

Paralyzed accident victim fights for right to die

Man, 27, battles Froedtert Hospital to remove ventilator



Dan Crews of Antioch, Ill., was injured in a car accident at age 3 and can move only his head. Now 27, he uses a pointer to change the TV station and gets help from nurses and his mother. He's battling Froedtert Hospital because he no longer wants to live. Credit: Rick Wood

By [Tia Ghose](#) of the Journal Sentinel

Dan Crews wants to die, but he can't.

The 27-year-old Antioch, Ill., resident has been a quadriplegic since he was in a car accident at age 3. Paralyzed from the neck down, he can speak and eat, but his diaphragm muscles cannot move air through his lungs.

A mechanical respirator, a clear box filled with pumps and tubes, connects to his throat and breathes for him.

Every day, Crews lies in bed for hours, staring at posters of cheerleaders, watching sports he will never play. When he wants to make a call or use the computer, he asks his nurses to bring him the telephone, which he pecks at with a stick he holds in his mouth. When he's thirsty, he calls for a nurse, or for his mom, Cheryl Crews, who lives with him. They bring a drink and hold the straw up to his mouth for him as he sips.

"I have no friends. I have no education. No education prospects. No job prospects. I have no love prospects," he said. "All I want is to no longer live like this."

He is physically incapable of ending his life.

"I feel like I'm the only person in the country who does not have a way or an option to kill myself," he said.

For the last year and a half, Crews has battled Froedtert Hospital in Wauwatosa to remove his ventilator. Hospital psychiatrists and mental health professionals say he is depressed and must be treated for it before they will consider such an irrevocable step, according to his medical records. Crews said his desire to die stems not from his depression, but from his poor quality of life and the low odds that it will ever improve.

Crews' desire to die is not uncommon for people with spinal cord injuries, who often struggle to gain control over their own lives. Their suicide rate is two to six times that of the general population, depending on their specific situation. Their inability to end their lives themselves often compounds their sense of helplessness.

Yet stories like Crews' are troubling to disability rights activists. They argue his quality of life doesn't have to be inherently bad; rather, they say, society doesn't provide the resources for Crews and others to live a satisfying life.

On paper, those who wish to refuse life-sustaining treatment have more than 100 years of legal precedent behind them, said Norm Fost, a bioethicist at the University of Wisconsin-Madison. In hospitals around the country, dying patients and their family members quietly - and legally - make the decisions to forgo surgeries, remove feeding tubes and turn off ventilators.

"Courts have nearly universally recognized that right," said Laura Leitch, general counsel to the Wisconsin Hospital Association.

But Crews isn't a cancer patient in hospice care. Other than needing a ventilator to breathe, he is young and has no other life-threatening conditions.

Legally he still has the right to discontinue treatment, Leitch said. But in practice, it can be difficult for non-terminal patients to refuse lifesaving treatment.

Before doctors honor a patient's wishes, they must determine whether the patient is competent, and hospitals have broad leeway in determining competency, Fost said. Even if a patient is

deemed competent, there is no law requiring a specific hospital or doctor to withdraw treatment, he said.

"We don't like to see people with disabilities decide not to go on," said Art Caplan, a bioethicist at the University of Pennsylvania. "And people will put up road blocks and try to slow that process in every way they can."

Gradual decline

Crews received a \$4 million settlement after the car accident that left him paralyzed 24 years ago. He graduated from high school, earned an associate's degree from the College of Lake County, a local community college, and longed to be a criminal prosecutor.

But once he realized the logistical difficulties of schooling away from home, he let his courtroom dreams slip away, he said.

The money allows him to employ two nurses and live with his mother in his own house. But he spends all day watching television - a few hours in the morning in bed, and a few hours sitting upright in a broken chair. Most days he sees only his nurses and his mom. (Crews' parents are divorced and his father is remarried).

Financial concerns also have arisen.

"The amount of money he received right from the start was designed for a 20-year life span, and already it's been 24 years. I don't think anybody thought he would make it this long," his father, Gerald Crews, acknowledged.

Crews wants to leave what's left of the money to his mother as a legacy.

"At least if I were gone, I know she'd have enough money to take care of herself for the rest of her life," he said.

Before the money runs out, his best bet was to apply for Medicaid and have the program pay for his nursing care. But to qualify, he would have to be broke. The one way to get around this requirement is to put his money in a special needs trust set up for the mentally and physically disabled, said Tom Wilson, an advocate at the Chicago-based Access Living, an independent living advocacy group for people with disabilities. That means a trustee would legally make his financial decisions.

"With my life being so guarded that I can't have much privacy, there's always people watching over me, I wanted one thing I control," Crews said.

And unlike in Wisconsin, Illinois Medicaid often denies requests for the 24-hour care he needs to stay in his home, so he risks being put in a nursing home, Wilson said.

