



HEALTH CARE RATIONING AND ACCOMMODATIONS: WHAT MASSACHUSETTS PATIENTS WITH DISABILITIES NEED TO KNOW DURING THE COVID-19 PANDEMIC

Are you a person with a disability facing discrimination in health care? Call the Disability Law Center (DLC) at: 800.872.9992.

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Are you a public health advocate, medical professional, or disability or civil rights organization? Contact [www.centerforpublicrep.org](http://www.centerforpublicrep.org)

The COVID-19 pandemic has resulted in a lack of health care resources like personal protective equipment. It also increased demand for hospital beds, intensive care treatment and ventilators. If there are not enough resources to treat everyone, health care providers will decide who receives critical life-saving care and who will not. This is known as health care rationing. If rationing becomes necessary, these decisions will be made by hospital “triage teams” and guided by a document called the Massachusetts Crisis Standards of Care. These Standards were issued by the State in April, 2020, and revised and finalized in October, 2020.

**This Fact Sheet explains your rights if the Standards are invoked. It also describes exceptions, or “reasonable accommodations” you can request if you or someone you care for is hospitalized during the COVID-19 pandemic.**

The Disability Law Center (DLC), the Center for Public Representation (CPR), and many others advocated for changes to these Crisis Standards of Care so that they comply with federal civil rights laws. They asked the MA Department of Health (DPH) to ensure that people with disabilities, seniors and people of color are not treated differently or unfairly, because of their pre-existing medical conditions, beliefs about their disabilities or quality of life, or because they have had difficulty getting health care in the past. The revised [Standards](#) contain important changes that should better protect these groups from discrimination, including:

- removing predictions of 2-5 year life expectancy as a way to prioritize patients for care;
- eliminating age as a “tie breaker” between two adult clients with the same priority score; and
- prohibiting policies that pressure patients to make end-of-life decisions like Do Not Resuscitate (DNR)/Do Not Intubate (DNI) orders.

## **What concerns do DLC and CPR have about the Standards?**

The revised Standards still consider prognosis, or life expectancy, when determining who receives care. Individuals who are expected to die within 1 year, even after receiving treatment, will be given a lower priority for medical treatment.

These predictions can be subjective, unreliable, and influenced by unconscious (or explicit) bias, resulting in discrimination. People with disabilities and individuals from communities of color are more likely to have pre-existing health conditions caused by a lack of access to regular, quality health care, environmental hazards in their communities, poverty, or other disparities. These groups have been disproportionately affected by COVID-19, with devastating results.

If one year life expectancy is used in the triage process, it must be based on individualized medical evidence, and two doctors must agree with the prognosis.

## **What protections are available for people with disabilities and others in the event there is health care rationing?**

Under the revised Standards:

- You cannot be denied critical, life-saving care based on your disability, race, national origin, sexual orientation, or ability to pay.
  - You cannot be denied care based on a prediction of your long-term prognosis or life expectancy
  - You cannot be denied care based on stereotypes or beliefs about your perceived social worth, quality of life, or intensity of need.
  - Triage decisions must be based on individualized patient assessments and objective medical evidence and not discriminatory assumptions about a person's diagnosis or underlying medical condition.
  - You have the right to appeal a decision to withhold or withdraw critical care. Appeals are heard by the hospital Triage Review and Oversight Committee.
  - You have a right to receive information about your care, the hospital's triage decision, and the appeal process in a way that you can understand, with access to interpreters, assistive technology or other reasonable accommodations, where needed.
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- If you have a ventilator for personal use, this equipment cannot be taken from you if you go to a hospital for care and treatment.
- Each hospital must have crisis standards published on their website.

## **What should you do if you are hospitalized and rationing is being implemented?**

Make sure it is clear who can make medical decisions on your behalf. This may be a Health Care Proxy, guardian or other family member you choose to carry out your wishes under an Advanced Directive or a Supported Decision-Making Agreement. Have a copy of these documents with you if you need to go to the hospital.

You should have important medical information written down and available to share with hospital staff so they can make an individualized decision about your health care needs. Include contact information for your treating doctors in the community. If you regularly use a communication device or aid, bring this with you to the hospital. While the hospital has an obligation to assist you regardless, it will be easier to get their cooperation if you bring what is available to you.

It is important to ask for any reasonable accommodations you need because of your disability, including assistance communicating with hospital staff, having your personal care needs met, and participating in your treatment. You should make your request clearly, firmly, and politely. If possible, make your request in advance of your hospitalization, and follow up right away in writing.

## **Below are examples of reasonable accommodations you might request:**

### Accommodations to the Triage Process

When health care rationing is in place, hospitals will be using a process to prioritize people for care, called a “triage protocol.” This protocol results in a numerical score. The higher your score, the less likely you are to receive life-saving treatment.

Your triage score should not be increased simply because you have underlying disabilities or pre-existing conditions, unless there is medical evidence that they impact your ability to survive for one year with treatment. Make sure that health care providers are aware of disabilities or conditions that may affect your triage score, like speech disabilities or neuro-motor impairments that prevent you from moving your body in response to verbal commands. If you have an underlying condition or disability and you need more time on a ventilator for treatment to be effective, your family provider, or health care agent should ask for an extension of the ventilator trial period.

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## **What should you do if you or a loved one in the hospital needs help understanding medical care or communicating with staff?**

Hospital patients have a right to ask for reasonable accommodations when they need assistance for disability-related reasons. This may include exceptions to policies that limit or prohibit visitors.

### Accommodations for effective communication/access to care

If you or your family member cannot communicate verbally because of a disability, ask for auxiliary aids, devices, or other reasonable modifications needed for effective communication with health care staff. This can include sign language interpreters, written materials in alternative formats, or use of an electronic device.

**If you have a disability you may need the assistance of a designated support person to assist you in participating in your treatment, or meeting your personal care needs while you are in the hospital. The State's September 2020 [Memorandum](#) on Patient Visitors in Hospitals makes clear that visitor restrictions should not apply to designated supporters, although these persons must be screened before entering the facility.**

A designated support person may include a guardian or other legally authorized decision-maker, family member, caregiver, personal care assistant or another disability service provider knowledgeable about the patient's care. The designated support person should be allowed to remain with you while in the hospital, subject to reasonable restrictions. Designated support persons should be provided reasonable access to treatment areas and food and bathroom facilities. The hospital should supply your designated support person with personal protective equipment. Remember to always document a request for a reasonable accommodation in writing and keep a copy for yourself.

## **What should you do if you believe you were wrongly denied critical care, or if you were denied a reasonable accommodation?**

If you are denied care, if care is withdrawn, if you have any other concerns about health care rationing, or if you are denied reasonable modifications or effective communication, you or someone you know should take the following steps:

Contact the hospital's patient rights or patient advocacy department.

Contact the Disability Law Center's Intake Hotline at 800.872.9992 or visit [www.dlc-ma.org](http://www.dlc-ma.org)

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Contact the Massachusetts Department of Public Health at 617.624.6000.

**How can we avoid health care rationing that discriminates on the basis of disability, race, ethnicity or age? How can civil rights and disability rights advocates become more involved?**

Contact the Center for Public Representation at: 617.965.0776 or [info@CPR.org](mailto:info@CPR.org) for more information on efforts to ensure fair and equitable Crisis Standards of Care, and to protect the needs of people with disabilities affected by COVID-19 at:

<https://centerforpublicrep.org/covid-19-medical-rationing>.



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