Health Care Decision Making

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General Resources

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| Personal Health Care Plans | Every individual over the age of 18 can make a personal care plan that directs their health care decisions. The Massachusetts Medical Society has partnered with Honoring Choices Massachusetts to provide tool kits and forms for individuals to create their own personal health care plans:  
  o Getting Started Tool Kit  
  o Health Care Proxy (Instructions and Document)  
  o Personal Directive (Living Will – Instructions and Document)  
  o COVID19-Specific Guide to Conversations About End of Life Care (The Conversation Project)  
  o 3-Step Health Care Planning Guide (Honoring Choices Massachusetts)  
  o Resources on health care proxies and personal directives are available in 10 languages |
| Supported Decision-Making and Health Care | Supported decision-making (SDM) is a way for people with disabilities who need support to maintain their autonomy by having others assist them in making decisions.  
  The Center for Public Representation (CPR) provides resources for helping individuals with disabilities establish and use SDM arrangements to make complex and challenging decisions around health care, including tools to make those decisions known. Check the CPR webpage for help with advanced planning before a medical crisis occurs. |

FAQs

How has decision-making been affected by the pandemic?

COVID-19 has made advanced discussions and planning around health care decisions more important than ever. While most people who get sick with the virus have mild illness and can recover at home, some will get a more severe form of the disease that requires hospitalization. The state publishes a resource on end of life care called Know Your Choices: A Guide for Patients with Serious Advancing Illness available in 9 languages.

Although the state is in Phase 3, Step 2 of Reopening, there are still limitations on visitation in hospitals because the virus is still very contagious. Hospitals are operating under the September 16 Guidance that allows one visitor unless visitors are members of the same household, in which case multiple visitors are allowed. Visitors are required to wear a face mask, be screened for symptoms, and perform hand hygiene (wash or sanitize hands) before visiting a patient. Individuals accompanying someone to the hospital as a birth partner, a parent or guardian of a child under the age of 18, an attorney of a patient, or a companion for a patient with intellectual and/or physical disabilities are exempt from visitation restrictions but are still subject to screening for symptoms of COVID-19.
Under Phase 3 there is also revised visitation guidance for other programs, such as Department of Mental Health residential programs. These changes will allow more visitation, but in cases where someone is hospitalized for COVID-19 treatment that person may not have access to the usual supports available for decision-making. Having a healthcare proxy or other form of advance health care directive can help assure that medical decisions concerning your treatment respect your values and preferences.

**What steps can I take now to help be sure my choices are known?**

There are several kinds of documents that you can prepare to make your healthcare preferences known. The Massachusetts Trial Court Law Libraries has a webpage listing laws, regulations, and web resources on health care proxies, living wills, and health care advance planning. Because of the current state of emergency, it may be more challenging to complete all the steps necessary to make an enforceable legal document (ex. having signatures from two witnesses). Preparing these documents is still a good idea since it informs your loved ones and medical care providers of the decisions you have considered.

- **Health Care Proxy** – This is a legal document that authorizes a person you choose (called your “agent”) to act on your behalf to make treatment decisions if you become incapacitated and are unable to make decisions for yourself. You may include specific instructions to your agent in your Proxy document. The health care proxy form with instructions can be found here. If you need information on healthcare proxies in a language other than English, the same form can be found here translated in nine languages.

- **Trusted Decision Making Form** – This is not a legal document. Similar to a health care proxy, it is a way to let your doctors and loved ones know (1) which person or persons you trust to make decisions for you if you cannot make decisions for yourself and (2) what kinds of care and medical treatments you would accept to maintain the type of quality of life that is important to you. Even though this is not a legal document, it provides guidance to your medical providers and will be considered when treatment decisions are made.

- **Personal Directive (Living Will)** – This is not a legal document; it is a personal statement about what kinds of care you do and do not want. This document allows you to share with others your choices and preferences for medical care.

- **Medical Orders for Life-Sustaining Treatment (MOLST)** – This is a medical order filled out by your clinician (doctor, nurse practitioner, or physician assistant) after discussing treatment decisions with you and your family or supporters. A MOLST form is prepared by your clinician and signed by both you and your clinician. Information on MOLST translated in languages other than English is also available.

**Talking about end-of-life decisions or care in drastic situations is very difficult. Where can I find suggestions on how to begin this conversation?**

The Conversation Project has developed a free toolkit called Your Conversation Starter Kit as well as a COVID-19-Specific Guide to Conversations About End of Life Care. Another guide, called Caring Conversations in a time of COVID-19, provides six steps to follow to help you start a conversation about advanced care planning.

The National Institutes of Health’s Institute on Aging website discusses healthcare directives and the types of decisions to consider in developing an advance directive. The American Bar Association also provides Conversation Scripts for bringing up this sensitive topic. Prepare for your care is a website with a step-by-step tutorial, including video stories, on making medical decisions and asking someone to be your medical decision maker.

For people with disabilities, the Center for Public Representation’s Supported Decision-Making offers helpful resources related to supported decision-making and health care decisions.
Health Care Decision Making

If I am hospitalized during the COVID-19 crisis, will my family and supporters be able to help me make decisions?

Hospitals are still operating under restricted visitor policies during COVID-19. Although we have entered Phase 3 Reopening, these policies remain in place until further notice. The Attorney General has released guidance directing hospitals to consider requests for exceptions to the visitor policies where the exception is necessary for the provision of equal care to persons with disabilities and “where the additional risk does not create an undue burden” to the hospital. If you have questions about visitor policies at your local hospital, it’s a good idea to check their website or call to learn about their policies.

If you are giving birth, are a minor child, or someone with a disability, the hospital should permit you to be accompanied by a companion. Hospitals are encouraging patients and their families to communicate using mobile phones while the patient is hospitalized. Some hospitals are providing patients with assistance with these technologies. Because of the limitations on visitors in the hospital, it is very important that you talk to your family or supporters about what you want concerning your care.

If you are a person with a disability and you require the assistance of a caretaker or supporter because of your disability, the hospital should accommodate your need, regardless of the hospital’s official visitor policy. Information about your rights to access communication supports while receiving COVID-19 treatment can be found in this COVID-19 Communications Rights Toolkit, which includes a form you can print and fill out for your medical provider explaining the accommodations you require.

How has guardianship been affected by COVID-19?

Under normal circumstances, the process for obtaining a guardianship is complex. COVID-19 has introduced challenges, such as reduced in-person court services and some court services still being held remotely at Massachusetts Probate and Family Court.

If you go to the courthouse in person, you must wear a mask and social distance while there, and may be screened for COVID-19 before entering. You can find information about guardianship and alternatives to guardianship on the Massachusetts Association for Mental Health’s website.

Additional links to information about guardianship, health care proxies, and supported decision-making are available here.

The authority of a guardian to make health care decisions for the person under guardianship varies depending on the nature of the treatment. There are some decisions a guardian can make and some which only a judge can make, such as those affecting life-sustaining treatment. If time allows, individuals and guardians are strongly encouraged to consult with an attorney when asked to make important health care decisions. Guardians also should always discuss options with the person under guardianship and in most cases should follow the person’s wishes.

If you have a guardian and seek treatment for COVID-19, you should insist that both you and your guardian be informed about your condition, the treatment you are receiving, and that you both are consulted when important decisions have to be made. If you are a guardian, click here for advice and guidance on how the COVID-19 pandemic impacts your responsibilities.