDICAL DEVICES PUT INSIDE ME TO HELP ME BREATHE
- FOOD AND WATER SUPPLIED BY A MEDICAL DEVICE
- CARDIOPULMONARY RESUSCITATION (CPR)
- MAJOR SURGERY
- BLOOD TRANSFUSIONS
- DIALYSIS
- ANTIBIOTICS
- ANYTHING ELSE MEANT TO KEEP THEM ALIVE (*If yes, ask what they consider to be life-sustaining.*)

WHEN WOULD THE INCAPACITATED PERSON WANT TO RECEIVE LIFE-SUSTAINING TREATMENT?

Near Death

Explain to the incapacitated person that a near-death situation is one in which their doctor decides that they are likely to die in a short period of time and that life-sustaining treatment would only delay death.

- I WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.
- I DO NOT WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.
- I ONLY WANT TO RECEIVE LIFE-SUSTAINING TREATMENT IF MY DOCTOR BELIEVES IT COULD HELP. IF MY DOCTOR BELIEVES THAT LIFE-SUSTAINING TREATMENT WILL NOT HELP MY HEALTH CONDITION OR SYMPTOMS, I DO NOT WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.

DECISION-MAKING TOOL

Discussing Medical Treatments

WHEN WOULD THE INCAPACITATED PERSON WANT TO RECEIVE LIFE-SUSTAINING TREATMENT?

Permanent and Severe Brain Damage with no Expectation of Recovery

Explain to the incapacitated person this situation is one in which their doctor decides that they have permanent and severe brain damage and are not expected to get better. In this situation, life-sustaining treatment would only delay death.

- I WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.
- I DO NOT WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.
- I ONLY WANT TO RECEIVE LIFE-SUSTAINING TREATMENT IF MY DOCTOR BELIEVES IT COULD HELP. IF MY DOCTOR BELIEVES THAT LIFE-SUSTAINING TREATMENT WILL NOT HELP MY HEALTH CONDITION OR SYMPTOMS, I DO NOT WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.

WHEN WOULD THE INCAPACITATED PERSON WANT TO RECEIVE LIFE-SUSTAINING TREATMENT?

In a Coma with no Expectation of Waking Up or Recovery

Explain to the incapacitated person that this situation is one in which their doctor decides that they are in a coma from which they are not expected to wake up or recover. In this situation, life-sustaining treatment would only delay death.

- I WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.
- I DO NOT WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.
- I ONLY WANT TO RECEIVE LIFE-SUSTAINING TREATMENT IF MY DOCTOR BELIEVES IT COULD HELP. IF MY DOCTOR BELIEVES THAT LIFE-SUSTAINING TREATMENT WILL NOT HELP MY HEALTH CONDITION OR SYMPTOMS, I DO NOT WANT TO RECEIVE LIFE-SUSTAINING TREATMENT.

DECISION-MAKING TOOL

Values Questionnaire

The following questions can help aid a conversation between guardians and incapacitated persons about the incapacitated person's values and how they relate to end-of-life care decisions. These questions just provide guidance for a conversation about the incapacitated person's values. Adjust and tailor the questions to fit what is most helpful for the incapacitated person.

