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INVESTIGATIONS

As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?

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Heard on All Things Considered



JOSEPH SHAPIRO

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Kimberly Conger, Sarah McSweeney's nurse at her group home, shows a photo of McSweeney on her phone. She says McSweeney was outgoing and fun: "She absolutely adored going into malls and getting her makeup done and getting her hair

done."

Celeste Noche for NPR

On the morning of April 21, Sarah McSweeney woke up with a temperature of 103 degrees — and it kept rising. Staff at her group home worried that the woman with multiple disabilities — she couldn't walk or speak words — had contracted COVID-19. They got her into her bright pink wheelchair and hurried to the hospital, just a block down the street from the group home in Oregon City, Ore.

That afternoon, Heidi Barnett got a phone call from the doctor in the emergency room.

He was puzzled, she says, by a one-page document that McSweeney's caregivers brought with her. It was a legal document that explained what medical care this disabled woman — who couldn't speak for herself — wanted.

"We had her at full code. So all treatment. Because she was young and vibrant and had a great life," says Barnett. "And that was her wishes, that's what we gathered from her. She wanted to be alive."

Barnett works for The Arc Oregon, the agency that was McSweeney's guardian. She had helped McSweeney fill out that document, called a POLST form, for a moment just like this.

It's normal for a doctor to want to understand a patient's wishes. However, Barnett, who kept daily notes on her conversations with medical workers about McSweeney, felt the doctor was challenging the order.

"They wanted it to be a DNR," says Barnett.

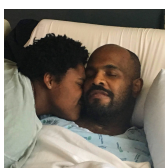
A Do Not Resuscitate Order is a medical order to doctors not to treat a patient — like McSweeney — if she stops breathing or her heart stops.

That emergency room doctor would be the first at the hospital to raise a question that would shadow decisions about McSweeney's care over nearly three weeks at the hospital: Why does a woman with significant and complex disabilities have a legal order that requires the hospital to take all measures to save her life?

McSweeney was 45 when she died on May 10. Her death would raise another question, one that people with disabilities and the elderly have worried about since the start of the coronavirus pandemic: Are they denied care when it gets scarce — like drugs or treatment, including ventilators — that might save their lives?

An NPR investigation looked into McSweeney's death and about a dozen reports of discrimination in Oregon: Of doctors and hospitals denying equipment like ventilators; insisting that an elderly or disabled person sign a DNR — maybe when they couldn't understand it and in the middle of a crisis — or even denying a COVID-19 test.

These decisions are made behind closed doors, NPR found, and as a result are little known and little understood. McSweeney's case offers a rare look at how those decisions are made.



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When people met Sarah McSweeney they saw different things.

Most saw what she couldn't do. McSweeney had quadriplegia, cerebral palsy and other disabilities.

Because she couldn't walk, or even use her hands, someone had to push her in her wheelchair.

Because she couldn't speak words, she communicated by making sounds and gestures.

Because she couldn't eat solid foods, someone fed her a supplement of nutrients through a tube to her stomach.

A smaller number of people, but the ones who knew her best, saw something different. They saw what was possible for McSweeney. They saw the choices she made and the things she did.

"She absolutely adored going into malls and getting her makeup done. And getting her hair done and doing typically girly stuff that girls like to do — get pedicures and manicures," says Kimberly Conger, the nurse manager for Community Access Services, or CAS, the nonprofit agency that provided services and ran the group home where McSweeney lived.

Kimberly Conger, the nurse manager for McSweeney's group home, objected when a doctor said the disabled woman needed to be on a ventilator but then questioned her quality of life: "I feel like they didn't feel like she was worth that."

Celeste Noche for NPR

She loved country music, especially Kenny Chesney, whose poster she had on the wall of her room. She enjoyed when her staff took her to country music concerts — she'd met Tim McGraw twice — and to country bars to watch people in boots and denim do the flips and swing of country dancing.

The people who worked with her enjoyed her vivacious personality. She smiled and laughed and loved to make others smile and laugh. There's a picture of McSweeney sticking out her tongue and laughing at the camera. Her dark hair is dyed a bright red, a color that clashed with her neon-pink wheelchair.

"Her smile would bring a smile to everyone in the room," says Anna Keenan-Mudrick, who runs CAS.

The two views of Sarah McSweeney would collide once she went to the hospital — and during the nearly three weeks she was there.

On April 21, a Tuesday, in the emergency room at Providence Willamette Falls Medical Center, the doctor wrote down his diagnosis: "acute cystitis with hematuria," a urinary tract infection with the presence of blood in the urine.

