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Strangling of patient in nursing home a shuddering reminder of subpar care for Huntington's disease

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▼ 2013 (30)
 - ▶ December (3)
 - ▶ November (3)
 - ▶ October (3)
 - ▶ September (3)
 - ▶ August (2)
 - ▶ July (1)
 - ▶ June (1)
 - ▼ May (3)
 - [Strangling of patient in nursing home a shuddering...](#)
 - [Do we need to shock the world to strengthen the Hu...](#)
 - [Memories of genetic testing: from my mom to Angeli...](#)
- ▶ April (4)
- ▶ March (2)
- ▶ February (3)
- ▶ January (2)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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FRIDAY, MAY 31, 2013

Strangling of patient in nursing home a shuddering reminder of subpar care for Huntington's disease

The strangling and serious injury of a 49-year-old, late-stage Huntington's disease patient at an Oregon nursing home has shocked the HD community and provided a shuddering reminder of the subpar care, fueled by ignorance and approaching neglect, that some affected by the disease face.

Anne Haskins was allegedly strangled by another patient who used a call cord ripped from the wall after Haskins, wheelchair-bound and cognitively disabled, wandered into the other woman's room shortly before 9 p.m. PDT on May 28, said Rebecca Ambrose, 29, Anne's daughter.

There's no evidence Anne deliberately provoked the other patient, whom police described as suffering from "severe dementia," but her HD chorea – the involuntary movements typical in HD – means she can inadvertently hit people with her arms.

Anne was taken to Bay Area Hospital, located in Coos Bay, OR. After the attack, her heart rate dropped to the dangerously low rate of around 30 beats per minute, said Rebecca in a phone interview on May 30.

Anne is currently in the hospital's cardiac unit. Doctors offered the option of a pacemaker, but the family decided against one because they believe it would simply help to prolong suffering, Rebecca said.

"She may have lost too much oxygen to the brain to recover from this," she added.

The incident took place at [Avamere Rehabilitation of Coos Bay](#), a private facility where Anne has resided since August of 2009.

HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
[HD Free with PGD!](#)
[Stanford HOPES](#)
[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)



Anne Haskins, grandson Andrew, and dog Scarlet, about ten years ago, before HD left her unable to speak and care for herself (family photo)

'Where was the staff?'

According to the Coos Bay police, the alleged perpetrator is under observation in the psychiatric ward at Bay Area Hospital. Avamere has prohibited the alleged perpetrator from returning to its facility, Rebecca added.

"Where was the staff???" Rebecca exclaimed in several private Facebook HD discussion groups. Rebecca agreed to allow inclusion of her Facebook comments in this article.

On the night of the attack, the certified nurses assistants (CNAs), the main caregivers at the facility, should have put Anne to bed by 7:30. However, she was still moving around in her wheelchair around 9. No CNA noticed that she entered the other woman's room. A CNA came upon the injured Anne sometime later, said Rebecca.

The police received a call for help at 8:49 p.m. According to Officer Randy Sparks, the lead detective on the case, a nurse, responding to the call alarm from the room, intervened to assist Anne.

"It just makes me angry," Rebecca said. "I felt that it could have been foreseen. It makes me angry to think that my mom could be killed, and neither the person who did it nor the nursing home could be liable for it.

"How could one bedridden patient strangle another bedridden patient and no CNA have a clue? There were five CNAs on the floor, according to the director of the home."

According to Deborah Nedelcove, Avamere's vice president of risk management and its chief compliance and privacy officer, 42 residents currently occupy the 90-bed Coos Bay facility.



Above, the strangulation mark on Anne's neck. Below, daughter Liz with Anne in Bay Area Hospital (family photos)



Detective Sparks has concluded his investigation and forwarded his report to the district attorney's office. However, those authorities have already informed Rebecca that criminal charges will not likely be filed because of the mental state of the alleged perpetrator, Rebecca explained.

The alleged perpetrator is not currently under arrest.

“The police can investigate if there is a criminal action by a patient,” she added. “They cannot investigate neglect by nursing home staff.”

Avamere’s response

Debbie Lane, the Avamere director of nursing, refused comment on the case, as did Britta Milius, the nurse in charge when I called the facility the evening of May 30.

VP Nedelcove, who works at the Wilsonville, OR, corporate headquarters of the 50-facility private company primarily doing business in Oregon and Washington, declined to comment on specifics of the case but offered some observations about the facility and Avamere’s policies, procedures, and philosophy.

“I have never heard of an incident like this,” Nedelcove, who has some thirty years’ experience in health care, said of the strangulation and Rebecca’s allegation of inadequate monitoring of patients. “This is an isolated incident. It was not expected. You can’t account for people who decide at a moment’s notice to do something.”

