Care Rationing and Disability Rights

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Resources

At this time, Massachusetts has enough hospital bed capacity to handle the number of COVID-19 patients requiring care. If there is a surge in cases that overwhelms the healthcare system (that is, if the demand for care resources is larger than the supply), then hospitals may have to put into place care rationing policies, called Crisis Standards of Care. Crisis Standards of Care are used to determine which patients will receive certain kinds of treatment and which patients will not.

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>INFORMATION AND RESOURCES</th>
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<tbody>
<tr>
<td>Massachusetts Crisis Standards of Care</td>
<td>The Massachusetts Department of Public Health issued Crisis Standards of Care Planning Guidance. Hospitals can use this Planning Guidance or they can create their own crisis standards. If a hospital activates its crisis standards, the hospital must notify the state.</td>
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<tr>
<td>Medical Rationing</td>
<td>Center for Public Representation’s website includes extensive information about COVID-19 Medical Rationing and provides links to other resources, including some media coverage.</td>
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FAQs

How is treatment under Crisis Standards of Care different from treatment that I can typically expect when I go to the hospital?

Crisis Standards of Care are only used when a hospital’s treatment capacity is overwhelmed by the numbers of patients requiring intensive treatment. While the state continues to report new cases, hospitals in Massachusetts still have the ability to provide treatment to all patients who need it.

If you would like more information about Crisis Standards of Care, here are several links to websites and media coverage that discuss why Crisis Standards of Care are necessary to prepare and under what circumstances they would be used:

- Massachusetts Health and Human Services: Video of the Secretary of Health and Human Services discussing crisis standards of care
- National Academies of Sciences, Engineering, and Medicine: Doing the ‘Greatest Good for the Greatest Number of People’
- Boston Globe: “State revises guidelines for who gets ventilators in crisis, following complaints about equity”
- Washington Post: “Who gets a shot at life if hospitals run short of ventilators?”

How will I know if the hospital I go to for COVID-19 treatment has activated Crisis Standards of Care?

The latest models show that hospitals are expected to have enough capacity to treat all the patients that need treatment. If cases surge and hospitals are overwhelmed, a hospital must report to the Massachusetts Department of Public Health that it is using its Crisis Standards of Care Planning Guidance.

The Department of Public Health maintains a COVID-19 resource page with updated information on the state’s response to the crisis and hospital capacity. If you have a choice of which hospital to go to, check the hospital’s website or the Department of Public Health’s website to see which hospitals have activated Crisis Standards of Care.
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Care. If a hospital has adopted the state’s Crisis Standards of Care Guidance, you will be notified if a decision affecting you or your loved one has been made under the Crisis Standards of Care.

If the hospital I go to has not activated Crisis Standards of Care, will I have full access to all treatments?

Even if a hospital has enough available beds and ventilators to treat COVID-19 patients, it is still possible that the hospital could be short on certain medications or treatments. As drugs are newly developed or found to be effective in the treatment of COVID-19, there may be initial shortages before production can be increased.

For example, an experimental drug, remdesivir, recently has been found to help shorten the period of recovery from COVID-19 in some patients. Doctors are still figuring out which patients can benefit the most from the drug that is in limited supply.

Can I get tested for coronavirus whenever I want to?

Though testing capacity is increasing, Massachusetts does not currently have the capacity to test everyone who wants to be tested. COVID-19 tests were initially reserved for individuals showing severe symptoms and for certain eligible public safety personnel, including healthcare providers, emergency responders, and grocery store workers. On May 13, 2020, the Executive Office of Health and Human Services at the Department of Health released new guidance on who is eligible for testing:

- Anyone who is showing symptoms, including mild ones.
- Anyone who has been identified as a close contact with someone who has COVID-19, even if the close contact is showing no symptoms. Close contact is defined as being less than 6 feet for at least 10-15 minutes from a COVID-19 case or having direct contact with infectious secretions without wearing personal protective equipment.
- Someone without symptoms who has been recommended for testing at the discretion of their healthcare provider, a state agency, or an employer.

You should contact your health care provider to find out if you are eligible for receiving a coronavirus test and your health plan to see if your coronavirus test will be covered. You can access an interactive testing map and a full list of testing sites in Massachusetts here.

What should I do if I, or a loved one, am discriminated against in the type of treatment given under a Crisis Standards of Care?

Whether or not the hospital is operating under Crisis Standards of Care, treatment decisions should be made in a fair way that does not involve bias against persons with disabilities. If you feel that your care provider has made a biased decision regarding your treatment, you can appeal the objectionable decision directly to your treatment provider or the hospital representative who informed you of the decision. Also, you should ask to speak to the hospital’s Human Rights Officer.

If you need more help or advice, these links direct you to agencies and organizations that can help you file a complaint.

- Massachusetts Attorney General’s Civil Rights Division
- Disability Law Center
- Office of Civil Rights, Department of Health and Human Services

Can I have someone with me in the hospital to help me if rationing decisions are being made using Crisis Standards of Care?

Currently, Massachusetts is in Phase 2 of re-opening, and patients are permitted one visitor who must be screened for symptoms and wear a face mask. Under the Phase 2 guidelines, individuals with disabilities must be permitted a companion, who is not considered a visitor under the visitation policy.
If infection rates increase again and Massachusetts moves back to Phase 1, hospitals may again return to no-visitor policies. 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 for a visitor, regardless of the hospital's official visitor policy. The Attorney General has released guidance directing hospitals to consider requests for exceptions to the no-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.

Information about your rights to access your 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. Under the state’s recommended Crisis Standards of Care, you, your family, or your emergency contact will be notified if a decision about your treatment is made using Crisis Standards of Care. If no visitors are allowed, the hospital will attempt to contact your family or emergency contact.