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Access denied: Oregonians with disabilities face extra challenges meeting care needs during pandemic

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By: Jayati Ramakrishnan | The Oregonian/OregonLive

In early April, Christine Getman had been quarantined for three weeks when she developed a bad headache — the kind she'd only had once before in her life.

"I immediately knew the type of headache it was," she said. "It was bacterial meningitis."

What followed was a hospital stay that shed a light on the strain the coronavirus pandemic has placed on people with chronic illnesses as they try to access care, both during health emergencies and in meeting their daily needs.

But Getman said OHSU's policies posed a host of problems for her that she felt put her in danger.

OHSU's no-visitor policy during the pandemic meant Getman, who has Spinal Muscular Atrophy, had to navigate her stay in the hospital alone, without her fiancé, who is also her full-time caregiver. The issue is one other Oregonians with disabilities have faced since the pandemic started, according to Emily Cooper, a lawyer for Disability Rights Oregon.

"I could inundate you with stories of individuals with disabilities and family members who have been denied access because of visitation policies," Cooper said.

But Cooper said the pandemic has impacted people with long-term disabilities in all kinds of ways — from those with hearing issues who struggle to communicate as mask-wearing becomes commonplace, to people with neuromuscular issues unable to meet with regular medical providers because of stay-at-home orders or the heightened risks they face leaving home.

"It's really a test of how our state is going to protect the public," Cooper said. "Lots of us in the disability community are scared we're not going to have the same access to care."

A scary hospital stay

Getman has Type 2 Spinal Muscular Atrophy, a rare neurological disorder that weakens a person's muscles over time. Getman uses a wheelchair, can only move one finger on one hand, and has a tracheostomy tube for breathing. When she first developed bacterial meningitis , she called her doctors, trying to arrange treatment that would allow her to stay home.

Within a few hours, her condition worsened to the point where she needed to go to the emergency room, and was admitted to a room at OHSU Hospital in Portland the next day.

First, she said, doctors tested her for coronavirus and placed her on a floor that housed coronavirus patients, even though she had quarantined for three weeks. She remained there for two days after her results came back negative. Getman's chronic disease puts her in a high-risk category for contracting the virus.

Christine Getman, a woman with Spinal Muscular Atrophy, was subjected to a traumatic hospital stay and denied access to her caregiver, Scottie Foertmeyer, right, because of coronavirus policies. Mark Graves/Staff

Getman's fiancé, who is her full-time caregiver, was also not allowed to be with her in her room — as per hospital policy during the pandemic. Getman needs assistance from a caregiver to eat, reposition her body or use the bathroom. She says the hospital denied several requests from her to allow her fiancé to help and to advocate for her.

"It felt like it made more sense to have one person who knows all my needs and can provide care — I felt like that was very reasonable. Instead I was given lectures about how bad other people have it," she said.

Cooper said issues like visitor limitations during the pandemic raise the issue of patients being able to make informed medical decisions.

She said in many cases, the issue could be resolved after a simple conversation with hospital administrators. But often, the issue is resolved by the time hospitals respond: either the patient gets discharged, passes away, or the visitor has already been allowed in.

In the hospital, Getman said she asked for a compromise to have the hospital assign one nurse or caregiver to her, so she wouldn't be alone in the room. She said the hospital denied the request.

Getman, who has a Master's in Public Health, said the hospital also didn't allow her fiancé to bring her computer — the device she uses to communicate — or other supplies she needs.

After five days in the hospital, Getman said she was allowed to continue treatment at home, where her fiancé administered intravenous antibiotics. She recovered from the meningitis and didn't develop coronavirus, but said the hospital experience was traumatic and impacted her heavily.

"I don't just want some sob story. I want to see change," said Getman, who works as the executive director of Magic Wheelchair, a company that makes costumes for children in wheelchairs. "Specific to COVID, or anything else with visitor restrictions, people with disabilities need to be considered in the fine print. I don't want to see any more headlines of people dying due to improper care or poor policies."

OHSU spokeswoman Franny White said the hospital can't discuss specific patients. But she said the hospital's no-visitors policy only makes exceptions for children, infants, patients in labor or who had just given birth, patients with limited mental capacity, or for patients on end-of-life care.