Nedelcove insisted that Avamere CNAs “definitely keep an eye on all of our residents all the time.... There are many residents in our facilities, and many of them have behavior issues.”

Avamere is conducting an internal investigation of the incident and, based on its conclusions, may alter procedures at the facility, Nedelcove added.

Seeking assistance

However, Rebecca has already contacted state oversight agencies and local media outlets.

She has also obtained assistance from the [Northwest Chapter](#) of the Huntington’s Disease Society of America (HDSA). However, HDSA cannot assist with placing Anne in a different facility because Anne, before symptoms worsened, had refused to give power of attorney to any of her relatives, preventing the sharing of medical information with an outside agency, Rebecca explained.

Rebecca posted pictures of her mother’s injury on the Avamere Facebook page, but the company removed them and then blocked her from posting additional images. She also placed a sign on the front door of the facility denouncing the strangling but doesn’t know if it remains.

Rebecca and other family members fought a hospital’s staffer’s recommendation that Anne return to Avamere and will place her in a different facility, [Myrtle Point Care Center](#).

Rebecca is also consulting private attorneys about potential legal action.

Denouncing neglect

“I’m really disgusted with this,” said Rebecca, a family advocate for a non-profit who tested negative for HD in 2006 and has identified some 50 descendants of an HD-stricken great grandmother who are at risk of inheriting the mutation. “I’ve told them I’m not going to be quiet about this.



Rebecca Ambrose (personal photo)

“I feel like I already have to be robbed of my mother. I feel a lot of times like I have to be the mother to my siblings and my child, and I have to take on a lot of what a grandparent would do, because my mom isn’t able to.

“I can still visit my mother. That’s being taken from me slowly. I didn’t expect my mom to be in a nursing home and have an incident that could cause her death. I always thought her disease process would cause her death. I understand that there are going to be falls out of the shower or the bed. But there’s no excuse for somebody to strangle my mother and for her not to be protected in facility that gets \$80,000 a year to care for her.

“I’m livid and I’m horrified. My mom used to watch that movie *One Flew Over the Cuckoo’s Nest*. I hate that movie. It’s one of the saddest movies I’ve watched in my life. That’s the state of nursing homes in America today.

“I just want to talk to whoever is going to listen to me. This can’t happen to people –when you entrust someone’s life! My mom is in a facility for her own protection, not to be neglected. I can assure you that nobody in my home would strangle my mother. I wish there were options that were not for profit. These people do it for profit.”

Care providers: a mixed bag

According to Rebecca, in early 2012 a man visiting Avamere to see his wife became angry at Anne and tried to punch her because an employee had accidentally taken his chair to Anne’s room.

Anne also suffers from bed sores, and she sometimes does not get her spoon-fed evening meal until late at night, Rebecca said. The CNAs bathe Anne, left incontinent by HD, just once a week, which understandably leaves a patient uncomfortable.

“It’s really a mixed bag with the care providers,” Rebecca said, referring to the CNAs, the main caregivers but also the lowest rung in the nursing home hierarchy. “Some love and care for her and take the time to feed her and meet her needs. Others fear her and skip over her as a patient or try and put it off on somebody else.”

Rebecca said that she has witnessed CNAs taking as long as two hours to respond to a call for assistance from patients. Nedelcove said CNAs usually respond within minutes.

Because the law prohibits a patient from being restrained, the facility cannot legally set the brakes of Anne's wheelchair, to which she is bound by two straps.

As a result, Anne bumps into other residents in the dining room, knocks over food, and inadvertently hits people with her arms because of her chorea. To avoid these difficulties, Anne takes her meals in her room, Rebecca said.

Many of the CNAs have few or no qualifications, Rebecca continued.

Nursing homes hire "anybody off the street," she said, adding, however, that several good facilities exist for HD people in various parts of the country.

"It's an entry-level job," Nedelcove admitted, noting that it's "not a glamorous field."

"It's a calling rather than a profession," she said.

However, she emphasized that all Avamere CNAs receive academic and clinical training and are state-certified.

"Most of them come to us with a great deal of experience," she said.

A criticism of public agencies

In 2009, Anne was sent to the nursing home to recover from an operation needed after her HD symptoms had caused her to fall and injure her brain.

For a while, Anne had hospice care, as her weight had fallen to about 90 pounds. However, after her diet and weight improved, she no longer needed hospice.

Public agencies will not fund the 24-hour home care that would serve as an alternative to placing the patient in a nursing home, Rebecca explained.

"They will pay the nursing home over \$6,000 a month to pay for somebody to give such little attention to my mother that she could get strangled, but they will not pay for better care at the same rate in my home," she said.

Grossly misunderstanding HD

CNAs, Rebecca said, need better preparation in order to take "care of our elderly and the most vulnerable in society."