- WHAT DO YOU VALUE MOST ABOUT YOUR LIFE? WHAT BRINGS YOU JOY?
- HOW DO YOU FEEL ABOUT DEATH AND DYING? DO YOU FEAR DEATH AND DYING?
- HAVE YOU EXPERIENCED THE LOSS OF A LOVED ONE? DID THAT PERSON'S ILLNESS OR MEDICAL TREATMENT INFLUENCE YOUR THINKING ABOUT DEATH AND DYING?
- DO YOU BELIEVE LIFE SHOULD ALWAYS BE PRESERVED AS LONG AS POSSIBLE?
- IF NOT, WHAT KINDS OF MENTAL OR PHYSICAL CONDITIONS WOULD MAKE YOU THINK THAT LIFE-PROLONGING TREATMENTS SHOULD NO LONGER BE USED?
(For example, it may be when you are: unaware of your life and surroundings, unable to appreciate or continue the important relationships in your life, unable to think well enough to make everyday decisions, or in severe pain or discomfort.)
- CAN YOU IMAGINE REASONS FOR TEMPORARILY ACCEPTING MEDICAL TREATMENT FOR THE CONDITIONS YOU HAVE DESCRIBED? WHAT MIGHT THEY BE?
- HOW MUCH PAIN AND RISK WOULD YOU BE WILLING TO ACCEPT IF YOUR CHANCES OF RECOVERY FROM AN ILLNESS OR INJURY WERE POOR (LESS THAN ONE IN TEN)?
- DO YOU HOLD ANY RELIGIOUS OR MORAL VIEWS ABOUT MEDICINE OR PARTICULAR MEDICAL TREATMENTS? WHAT ARE THEY?
- SHOULD FINANCIAL CONSIDERATIONS INFLUENCE DECISIONS ABOUT YOUR MEDICAL CARE? EXPLAIN.
- WHAT OTHER BELIEFS OR VALUES DO YOU HOLD THAT SHOULD BE CONSIDERED BY YOUR GUARDIAN WHILE MAKING DECISIONS ON YOUR BEHALF, IF YOU BECOME UNABLE TO SPEAK FOR YOURSELF?
- ARE THERE ANY DIFFICULT END-OF-LIFE SITUATIONS YOU HAVE HEARD OF, AND WHAT WERE YOUR REACTIONS TO THEM?

(Adapted from Values Questionnaire by Vermont Ethics Network, www.vtethicsnetwork.org)

DECISION-MAKING TOOL

Religious Considerations for End-of-Life Decisions

Religious Beliefs

- What is the incapacitated person's faith or belief system? (It may be a traditional religion, a personal spiritual connection or no religion.)
- Is the incapacitated person actively practicing their religion or spirituality?
- Are the doctors aware of the incapacitated person's beliefs? If not, what do you need to tell the doctors?
- Does the incapacitated person's belief system play a role in their other life decisions?

Religion and Healthcare

- Does the incapacitated person's belief system play a role in their healthcare decisions?
- What does the religion say about the obligation to keep fighting and to stay alive, regardless of the outcome?
- Does the incapacitated person's religion say what can and cannot be chosen when it comes to healthcare decisions?
- Do you need to ask questions about what services may or may not be provided at a religiously affiliated hospital or clinic?
- Does the incapacitated person's religion have rules about how the body can be treated?
- Are there certain fasting or food restrictions in the religion?

Religious Community

- Can the religious community provide comfort and support for the incapacitated person?
- Do you need to call in the incapacitated person's religious leader to help make these decisions?

Religion and Death/Dying

- What are the religion's views on end-of-life decisions?
- What does the incapacitated person's religion say about death and dying?
- Does the incapacitated person's religion have certain rituals or prayers that are part of the healing or dying process?
- Before the incapacitated person dies, should certain things be done in preparation, either spiritually or physically?
- After the incapacitated person dies, should certain things be done to prepare and respect the body?

No Religious Beliefs

- How can you show the incapacitated person respect without using religion?
- How can the incapacitated person be comforted while dying, without using religion?
- What values and personal beliefs of the incapacitated person can guide you when making these decisions?