"We understand hospital-staff provided care is not the same as having the loving companionship of a known caregiver," White said in an email to The Oregonian/OregonLive. "But the unique and pressing circumstances of the pandemic require us to make very difficult decisions to reduce the spread of COVID, preserve protective equipment, and maintain a safe healthcare environment."

Everyday needs

Outside of hospitals, people with long-term disabilities and chronic illnesses have also faced more challenges accessing daily needs.

Donnie Graham, who was diagnosed with Amyotrophic Lateral Sclerosis in late 2014, said life looks a lot different than it did pre-pandemic.

The pandemic has prevented many people who have ALS, or Lou Gehrig's Disease, from leaving the house to attend regular checkups and support groups. ALS is a degenerative neurological disease. Patients lose the ability to use their limbs, swallow, talk and breathe.

Lance Christian, the executive director of the ALS Association in Oregon and Southwest Washington, said patients usually rely on care from a multidisciplinary clinic, where they can see as many as 10 providers during one visit and access doctors for things like pulmonary functions, feeding tube placement and rehab services to help with the disease's paralyzing effects. ALS patients are now receiving most of their care through telehealth services, and mostly through contact with their neurologists, Christian said.

Graham and his wife, Jan Steinbock, are no longer able to attend their support group meetings in-person, and have not visited the ALS clinic since December.

Graham, seated, has ALS. He can't wear a mask because he uses a ventilator to breathe. He takes a sip of air from the straw and it gives him a full puff of air to fill his lungs. He constantly sips water because breathing from the straw dries out his mouth. Jan Steinbock

Graham is losing his ability to swallow and eat. He said the support from medical professionals and family and friends is crucial to managing the fast-progressing disease. But he also knows leaving home poses a huge risk for him, as he is in a high-risk category for contracting the virus.

"We're more than five years past his diagnosis," Steinbock said. "I don't want this to be the thing that cuts him short."

Graham has created some speech-generating devices of his own to help him communicate, but still needs the help of a speech therapist to deliver communication technology.

When they do occasionally let specialists in to help with such equipment, they require people to wear masks and face shields, and only allow them into specific parts of the home.

"In order to get that support, we have to let people into the bubble," Steinbock said.

The pandemic has placed a strain on other activities too — the days of going to the store or anywhere else are gone, for now, and they rely on ordering groceries online or having friends pick them up.

The pandemic has put additional strain on Steinbock, as well. With Graham needing 24/7 care, they can no longer allow family and friends to come and help her with household chores or stay with Graham so that she can rest or have a few hours to herself.

The couple says they're not sure when they'll feel comfortable leaving the house and allowing people to start coming back in — but it will likely coincide with coronavirus testing becoming more widely available.

More barriers

Even efforts meant to slow the spread of the coronavirus, such as mask wearing, can create barriers for people whose disabilities aren't immediately obvious to others.

"You have a demographic of people for whom, if they can't see a person's face, it can be anywhere from just a little bit challenging to absolutely devastating," said Alison Metcalf, an audiologist who runs the practice Audiology Associates in Northwest Portland.

Not only do masks obstruct sound, but they prevent people who are deaf or hard of hearing from reading lip movements, and even make it difficult to decipher the speaker's emotions — all of which can be isolating for people.

Metcalf said there are some masks that have clear panels, which better allow for lip reading. Sunset High School student Eric Kim has been creating such masks for people who are deaf or hard of hearing. But those types of masks aren't widespread.

Accommodating those with disabilities during the pandemic will require ongoing assessment from all places that serve the public, said Cooper, the Disability Rights Oregon lawyer.

"Certain stores require all customers to wear face coverings, which makes sense from a public health perspective," she said. "But if you have a respiratory illness or a tracheostomy, that impacts your ability to breathe."

Such issues require stores to think about potential solutions, Cooper said. For example, businesses could offer clear masks for those who need to read lips or curbside pickup for those who can't wear masks.

Christian said it's important for able-bodied people to remember that the risks of the pandemic will linger for people with disabilities.

"When the world seems like it's going to return to normal for everybody else, for people with ALS and other chronic diseases, it's going to stay locked down for a long time," Christian said.

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