Still, Crews recently put his money in a trust and is applying for Medicaid.

Pursuit of death

The possibility of removing Crews' ventilator was raised in a meeting June 1, 2009, with William Waring, his spinal cord rehab physician at Froedtert. Crews has gone to Froedtert Hospital for medical care since he was taken there by Flight for Life after his accident. Froedtert physicians declined to comment on his case; the rest of his medical history comes from medical records he provided.

Waring referred him to a palliative care team at the hospital. As part of that process, several mental health professionals were required to see Crews to determine whether he was able to make the decision. Initially, palliative care doctor Sean Marks wrote in patient charts an impression that Crews was competent.

After about a month, psychiatrists and psychologists expressed concern that his money troubles and desire to help his mother were clouding his judgment, according to his records. They also wanted to treat him for depression. Crews refused treatment. He said it wouldn't change his decision and he couldn't afford the hassle and expense of visiting Froedtert regularly for treatment, according to records. At that point, talks between Crews and Froedtert stalled.

For the next year, Crews considered moving to states with death-with-dignity laws, but was told he would need to be a resident for six to 12 months before they would consider removing his ventilator, he said.

In June, he initiated a hunger strike - one of the few ways he can choose to die, but one that is agonizingly slow and painful. After four days, his body began to fail, his nurses quit, and his mother, distraught and unable to care for him, called Froedtert Hospital to get him admitted.

He finally resumed eating because he faced the possibility of having a feeding tube put in if he tried again, according to the medical records. Doctors at Froedtert told Crews he would need to have a year of counseling and treatment for depression before they would consider removing his ventilator; even then, they would not guarantee it, according to the medical records.

His father is torn. As a Catholic, he doesn't agree with Crews' wishes, he said.

"But from a father's point of view, I truly understand," he said. "I just think the life challenges have been mounting on him consistently to where, quite frankly, he's lost the will to live under the conditions he's in."

His mother does not want him to die. But she respects his right to make the decision. "I would rather the decision be his, and if he wants to (die), yes, I'll back him to the hilt; if he wants to stay, I'll back him to the hilt."

What is a life worth living?

In 1989, Larry McAfee, a Georgia engineer paralyzed in an accident, successfully argued before the Georgia Supreme Court for the right to have his ventilator removed. The state had put him in an institution, and McAfee deemed his dependent lifestyle not worth living.

Yet after winning his suit, he befriended a doctor at another institution, who persuaded him to give life another try. He found work, and was able to live independently for several years before dying of natural causes.

Some disability rights activists see the right to die as fundamental to independence. In the May 1991 *Western Journal of Medicine*, Andrew Batavia, a disability rights advocate who was instrumental in passing the landmark Americans with Disabilities Act, wrote that "people who believe they have no control over the fundamental decision to live cannot claim to have autonomy over their lives."

But many disability rights activists disagree. They say that right-to-die arguments are just veiled discrimination and are predicated on the assumption that disabled lives are not worth living.

"People who help people to die, like (Jack) Kevorkian, are heroes in some people's minds. He's a serial killer in my mind," said Wilson, of Access Living.

In one study, about 68% of people who experience a spinal cord injury are either very or somewhat satisfied with their lives. To independent living advocates, the underlying problem is the lack of autonomy and dignity afforded to patients with high-level disabilities.

"The reality is they shouldn't have to live that way, and we should provide the services that make people's lives bearable," Wilson said.

Those arguments are academic for Crews, whose discussions with Froedtert have stalled, and who is waiting to hear about his Medicaid. He rarely leaves the house because his motorized wheelchair is broken. He agreed to take anti-depressants a few months ago, but said they have not changed his outlook or wishes.

His mother said his discontent is plain to see.

"I can put myself into his shoes every day, and he's just not happy anymore," she said.

Nov 28, 2010

Quadriplegic Dan Crews Swamped With Letters: Don't Die

- By Susan Donaldson James

Dec. 7, 2010

Dan Crews, who has been a [quadriplegic](#) since childhood, has been swamped with handwritten letters, e-mails and phone calls from well-wishers who don't want the 27-year-old to die.

Crews, who lives with his mother in Antioch, Ill., is paralyzed from the neck down and is begging doctors to take him off the mechanical ventilator that allows him to breathe.

For the last 18 months, he has been fighting a losing battle with officials at [Froedtert Hospital](#) in Wauwatosa, Wis., where he has been treated since the age of 3.

He has the legal right to refuse treatment, but only with the blessing of his doctors. They say he is too depressed to make that decision.

But since ABCNew.com ran a story on Crews' dilemma, letters have poured in, most telling him to "keep the faith."

"It's been very pleasant, but my mood is the same," he said of his decision to die.