Your Personal Religious Beliefs

- When you are making decisions for the incapacitated person, how does your religion affect your decision making?
- Are you remembering to respect the beliefs of the incapacitated person and to not impose your own religious beliefs? (*It is your responsibility to make sure that others involved in the incapacitated person's care are not imposing their own religious beliefs on the decision-making process.*)

(Adapted from The Caregiver's Path to Compassionate Decision-Making Resource Workbook by Viki Kind, MA www.KindEthics.com)

DECISION-MAKING TOOL

Cultural Considerations for End-of-Life Decisions

The Incapacitated Person's Culture

- How much does the incapacitated person follow the customs of their culture?
- What would the incapacitated person say about their cultural values and how they would apply in this situation?
- What is the incapacitated person's view of the illness or health condition in the context of their life?
- How would a doctor from the incapacitated person's culture handle this situation?
- How would a doctor from the incapacitated person's country handle this situation?
- Are there fears, concerns, or misperceptions about the proposed treatments because of cultural beliefs?
- Does the incapacitated person want to be told the truth about the health condition or would they rather not know?

Language Barriers

- Do you speak the same language as the incapacitated person, or do you have a way to communicate with the incapacitated person about their wishes?
- Does the incapacitated person speak the same language as the healthcare team, or should a trained medical interpreter be used?
- Are the forms and written information available in the incapacitated person's language?
- Can the incapacitated person read the forms and the written information about the disease/condition and treatment options?

Choosing a Decision Maker

- What does the culture say about who should be the decision maker?
- Should the decision maker be one person or a group of people?

Family Involvement

- Does the incapacitated person want family members to be involved in the decision making?
- Does the family cultural values impact the incapacitated person's wishes?
- What does the incapacitated person or the family say would help in this situation?
- Are there community resources available to help the incapacitated person?

Culture and Healthcare

- Are there certain treatments the incapacitated person cannot receive because of cultural customs?
- Are there certain things the incapacitated person cannot eat because of cultural customs?
- Are there gender restrictions on who can take care of or touch the incapacitated person? If so, what would be okay?
- How would the incapacitated person want to be shown respect?

DECISION-MAKING TOOL

Cultural Considerations for End-of-Life Decisions

Alternative Medicine and Healers

- Is the incapacitated person going to a healer, herbalist, spiritual healer, or other person for help?
- Do you need to call in a healer or someone to pray?
- Does the incapacitated person trust Western medicine?
- Does the incapacitated person trust healthcare providers in general?
- Does the incapacitated person want to receive the medicines or alternative medications that are used in the incapacitated person's country or culture?
- Is the incapacitated person taking alternative medications?
- Do you need to tell the doctor the truth about the alternative medications or treatments the incapacitated person is receiving outside the doctor's care? (*You should tell the doctor the truth, in order to keep the incapacitated person safe from any side effects from combining the treatments.*)

Culture and Death/Dying

- What does the incapacitated person's culture or customs say about death and dying?
- What are the culture's views on end-of-life decisions?
- Are there cultural healing or dying rituals that need to be performed?
- After the incapacitated person's death, are there rituals that need to be performed or are there certain ways that the body needs to be treated?

Your Cultural Beliefs

- When you are making decisions for the incapacitated person, how does your culture affect your decision making?
- Are you remembering to use the culture of the incapacitated person and to not impose your own cultural beliefs?
- What else do you need to understand about the incapacitated person's culture so that you can make decision that reflect their cultural values?

ADDITIONAL RESOURCES

***For other free communication aids, including bilingual resources, visit:
<https://www.patientprovidercommunication.org/>***

***Everyone has a right to access care and services in a language that is comfortable for them. If the incapacitated person in your care is Limited English Proficient (LEP), they have a right to health care interpreter at hospitals and health care facilities in Massachusetts. For more information, visit:
<https://www.mass.gov/interpreter-services-at-health-care-facilities>***

DECISION-MAKING TOOL

Medical Goals and Values

The medical community expresses concerns associated with end-of-life decision making that guardians should consider. Some of the issues stem from medically futile treatment, which can arise when a guardian is unable to quickly and effectively change a patient's code status. Medically futile treatment occurs when a patient is receiving a treatment that will unlikely have beneficial results – therefore, it is futile.