Hospital medical records indicate the ER doctor was thorough. With his stethoscope, he listened to McSweeney's lungs. "No wheezes, no crackles," he'd write. Those would be signs of pneumonia, a common killer of people with intellectual and developmental disabilities.

But to be sure, he ordered an X-ray. It would show a small pneumonia. It is not unusual for people with swallowing problems to have a chronic build up of saliva in their lungs that they live with every day, sometimes called "silent aspiration."

NPR reviewed hospital records from McSweeney's case file. The information in the records was shared with an NPR reporter by someone with access to them.

NPR made multiple requests to speak to doctors, staff, and officials at the Providence Willamette Falls Medical Center. "We are not able to comment on the care of a specific patient," a spokesperson for the hospital said. "We do not pressure or force anyone to sign a DNR order, and we are unaware of any evidence to the contrary. We honor decisions by patients and/or their legal representatives. We are not aware of any care needed by any of the patients that was not provided."

As a precaution to prevent the spread of COVID-19, McSweeney was moved to the ICU.

Within a day or two, Barnett says, she got word that the COVID-19 test had come back negative. A second test would return a negative result, too. After the first test, McSweeney was moved from the ICU, back to the general floor of the hospital.

The hospital had a strict limit on visitors because of the pandemic. Barnett and Conger, the nurse manager for McSweeney's group home, spoke every day to doctors, nurses and social workers over the phone and in Zoom calls.

Nearly a week later, on Monday, April 27, another doctor who was leading the care team called Barnett, and said it was "urgent" that she come to the hospital. McSweeney's left lung was "kaput," he told Barnett. She asked what that meant "in medical terms" and he explained that her lung was filled with fluid and not receiving oxygen.

"She was young and vibrant and had a great life," says Heidi Barnett, who works at The Arc Oregon, of McSweeney. "She wanted to be alive."

Celeste Noche for NPR

Barnett and Conger hurried to the hospital. The doctor showed them the X-ray of McSweeney's lung.

The doctor told them the pneumonia had developed on Friday.

Conger and Barnett told the doctor they should have been notified of the problem then or over the weekend.

This was not the kind of pneumonia associated with COVID-19. Or the small pneumonia, Conger says, that may have shown up on the X-ray on April 21. It was aspiration pneumonia, which occurs when food, saliva or liquids are breathed into the lungs or airways, instead of being swallowed into the esophagus and the stomach, because McSweeney was fed through a gastrostomy tube — or G-tube — directly to her stomach.

Conger says McSweeney did not have a history of that kind of pneumonia at the group home. She had lived there since 2005.

In the hospital that Monday, the doctor said McSweeney, as a result of the aspiration pneumonia, needed to be on a ventilator. It was "critical" that she go, Barnett recalls him saying.

Conger agreed because that's standard treatment. It's what, she felt, a hospital would do for anyone.

"We discussed the possibility of her being intubated and letting that lung rest, giving her time to heal and letting the antibiotics do their magic," Conger recalled.

But then the doctor surprised Conger and Barnett, the women say, when he pushed to rewrite McSweeney's care document. He wanted a new order that would say the disabled woman should not be resuscitated or intubated.

That would be an order to deny McSweeney the ventilator the doctor had just said she needed.

"He said intubating her was a matter of risk versus quality of life," Conger recalls. "I was like, 'But she has quality of life.' And he looked at me and goes, 'Oh, she can walk? And talk?'"

The doctor lifted his index and middle fingers and moved them in a walking motion, like in the old advertisements for the Yellow Pages.

Conger pushed back: "And I said 'Well, no, but there's a lot of people who don't walk who have full quality of life.' And he gets kind of irritated with me and left the room at that point."

When the doctor walked out, Conger and Barnett understood that they had failed to change the medical team's negative view of McSweeney.

Conger — "she was livid," Barnett says — called her bosses at CAS, the women who were in charge of McSweeney's care. They decided to file a formal complaint with the hospital.

The next day, Tuesday, April 28, Conger filed the complaint, in a phone call with a hospital official. Keenan-Mudrick, the executive director of CAS, would later testify, in the state legislature, about this incident and the doctor's "pressure" to change McSweeney's orders to a DNR.

Anna Keenan-Mudrick, executive director of Community Access Services, told state lawmakers how her staff pushed back when doctors and social workers wanted to override McSweeney's legal document asking for full medical care.

Celeste Noche for NPR

Conger, in her complaint with the hospital, too, protested the pressure to change McSweeney's stated wishes for health care. She said that staff at the hospital failed to see McSweeney, as she put it, as "a whole person."

At The Arc Oregon, Barnett spoke with her bosses and decided they should try to find another hospital for McSweeney. Barnett notified the hospital. She got a call back from another doctor who told her that insurance would not pay to transfer McSweeney, according to Barnett's notes.

