



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

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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 part of a disability or civil rights organization? Call the Center for Public Representation at: 617.965

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 need to decide who gets critical life-saving care and who does 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 first issued by state government in early April, 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 unfairly, because of their pre-existing medical conditions, assumptions about their disabilities, or quality of life, or because they have had difficulty getting health care in the past. On April 20, 2020, DPH revised its [Standards](#) to better protect these groups from discrimination.

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

DLC and CPR believe the revised Standards still violate federal civil rights laws and are proposing additional changes. Those changes include:

- Limiting any consideration of prognosis/life expectancy to less than 1 year with treatment. Currently, people with a prognosis of death in five years or less are given a lower priority for critical care. These predictions can be subjective, unreliable, and influenced by unconscious 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 care, environmental racism, poverty, or other health disparities. Already these communities have been disproportionately affected by COVID-19, with devastating results.
- Removing age as a “tie breaker” between two patients with the same triage scores. We believe this policy unlawfully discriminates on the basis of age.

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 (more than 5 years after treatment of your acute illness).
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- You cannot be denied care based on stereotypes about your perceived social worth, quality of life, or intensity of need.
  - All rationing 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 any 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 triage decision, and the appeal process in a culturally competent manner, and with access to interpreters, assistive technology or other reasonable accommodations, where needed.

### **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 designate to carry out your wishes under an Advanced Directive or Supported Decision-Making Agreement. Have a copy of these documents with you if you need to go to the hospital.

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, try to bring this with you to the hospital. While the hospital has an obligation to assist regardless, it will be easier to obtain their cooperation if you bring what is available to you.

Ask for any reasonable accommodations you need because of your disability. Given the difficult environment in hospitals, you should make your request clearly, firmly, and politely. If possible, make

your request in advance of your hospitalization so staff have more time

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to prepare and respond, and always 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 because of underlying disabilities or pre-existing conditions unless there is medical evidence that they impact your ability to survive 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.

**What should you do if you or a loved one in the hospital need 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 cognitive, developmental or intellectual disability, behavior support needs, or a sensory disability, you may require a designated support person to assist you in accessing and participating
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in your care. Under the [state's latest hospital visitation guidance](#), restrictions on visitation should not apply to companions to people with intellectual or physical disabilities, although companions may be screened.

This is an adult who can help with communication, emotional or physical assistance. Under the Americans with Disabilities Act, hospitals should modify visitation policies to allow for a designated support person to be present during hospitalization. A designated support person can be a family member, caregiver, personal care assistant, or another disability service provider knowledgeable about your care. They should be allowed to remain with you while in the hospital, subject to reasonable restrictions. 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)

Contact the Massachusetts Department of Public Health at 617.624.6000.

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**How can we avoid health care rationing that discriminates on the basis of disability, race, ethnicity or age? How can**

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## 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 state and national efforts to ensure fair and equitable Crisis Standards of Care, and to protect the needs of people with disabilities affected by COVID-19, see

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

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