Guardians should consider is that 70% of Americans would prefer to die at home, while only 25% do. Therefore, it is often essential to find out the patient's values and goals in order to make decisions that reflect their personal wishes. One way to do this is by distinguishing between values, which underlie goals. The Elder Law Journal, in an article titled *Making End-of-Life Care Decisions for Older Adults Subject to Guardianship*, provided examples of ways to follow up on statements in order to figure out underlying goals. Goals refer to actions, whereas values refer to sentiments. It is important to distinguish the values behind people's goals because sometimes, a guardian may need to find a different outcome.

GOALS (IF A PERSON SAYS...)	VALUES (ASK...)
I WANT YOU TO DO EVERYTHING POSSIBLE	WHAT MAKES LIFE GOOD OR MEANINGFUL FOR YOU? WHAT FACTORS MIGHT SWAY YOU TO UNDERGO A HEALTHCARE TREATMENT, EVEN IF IT HARMED YOUR QUALITY OF LIFE? WHAT CIRCUMSTANCES MAY LEAD YOU TO DECLINE A TREATMENT THAT COULD POSSIBLY EXTEND YOUR LIFE?
I WANT TO STAY AT HOME	WHY IS BEING HOME IMPORTANT TO YOU? WHAT ASPECTS OF BEING AT HOME ARE MOST IMPORTANT? WHAT MAKES A PLACE FEEL LIKE HOME?
I DON'T WANT TO BE A BURDEN	HOW MIGHT YOUR FEELINGS ABOUT BEING INDEPENDENT AFFECT DECISIONS ABOUT YOUR HEALTHCARE? ARE THERE ANY ABILITIES THAT ARE SO IMPORTANT TO YOUR LIFE YOU CAN'T IMAGINE LIVING WITHOUT THEM?

Most Americans would prefer to die at home, which typically happens when they are involved in hospice or palliative care. Palliative care is a type of care that can be used in conjunction with end-of-life care. It may be a less expensive option, as it may decrease overall costs and improve the patient's care. Once treatment for a terminal illness has been exhausted, the patient can receive hospice care. This type of care can be administered at home or in a healthcare facility, in order to manage pain, rather than prolong life.

Sources:

Thanh Huynh et al., *The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care*, 20 JAMA Intern Med. 1887-1894 (2013)
<https://www.pbs.org/wgbh/pages/frontline/facing-death/facts-and-figures/>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6660004/>
<https://www.nbcnews.com/health/health-news/palliative-care-saves-money-study-finds-n870226>
<https://tincture.io/the-hidden-costs-of-dying-in-america-2da0b81bbcd1>

DECISION-MAKING TOOL

Communicating with Non-Verbal Patients

It is crucial for guardians to communicate with the incapacitated person about their end-of-life care preferences. However, not every incapacitated person can verbally communicate. In order to help guardians communicate with non-verbal patients, **Northern Speech Services** has created the **EyeLink2 Letter Board**. This non-electronic communication device was designed to allow for nonverbal incapacitated people to let their wishes be known.

Below are EyeLink2 instructions and a printable EyeLink2 board.

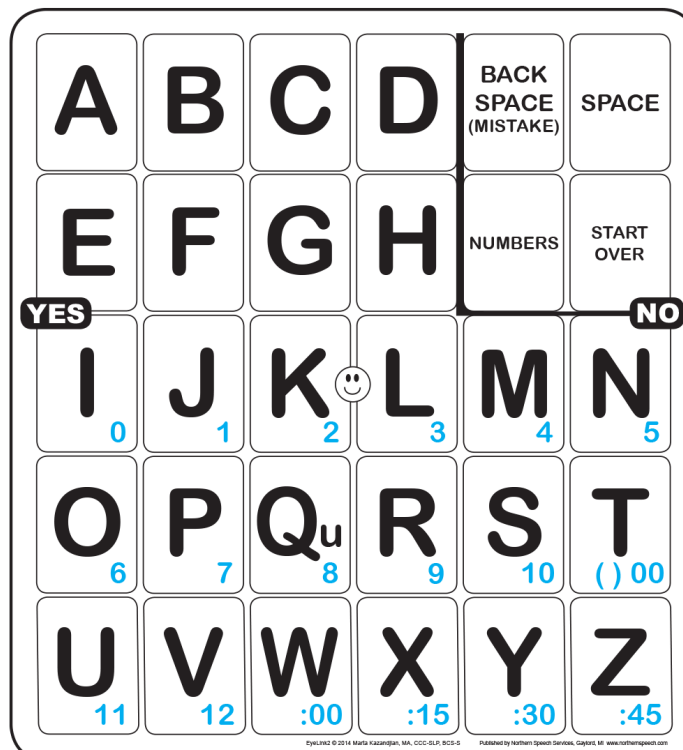
For a larger board, and other resources for non-verbal communication, visit:

