



Disability
Rights
Oregon

FOR IMMEDIATE RELEASE:
May 18, 2020

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Portland hospital failed to accommodate patient with neuromuscular disease due to COVID-19 policy, leaving her cut off from the outside world

Advocates called for Oregon's COVID-19 hospital visitation guidance to accommodate people with disabilities

Portland, Oregon—Last month, a local hospital denied a Multnomah County woman with severe physical disabilities her request for the personal support she needed to both communicate and self-care while being in the hospital, due to a new policy regarding coronavirus.

Christine Getman is unable to use any of her extremities with the exception of one finger. She was denied her request for one-to-one care and access to her personal care attendant (PCA) while being treated for meningitis. Without the support of her PCA while hospitalized, she was put at risk of being exposed to COVID-19 and missed numerous opportunities to communicate with key medical staff during her hospitalization. The lack of interaction left her in the dark about her care and discharge. She lived in fear of receiving improper care.

To prevent other patients with disabilities from facing similar barriers to basic human rights, Disability Rights Oregon (DRO) and Getman called on the Oregon Health Authority (OHA) to reissue its Visitation Guidance for Acute Care Facilities to allow personal care attendant exceptions alongside proper precautions to prevent the spread of COVID-19.

“This experience reminded me how quickly I can become cut off from the outside world and lose my independence when I don’t have my most important accommodation – my personal care attendant. Being wheeled onto the coronavirus floor by myself was one of

my worst nightmares coming true,” said Christine Getman. “As a person with a disability, I already knew all the reasons to avoid coronavirus but I didn’t anticipate what would happen if I needed other medical care during the crisis. Access to my personal care attendant is a basic human right that’s central to my ability to live in the world like everyone else. We have to ensure that this doesn’t happen to anyone else. Check your local hospital’s coronavirus visitor policy exceptions. If they are denying basic human rights, it’s time to speak up.”

“We know that healthcare professionals are working tirelessly to stop the spread of COVID and to save lives. But COVID-19 doesn’t mean people with disabilities lose their right to communicate and interact when they need medical care. A life-threatening pandemic only heightens the need for proper accommodations so that people with disabilities can safely have their needs met during this emergency,” said Jake Cornett, Executive Director of Disability Rights Oregon. “This is why the state must do more to make sure Christine Getman’s most basic rights are not taken away from her.”

About Christine Getman’s Experience

Getman lives with the neuromuscular disease Spinal Muscular Atrophy, type 2. She serves as the Executive Director of the national non-profit organization Magic Wheelchair, and advocates on several disability organization boards. Though she can feel everything in her extremities, she experiences muscle weakness and require a full assist with daily activities like eating, bathing, using the bathroom, and getting dressed. She can’t hold her head up without specific positioning and uses a power wheelchair to get around. She has a trach tube to breath and, if she is moved the wrong way, she can suddenly lose her ability to speak.

Because of COVID-19, staff at the hospital where she received care were minimizing in-room consultation and conducting their daily rounds via phone. Without access to her PCA, Getman was unable to answer the phone as she laid in her hospital bed. She missed calls from critical hospital staff like a patient advocate, caseworker, and home infusion staff. In order to reach the nurse “call” button, Getman was forced to position herself in a way that increased her joint pain.

To speak more clearly, Getman also needs someone to place her hand on her trach so she can breathe out through a hole. She asked the nurses to move her hand to her trach every time a doctor came into her room.

Blocking her access to her PCA also likely increased her exposure to COVID-19 by necessitating that she be in close contact with more hospital staff. She was exposed to roughly eight to twelve different hospital staff members in a shift because of her need for help with eating and assistance in using the bathroom. The patient requested a one-on-one personal care attendant from the hospital, which it denied. Getman even offered in a secondary request that her PCA not leave the room or have in-and-out privileges, until they were both discharged together, assisting in reducing her exposure to COVID-19.

Partner organizations, friends, and nurses from across the country who know Getman joined her and advocated for her by calling the hospital's Patient Advocate office, national hotlines, and DRO.

Oregon Health Authority Visitation Guidance for Acute Care Facilities

This guidance, which was revised on April 23 by OHA, now mentions visitors who also provide care regarding activities of daily living that are not otherwise available in hospital settings. Not all hospitals are following this revised guidance.

In a complaint filed with the Office for Civil Rights at the U.S. Department of Health and Human Services (OCR), DRO included a demand that people with disabilities be allowed to bring a support person with them to the hospital.

Many individuals with physical disabilities need a family member, personal care provider, or communicator who is knowledgeable about their care, able to assist them with communicating their needs, or able to provide ongoing personal care assistance.

Disability Medical Rights

People with disabilities can ask for hospitals, doctors, or clients to change their policies to accommodate your disability. They can fill out an accommodations request form to bring with them to the hospital. Show the form to everyone and make sure a copy is put in their medical chart.

Resources

- [Know Your Rights: Reasonable Accommodations in Hospitals during COVID-19](#)
- [Oregon Health Authority Visitation Guidance for Acute Care Facilities](#) (Revised June 8, 2020)
- [DRO letter to Oregon Health Authority requesting Change in Oregon Health Authority Visitation Guidance for Acute Care Facilities](#) (April 17, 2020)
- [Federal civil rights complaint](#) (May 8, 2020)

About Disability Rights Oregon

Disability Rights Oregon upholds the civil rights of people with disabilities to live, work, and engage in the community. The nonprofit works to transform systems, policies, and practices to give more people the opportunity to reach their full potential. For more than 40 years, the organization has served as Oregon's Protection & Advocacy system.

About Magic Wheelchair

Magic Wheelchair is a non-profit organization that brings communities together to create unforgettable moments for children around the world by transforming their wheelchairs into

magic. The organization builds epic costumes for kiddos in wheelchairs — at no cost to families. Due to COVID-19, the organization has shifted its volunteers to creating PPE for frontline healthcare workers.

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