The doctor apologized, too, Barnett says, for the lead doctor's brusque manner and promised she and other advocates for McSweeney would be kept up to date about the woman's condition.

The lead doctor was trying harder, too. Later that day, he called Barnett to say he had called in a specialist, a pulmonologist, to see McSweeney.

On that same day, April 28, Kelly Gauthier, one of McSweeney's direct service professionals — a caregiver from her group home — was allowed to visit. She showed the nurses how to communicate with the disabled woman. She explained how they could ask McSweeney direct questions and she could indicate yes or no.

Gauthier brought a sheet of paper, a one-page introduction to McSweeney. It listed things she liked — country music, getting her hair done, trips to the mall — and things she didn't like. The aide played some Kenny Chesney CDs for McSweeney. In the hospital notes that day, someone writes that McSweeney responded positively to the visit and the music. And that she was breathing "more easily" and at "normal depths."

It's common that doctors often see someone with multiple disabilities, like McSweeney, one way and the person's friends, family and caregivers see her another.

Researchers call this the "disability paradox" — the large gap between how a person with a disability rates the quality of their life and what a doctor would rate it.

A "vast majority" of doctors say people with a significant disability have a worse quality of life, according to a recent poll by Dr. Lisa Iezzoni, a Harvard Medical School professor and physician who studies health care disparities for people with disabilities. Her research will be published in the journal *Health Affairs* in early 2021.

There are, for sure, doctors who take extra steps to understand the lives of their patients with disabilities and who work to help them achieve health and independence.

Still: Doctors save lives. They cure people. They help them get better.

But Iezzoni says, they often hold a bias — often an unconscious bias — about people who won't be cured and as a result "do not make the same effort to restore patients to their baseline health."

McSweeney's advocates at CAS and The Arc Oregon saw their job differently. It was to help the disabled woman live as full a life as possible, according to her wishes.

For example, when McSweeney said she wanted to work--maybe as a greeter in one of those stores in the mall she loved — Susan Gustavson, a veteran advocate at CAS said: OK, let's figure it out.

Gustavson arranged for McSweeney to get trained to use a voice output device called a Tobii Dynavox.

Because McSweeney couldn't move her fingers to type on a keyboard, the Dynavox was set up to track where her eyes gazed. She could look at a letter or a symbol on a computer screen and the device would read and then speak it for her.

Gustavson told the doctors and medical staff about McSweeney's dream to work, and how she was working on the machine when she went to the hospital. And when they asked — why does this disabled woman have medical orders for a full code — she explained something else.

That what was an acceptable part of life for McSweeney was different than what might be acceptable for others.

McSweeney wasn't afraid of being on a ventilator, for example. She'd been ventilated before — in 2017 when she was hospitalized for pneumonia.

When McSweeney wanted a job, Susan Gustavson, associate director of Community Access Services, arranged for McSweeney to get trained on a special voice output device.

Celeste Noche for NPR

But mostly she wasn't afraid because, as Gustavson explained, "Sarah has friends who are vent dependent, 24 hours a day, with traches," a reference to a tracheostomy, a surgical opening in the windpipe to insert a breathing tube.

"These folks were her friends," says Gustavson. "They participate in the same community activities together. They hang out."

They went to the mall and to the movies.

"That is the norm for Sarah. That is not extraordinary," says Gustavson. "It was definitely received as extraordinary from the hospital staff. They were blown away."

Hospital records say the medical team was debating the best course for McSweeney, who was now dealing with aspiration pneumonia. According to hospital records, on Thursday, April 30, a hospital palliative care team met to discuss whether to put her on a ventilator.

The palliative care nurse argued in favor of keeping McSweeney at full code, to honor her goal to try to get better and go home. But a hospital ethicist argued that intubating McSweeney put her at risk of cardiopulmonary risk and other bad outcomes, according to hospital records. Aggressive treatment, he said, according to the records, could cause "more harm than benefit."

The ethicist, according to the records, said if McSweeney's guardians at The Arc Oregon disagreed, they could seek a second opinion or they could move her to another hospital. But the women in charge of her guardianship say they were never told of this.

Still, hospital staff — after the complaint was filed — started calling with regular updates. Conger, the agency nurse, complained that she, with her medical background, wasn't getting these calls. Her boss, Keenan-Mudrick, would tell state lawmakers that this was "grossly inadequate" communication — and unusual. "We typically do not have this issue of the hospital not directly returning calls to our RNs," she said.

But the hospital was notifying Barnett, McSweeney's certified guardian, and Barnett's boss, Emily Braman, who runs the guardianship program for The Arc Oregon.