<https://www.northernspeech.com/aac-augmentative-and-alternative-communication/eyelink2/>

EYELINK2 INSTRUCTIONS

1. Determine a yes/no response system.
2. Hold sheet with the black letters facing the patient.
3. Have the patient at the same time as you focus on the smiley face in the middle of the sheet.
4. Then, have the patient focus on the first letter of the desired word.
5. Move the sheet until your eyes “link” with the patient’s through the desired letter. It should be a straight line between you, the letter and your patient’s eyes.
6. Check with the patient to see if you are correct.
7. Continue with the process until you get the message.

EYELINK2 LETTER BOARD



CARE-GRIEVING

Resources for Guardians

Making end-of-life decisions on behalf of an incapacitated person can be every emotionally draining, even when you know the decision you made is what the incapacitated person would have wanted. To ensure that you are doing what is best for the incapacitated person, you must also take care of yourself.

WHAT IS CARE-GRIEVING?

Care-Grieving is when a caregiver or guardian is grieving or being emotionally impacted by the responsibility of caring for another or making choices on behalf of another. Acting as a caregiver can have significant impacts on the individual's own emotional, physical, social, and spiritual health. When a caregiver is responsible for making end-of-life decisions, the emotional impact of the decision may severely impact them. Grieving the decisions, you are responsible to make is okay. Included is some basic information about grief including symptoms and stages, as well as some resources for help. Remember, to be an effective guardian, you must take care of yourself as well.

SYMPTOMS OF GRIEF

Physical

- Crying
- Sighing
- Low energy/exhaustion/weakness/fatigue
- Headaches
- Stomach aches, loss of appetite
- Eating too much, particularly comfort foods
- Sleep disturbance – too much or too little, disturbed dreams
- Feelings of heaviness, aches, pains
- Being super busy, pushing yourself to do too much
- Reckless, self-destructive activities such as drinking too much

Social

- Feeling alone
- Wanting to isolate yourself from socializing
- Finding it hard to pretend to feel okay
- Feeling like you are being pushed to be social with others
- Feeling detached from others
- Feeling angry or upset that others' lives are going on as usual
- Not wanting to be alone, or feeling needy and clingy

Emotional

- Sadness or melancholy
- Anger, frustration, or rage
- Confusion or feeling overwhelmed
- Guilt
- Worry, anxiety, and panic
- Yearning
- On edge or irritable
- Memory problems, or feeling distracted and/or preoccupied
- Depression
- Euphoria
- Passive resignation
- Fluctuating emotions
- A sense of lack or loss of control

Spiritual

- Questioning your faith, the meaning of life, or suffering
- Questioning reason for the death/disease
- Anger at God or other Holy figures
- Growing closer to faith, or turning to God for solace

(Adapted from The Caregiver's Path to Compassionate Decision-Making Resource Workbook by Viki Kind, MA www.KindEthics.com and from Family Caregiver Alliance at the National Center on Caregiving, <https://www.caregiver.org/grief-and-loss>)

CARE-GRIEVING

Resources for Guardians

STAGES OF GRIEF

- 1 ***Shock/Denial***
 - Trouble accepting the fact of death, diagnosis or new reality, numbness
 - Inability to do usual activities