Those vulnerable include thousands of HD patients, who, along with their families, face enormous difficulties in finding facilities that understand the disease and will take in someone with HD.

Rebecca recalled her family's encounter with a past director of nursing at Avamere.

"They usually deal only in comatose patients, not the kind that can call down the hallway," she said. The nursing director told Rebecca that "my mother needed to stop calling down the hallway, because HD is not a crutch and my mom is responsible for her own behavior." The nursing director stated that if Anne couldn't control her calls down the hallway, she could be evicted from the home.

"If you even say the word Huntington's disease, nursing homes don't want to talk with you," Rebecca said, noting that most facilities focus on young people who are developmentally delayed or on the elderly, thus missing

the middle years, the period where most HD people experience onset of symptoms.

Rebecca worked to educate the Avamere staff about HD. She arranged for the facility's previous director to participate in HDSA-sponsored caregiving webinars. He passed on information about HD to many of the staff. This "gave them some enlightenment," Rebecca said.

However, because of recent high turnover at the home, including the removal of that previous director, few current employees have knowledge of HD, she said.

HDSA's response and recommendations

Staffers at the HDSA national office in New York expressed deep concern about the incident and are closely monitoring the situation in Coos Bay. However, HDSA cannot comment on the specifics of the case in order not to violate patient privacy.

HDSA urges families to carefully research facilities before placing a loved one. It provides a number of publications, articles, and other materials regarding long-term care on its [national website](#).

It also offers free in-service trainings for long-term care facilities.

As [previously reported](#), many in the HD community have asked HDSA to provide funding for care. However, with an annual budget of only \$8.5 million, the organization could not begin to provide such assistance. Families must rely on Social Security, Medicare, Medicaid, and other government programs, as well as long-term health care insurance and other private insurances.

(In a future article: how segments of the HD community have strived to provide better care for patients).

Posted by [Gene Veritas](#) at 6:20 PM



Labels: [Avamere](#) , [brain](#) , [caregiving](#) , [chorea](#) , [dementia](#) , [HDSA](#) , [Huntington's disease](#) , [Medicaid](#) , [Medicare](#) , [neglect](#) , [nursing home](#) , [Social Security](#) , [strangulation](#) , [symptoms](#) , [wheelchair](#)

7 comments:

Anonymous said...

Years ago, NJ had a dedicated ward in a nursing home just for HD patients. The staff had to request plane work assignment to work there and they received lots of training. Really, the employees seemed happy and we saw smiles and loving care. My M-I-L was there for 2 years and received excellent care. The total opposite of what this poor Anne received.

HD is such a complicated disease and as such, requires dedicated, compassionate, and educated healthcare workers to care for them.

Anne was neglected at Avamere, and if the state doesn't have appropriate homes that are able to provide appropriate care that meets the needs of HD patients, perhaps they too are negligent.

Good luck Rebecca and Anne. My thoughts and prayer are with

you. Lou (LBA)

8:38 PM, May 31, 2013

🌀 **Anonymous said...**

About 20 years ago a young man with hd was brought to Yale New Haven by the police, in a highly agitated condition. I think he was put in a straight jacket (can't remember the exact details) and he died. His death was ruled "a wrongful death". Because of this incident, CT now has a HD clinic at UConn. The services are (mostly) free. The staff is amazing- they "get" HD.
Lba

8:49 PM, May 31, 2013

🌀 **Anonymous said...**

This is just f*ckin disgusting. NOT ACCEPTABLE!!!!

11:57 PM, May 31, 2013

🌀 **Leanne Ritchie said...**

100% Neglect by this care facility!

11:09 AM, June 01, 2013

🌀 **Anonymous said...**

There has been a death from a similar neglectful situation in the Napa State Hospital, where my father resides. I would love to make a documentary regarding this type of crime against HD patients. Good luck with your advocacy.

6:03 AM, June 19, 2013

🌀 **Anonymous said...**

Nursing homes are a disgrace, I brought my son home. I get no assistance from the state for him although they paid the NH dearly. As soon as i brought him home his spend down amount for Medicaid services is over half of his SSDI. I pay a lady to come sit with him while I go drive my school bus in the afternoon. There is no help for families who want to take care of their loved ones at home. Could it be the powerful nursing home lobby in Washington and in the states?

4:25 PM, March 24, 2014

🌀 **Anonymous said...**

This is such bullshit. I understand the family is upset but Avamere is not to blame. CNA's have a tough job. There are two sides to every story. I have worked for Avamere for many years and we do not neglect our patients. We love our patients that's why we are there. It has nothing to do with the money obviously you have no clue how little we get paid.. This family has went above and beyond to destroy the Avamere name . This resident you are speaking of had a mental illness and I

understand she shouldve been place in a more appropriate facility. There is nothing any of us could do now .

5:59 PM, May 31, 2016

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