Over the course of McSweeney's second week in the hospital, McSweeney's health seemed to be getting better. The pulmonologist called Barnett twice, according to her notes, to say McSweeney's lungs were improving and that she was breathing more easily.

McSweeney's advocates started to plan for her to leave the hospital.

On Thursday, May 7, Barnett looked into possibilities to move her out of the hospital to a group home with nurses who would suction her lungs and provide medical care while she recovered. It would be a temporary stop before she moved back to her group house in Oregon City.

"We were getting notified that it sounded like she was getting better, that things weren't that bad," Braman says.

Then everything changed.

"All of sudden we got a call that it's dire straits," Braman says. On Friday, May 8, a case worker called to say McSweeney's lungs were failing.

There had been added episodes of aspiration pneumonia, on April 29 and May 7 and a clogged feeding tube on May 2 that, according to Braman, Barnett and Conger, had not been disclosed to them.

The next day, on Saturday, Conger and Barnett were summoned to the hospital to talk about McSweeney's worsening condition.

The pair got there early and went to McSweeney's hospital room. "We're standing there in the room waiting for the doctor to be paged and to come into the room," Conger says. "The case manager came up and she really didn't even say hi. She just said, 'So, I'm under the impression that Sarah was going to go for employment and she used to go get her hair done.' I said 'Yeah. She loved to get her hair done and she just finished Discovery for employment.'"

Discovery was the program that was helping McSweeney figure out a way to use that voice computer and find a job.

"And she looked at me and she pointed to Sarah and she's like: 'Her. She used to get her hair done and she was going to be employed?' And I was like: 'Yes.' I mean, it was gross," Conger says.

Barnett could see that Sarah, in her hospital bed, was listening. "She heard it and she understood it." Sarah used her eyes to communicate. And now her eyes followed the case manager — and then her friends — when each spoke.

"She had a very worried look on her face," says Barnett. "And it just broke my heart."

Now Conger could see something had changed. The treatment in the hospital was not working.

"Sarah was desperately trying to communicate something," she recalls. She didn't smile, as she usually did. "It was: Mouth wide open. Arms clinched up. Tears running down her eyes."

And she was in distress.

"She was struggling to get air," Conger remembers, "and you could just see the panic and the fear in her eyes. She would rest for a minute, take a nice long breath for a minute, close her eyes, then wake up in absolute fear. She could not take a breath."

Now, Conger and Barnett agreed with the medical staff that it was time to begin palliative, or comfort care for McSweeney.

They said goodbye to McSweeney and left the hospital.

Just hours later, at 3:30 Sunday morning, a phone call woke up Barnett at her home.

It was the charge nurse at the hospital. "I'm sorry to inform you," he said, "that Sarah passed away."

Painted rocks sit outside Sarah McSweeney's group home in Oregon City, Ore., on Nov. 24, 2020. McSweeney's housemates painted a rock to read "The World Just Lost Some Sparkle" in pink and purple after McSweeney's death.

Celeste Noche for NPR

McSweeney didn't die of COVID-19.

She died of severe sepsis due to aspiration pneumonia.

Aspiration pneumonia is a serious medical condition. But, usually, it's treatable.

Conger says doctors could have stopped the feeding tube and instead fed McSweeney through an IV line.

Conger and Barnett said they made repeated suggestions for the IV feedings. Hospital records say a doctor considered it and concluded there was "no evidence" that it would make a difference. But by then it was May 9, when the pneumonia was out of control and McSweeney was just hours from death.

Over more than two and a half weeks, doctors and social workers had questioned why this disabled woman had medical instructions for full care, instead of a Do Not Resuscitate order.

McSweeney's advocates had pushed back.

Says Conger of McSweeney's care at the hospital: "I don't feel like they — and this is my personal opinion — I feel like they didn't feel like she was worth that."

Because of the pandemic, there was no funeral service for McSweeney. Her friends were her housemates and the other disabled people in nearby group homes and the staff that helped her live independently.

In a rock garden outside McSweeney's group home, her housemates placed a stone they'd painted in pink and purple that said: "The World Just Lost Some Sparkle."

"She was so happy and goofy and funny," Barnett says of McSweeney. "I was lucky to know her for the last three years. And I got to know her and how she communicates and what's important to her and how she jokes around. I used to tease her that she was a princess and I was going to buy her a tiara and she'd laugh. And she was so much fun. And even though she had these medical issues, she was vivacious. She just lived her life."

Barnett pauses, and then apologizes for crying. "She was a beautiful person ... I just think she could have gone out better. They owed her more respect than she got."

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