- 2 ***Anger***
 - Anger at yourself, others, professionals (doctors, lawyers, judges), God, life
 - Feeling helpless and powerless, abandoned

- 3 ***Bargaining***
 - Making “deals” with God or other figures hoping to change the situation
 - Thinking about “what could have been” or “should have been done differently”

- 4 ***Depression***
 - Feeling overwhelmed with loss and change, sadness, regret, fear, anxiety
 - Lonely, isolated, self-pity, emptiness, lost

- 5 ***Acceptance***
 - Adjusting to the new reality, starting to move on
 - Sense of hope, healing, and integration

(Adapted from The Caregiver's Path to Compassionate Decision-Making Resource Workbook by Viki Kind, MA www.KindEthics.com and from Family Caregiver Alliance at the National Center on Caregiving, <https://www.caregiver.org/grief-and-loss>)

CARE-GRIEVING

Resources for Guardians

ONLINE RESOURCES

American Association of Retired Persons (AARP)
1-888-687-2277
<https://www.aarp.org/home-family/caregiving/grief-and-loss/>

Center for Loss & Life Transition
(970) 226-6050
www.centerforloss.com

Family Caregiver Alliance National Center on Caregiving
(415) 434-3388 | (800) 445-8106
www.caregiver.org
info@caregiver.org

Grief Healing Discussion Groups
<https://www.griefhealingdiscussiongroups.com/>

Grief Share
(800)395-5755
<https://www.griefshare.org/>
info@griefshare.org

Hospice Foundation of America
(202) 457-5811 | (800) 854-3402
[https://hospicefoundation.org/Grief-\(1\)](https://hospicefoundation.org/Grief-(1))

National Hospice and Palliative Care Organization
(703) 837-1500
<https://www.nhpco.org/patients-and-caregivers/>

MASSACHUSETTS RESOURCES

Boston Medical Center
One Boston Medical Center Place
Boston, MA 02118
(617)638-8000
<https://www.bmc.org/support-patients/bereavement-committee/adult-resources-and-grief-services>

Care Dimensions
75 Sylvan Street, Suite B-102
Danvers, MA 01923
(888)-283-1722
<https://www.caredimensions.org/grief-support/index.cfm>

Hospice & Palliative Care Federation of Massachusetts
20 Commercial Drive, Suite One
Wrentham, MA 02093
(781) 255-7077
<https://www.hospicefed.org>
hospicefed@aol.com

Massachusetts General Hospital, Bereavement Support & Referral
Todd Rinehart, LICSW
55 Fruit Street
Boston, MA 02114
(617) 724-4525
<https://www.massgeneral.org/medicine/pcgm/palliative-care/resources/support>
trinehart@partners.org

COMMUNITY GUARDIANSHIP Organizations

NATIONAL

National Guardianship Association

174 Crestview Drive
Bellefonte, PA 16823
877-326-5992
<https://www.guardianship.org/>

Community Guardianship Trust

One Elm Square, Suite 2D
Andover, MA 1810
978-775-3500
<http://www.guardiancommunitytrust.org/>

MASSACHUSETTS

Massachusetts Guardianship Association

<http://www.massguardianshipassociation.org/>

Massachusetts Guardianship Institute

<https://guardianship.institute/>

Honoring Choices Massachusetts

Post Office Box 444
Lincoln, MA 01773
<https://www.honoringchoicesmass.com/>

OTHER STATES

Alabama

Alabama Access to Justice Commission

Post Office Box 4129
Montgomery, AL 36103
334-387-1604
<https://www.alabamataj.org/>

Alaska

Alaska State Association for Guardianship & Advocacy (ASAGA)

