

Independence with a Ventilator: An Interview with Mark Boatman

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Kahn: Will you start by telling me about your family and where you were born?

Boatman: I was born and raised in Jamestown, North Dakota. I'm the only one in my family with a disability. I was diagnosed with Duchenne muscular dystrophy in 1980 when I was five.

Kahn: What were your parents told about your condition?

Boatman: My parents were told by my doctor that I would be lucky to live to 16. They were told to take me home and give me whatever life they could. I attended regular school. In high school I had an aide, and the school had an elevator. After I graduated in 1993, the big thing was what to do and where to go next.

Kahn: Where did you end up going?

Boatman: I found out that a company called Accessible Space Inc. was putting up a building in Jamestown that was going to have 18 apartment units for people with mobility impairments.

They were going to provide attendant care using a Medicaid waiver. In North Dakota, someone with a disability can qualify for four to five hours of attendant care per day. By combining everyone's hours together, the residents could have an attendant 24 hours a day. So I moved there.

Kahn: How was it living away from your family home?

Boatman: It was hard at first, because my parents were my caregivers until that point. They were nervous at first. But once I got used to the setup, I really, really liked being independent.

Kahn: What did you enjoy most about it?

Boatman: Being in control of my own life. I could go to the movies when I wanted to, or I could cook whatever I wanted to for supper. I didn't have to go to bed at a certain time. It was the freedom to run my own life with the proper support.

Kahn: When did you start having respiratory problems?

Boatman: In 2001 I started having some headaches, felt sluggish and short on energy. After a sleep study, the solution was a BiPAP® (Respironics, Inc.) machine to use during the night. I made an incredible turnaround. But after a while my symptoms came back again. I started losing weight, losing all my energy and retaining CO₂. By December of 2002 I had lost so much weight that I had to have a stomach tube put in. It went well, but in the recovery process my body just got stressed out too much. That was when the decision to trach me was

What is a Medicaid waiver?

Under Section 1915(c) of the Social Security Act, Medicaid law authorizes the Secretary of the US Department of Health and Human Services to waive certain Medicaid statutory requirements. These waivers enable States to cover a broad array of home and community-based services (HCBS) for targeted populations as an alternative to institutionalization.

To be a waiver participant, an individual must be medically qualified, certified for the waiver's institutional level of care, choose to enroll in the waiver as an alternative to institutionalization, cost Medicaid no more in the community under the waiver than he or she would have cost Medicaid in an institution, and be financially eligible based on their income and assets.

made. I got the trach at the very end of January 2003. I switched from the BiPAP® to an LP10 (Puritan Bennett).

Kahn: What happened after that?

Boatman: I couldn't return to where I had been living. Under North Dakota's Medicaid rules and regulations for attendant care services, you do not qualify if you require skilled nursing care. Having the ventilator and trach automatically put me into that category. The only option for me was a nursing home.

Kahn: What was it like for you to go from living independently in the community to living in a nursing home?

Boatman: It was kind of hell. The nursing home told me when I could shower, when lunch was going to be, and when I had to be in bed. To go from being an independent young guy and then have the nursing home control my life! They'd chart where I was going or if I had company. And I had to share a little room. There was just no privacy. I got very depressed.

Kahn: Did you think it was unfair that you couldn't live in the community?

Boatman: Yes. I was very capable of living in the community. I could direct everything that I needed. I knew my care. I just couldn't believe the State was not going to make any accommodations for me.

Kahn: What did you do to try to get out of the nursing home?

Boatman: I contacted my State Protection and Advocacy office, and they assigned me advocates. We put together a plan of care. Our goal was for North Dakota Medicaid to cover

the cost of my care in the community. But the State was going to make me go through an agency and use nurses and nursing aides. That made it too expensive, and they said that there was no way to do it.

Kahn: What happened next?

Boatman: It was taking forever. I had talked to everyone in the Department of Human Services, but they kept saying no. That's when I met Theresa and Dustin through a muscular dystrophy Internet support group. Theresa was Dustin's caregiver. He has a disability and uses non-invasive ventilation.

Theresa wanted to help me find a way to get out of the nursing home when the State was kicking its feet, and we had the idea of me coming to Missoula, Montana.

Kahn: Is that where you're living now?

Boatman: Yes. I can get funding for nine hours of nursing a day in Montana. I moved out here in September 2006.

Kahn: Had you met Theresa and Dustin in person before you moved?

Boatman: I had met Theresa. She stopped in North Dakota at the beginning of July. I just packed up, came 850 miles away, and made things work.

Kahn: What is your life like now?

Boatman: It's awesome! I have control. Little things like grocery shopping or errands in town are a big deal for me. I can go out to dinner with friends, stay up late, sleep until noon. Theresa and Dustin are very active



Mark Boatman

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Excerpt from Boatman's Blog ...

"Last Friday (February 2), I experienced a burning pain on the left side of my chest ... my heart checked out fine but my lungs were inflamed. I was given steroids and sent me home ... but the pain didn't subside ... and he got me in right away for a CT scan.

"The Radiology Department placed me on a HoverMat (www.hovermatt.com), which they inflate and glide me ... with a couple fingers. ... it made things much easier on me.

"... they couldn't find a good vein. We discussed our options and ... put a central line into my femoral vein ... which was pretty uncomfortable.

"To make a long story short, they found three small blood clots in my left lung. The doctor started me on blood thinners and put me in ICU for overnight observation. Tuesday afternoon they removed my central line and discharged me. I was sent home on Coumadin and there will be pretty frequent blood draws until my levels become stable."

Mark Boatman (Nodakwheeler) Disability Blog
<http://nodakwheeler.blogspot.com>

in Montana with disability advocacy. They bought a van last summer. We're going to Helena for the legislative session, lobbying and testifying.

Kahn: Is Theresa the sole caregiver for both of you?

Boatman: We have a nurse come in three days a week, but Theresa's the primary live-in caregiver. It really has turned out to be a good setup. The only drawback is that the State pays her for attendant care, but nothing for the vent care. That really offends me, because she is the most skilled attendant I've ever had.

Kahn: What else do you enjoy doing with your time now?

Boatman: I run an online ventilator support group called the Vent Support Network (<http://health.groups.yahoo.com/group/npventsupport>) that I started while I was in the nursing home. I spend a lot of time on that. There are more than 100 members. We talk

about various issues, and it's a great way to meet other people.

Kahn: And you have a blog. Tell me about it?

Boatman: The blog was a way to keep all the people who were supporting me in the loop with what was going on with my fight with North Dakota to get out of the nursing home. But it really blossomed when I moved out here, because I could share with friends, family and perfect strangers my experiences being out of the nursing home. Being out has given me a lot of confidence. What troubles me is that other folks are still in nursing homes.

Kahn: What do you think are the key changes that have to happen for ventilator users to live independently?

Boatman: The Nurse Practice Act needs to be amended to let caregivers who aren't nurses care for vent users. The board of nursing in each state has guidelines for what medical procedures need to be done by a nurse. If States free up some of these laws to allow non-nurses to do some of these procedures, it would lower the cost. I've had a lot of good nurses, but non-nurses can be excellent. Vent and trach stuff is pretty routine.

It still comes down to more money being put into attendant care throughout the country to allow people options. A nursing home is not the place for anybody to be stuck in, especially people who still have a life to live. I'm 31 years old, and according to the doctors shouldn't even be here. But I've never listened to the medical establishment too much. ▲