Post Office Box 220429
Anchorage, AK 99522
907-444-4015
<http://asaga.info/>

Arizona

Arizona Fiduciaries Association

8987 E Tanque Verde #309-125
Tucson, AZ 85749
520-338-0840
<https://www.azfid.org/>

California

CA Assoc. of Public Administrators, Public Guardians, and Public Conservators

717 K Street- Suite 424
Sacramento, CA 95814
916-382-4703
<http://capagpgpc.org/>

Colorado

Colorado Guardianship Association
<https://www.coloradoguardianshipassociation.org/>

Florida

Florida State Guardianship Association
800-718-0207
<https://www.floridaguardians.com/>

Idaho

Idaho Guardian and Fiduciary Association
Post Office Box 6599
Boise, ID 83707
<https://idahoguardianship.org/>

Illinois

Illinois Guardianship Association
Post Office Box 3575
Bloomington, Illinois 61702
312-458-9867
<http://illinoisguardianship.org/>

Indiana

Arc Indiana

143 W. Market Street Suite 200
Indianapolis, IN 46204
317-977-2375
<https://www.arcind.org/future-planning/guardianship/>

Iowa

Guardianship Association of Iowa Network

515-412-4969
<https://iowaguardianship.online/>

Kansas

Kansas Guardianship Program

3248 Kimball Ave.
Manhattan, KS 66503
785-587-8555
<http://www.ksgprog.org/>

COMMUNITY GUARDIANSHIP *Organizations*

OTHER STATES (CONT.)

Kentucky

Kentucky Guardianship Association

Post Office Box 25173
Lexington, KY 40524
859-543-0061
<https://www.kyguardianship.org/>

Louisiana

Louisiana Guardianship Services

(504) 830-2829 - New Orleans
(504) 453-5495 - Baton Rouge
(337) 393-2932 - Rayne
(318)253-4111 - Marksville
<http://laguardianship.org/>

Michigan

Michigan Guardianship Association

P.O. Box 693
Coldwater, MI 49036
586-996-3456
<https://michiganguardianship.org/>

Minnesota

Minnesota Association for Guardianship and Conservatorship

5001 Chowen Ave. S
Minneapolis, MN 55410
<https://www.minnesotaguardianship.org/>

Missouri

Missouri Association of Public Administrators

<http://www.mapainfo.org>

Nevada

Nevada Guardianship Association

<http://www.nvguardian.org/>

New Jersey

SCARC Guardianship Services, Inc.

11 US Route 206, Suite 100
Augusta, NJ 07822
973-383-5804
<https://www.scarcguardianship.org/>

New Mexico

New Mexico Guardianship Association

Post Office Box 92396
Albuquerque NM 87199
<https://www.nmguardianassoc.org/>

New York

Guardians Association of the New York State Courts

917-592-7142
<https://www.guardiansnysc.org/>

North Carolina

North Carolina Guardianship Association

Post Office Box 17673
Raleigh, NC 27619
<https://www.nc-guardian.org/>

North Dakota

Guardianship Association of North Dakota

PO Box 1693
Bismarck, ND 58502
701-224-1815 Ext 5
<http://www.gand.org/>

Ohio

Ohio Guardianship Association

Post Office Box 298114
Columbus, OH 43229
<http://guardianshipohio.org/>

Oregon

Guardianship/Conservator Association of Oregon

2000 NE 42nd Ave. #321
Portland, OR 97213
<https://www.gcaoregon.org/>

Rhode Island

The Rhode Island Disability Law Center

275 Westminster Street, Suite 401
Providence, RI 02903
401-831-3150
<https://www.ridlc.org/>

Tennessee

Conservatorship Association of Tennessee

PO Box 369
Greeneville, TN 37744
<https://catenn.org/>

Texas

Texas Guardianship Association

Post Office Box 24037
Waco, Texas 76702
888-399-9115
<https://texasguardianship.wordpress.com/>

Washington

Washington Association of Professional Guardians

<https://wapg.org/>

Wisconsin

Wisconsin Guardianship Association

<http://www.wisconsinguardianshipassociation.com/>