Many of the cards have been religious in nature: "God has a purpose; I hope you change your mind."

Crews, who is Lutheran, said he used to believe in God, "the devil, heaven and hell, faith and sinner and angels."

"Now, I think God is a distant relative who doesn't return phone calls and e-mails," he said. "I believe he exists, but doesn't listen."

Crews spends most of his time in a dark room with his legs strapped down to his bed, unable to do much except eat and watch television. He can operate a computer with a mouth piece.

Calls and cards have come in from as far away as Colorado, Texas and Seattle, including one woman whose husband has been a quadriplegic for 25 years.

"We'd like to be an inspiration to Mr. Crews," said Donna Jackson, 46, of Oklahoma City. "He has a purpose in this life."

She pledges to visit Crews personally if someone can donate a handicapped vehicle so the couple can drive from Oklahoma to Illinois.

Jackson met her husband in a nursing home where he was being rehabilitated after being shot in the head. "He had to learn to talk again," she said.

"There's nothing he can't do because he is a quad," she said. "My husband and I go everywhere: out to dinner, to social functions and have even traveled several times as far as California and Texas."

Jackson believes she can inspire Crews, if only she could arrange a meeting.

"I am really hoping he can hear my husband's testament," she said. "There are so many things available to him."

Many Spinal Cord Injury Patients Consider Suicide

An estimated 5 to 10 percent of spinal cord injury patients contemplate suicide, six times higher than in the general population, according to the [Kessler Institute](#) in New Jersey, one of the nation's top rehabilitation centers. It is where the late actor Christopher Reeve was treated, after he was paralyzed in a riding accident.

Crews became a quadriplegic after a car accident 24 years ago. No one expected Crews to live as long as he did, according to his mother. She was at the wheel when the car swerved off a slick country road into a ditch.

Cheryl Crews punctured a lung and broke her neck, but Dan, strapped in to his car seat, "came out looking like he hadn't even broken a bone."

"But he was all blue and they had to breathe life back into him," she said. He has needed a ventilator ever since.

Despite paralysis, Crews said he had a happy childhood. He was an honors student in high school and earned an associate's degree.

After the accident, the family won a lawsuit and received a \$4 million trust to take care of their son's medical expenses.

"We were told to bring him home and make his life count and to make him happy, because he wasn't going to live very long," said his mother.

Nursing care -- four a day working 92 hours a week -- has cost the family \$300,000 to \$500,000 year.

With the medical expenses and the economic downturn, the trust fund ran out, dashing any hopes for further education, seeking the second opinion of new psychiatrists or even a legal fight against the hospital.

The family has applied for Medicaid and worries Crews might end up in a nursing home.

"I would be lying if I said money was not a part of it, but that's never been the only reason," said Crews. "I am just tired of living like this."

Only in the last several years has he become despondent, mostly over the mounting bills that have overwhelmed his family.

Quadriplegic Dan Crews Still Wants to Die

He insists he will not change his mind about dying, unless someone can "donate millions and millions of dollars and help pay off my major debt."

Crews and his mother owe more than \$100,000 to the hospital and are behind on their mortgage and utility bills. His mother can't work because she helps care for her son, along with the two nurses.

Cheryl Crews, who is 60, is willing to stand by her son. "In the end, if this is what he wants, I have promised to support him," she said.

His parents are divorced and a 31-year-old brother, who lived with them, is soon leaving home.

His father, Gerald Crews, told ABCNews.com that he cherishes his son, and couldn't accept his decision to die, a sentiment shared by total strangers who have responded to Crews' story.

One woman from Seattle wrote Crews, "The world is in need of you."

"Please never give up hope," wrote another with no return address. "Please never give up hope. It's the reason you were put on this earth."

Another man from Boulder, Colo. sent photos and shared his love of sports with Crews, who is a Denver Broncos and Chicago Bulls fan. "I was touched by your story," he wrote. "I hope your Thanksgiving was nice."

"I am so sorry your life is so difficult," wrote a woman from Fort Worth, Texas, whose husband killed himself after a cancer diagnosis. "I really encourage you. Your life has great value beyond understanding."

One of her co-workers was a quadriplegic after an accident, and she wrote, "He was so inspirational for me and others."

"You are thinking your condition might not have impact or value in the future," she wrote. "But that is a lie. You made an impact on me that I stopped what I was doing to write you."

Crews, who has an independent streak and droll sense of humor, dismissed a suggestion that he could help other quadriplegics.

"I don't like talking to paralyzed people," he said. "They are too self-pitying."

For now, Crews is adamant about removing the ventilator, but continues to show an interest in his favorite television shows, "Big Bang Theory," and "NCIS."

He likes music from the 50s and 60s and his favorite movie is the 2004 film, "National Treasure."

The letters and thoughts from strangers are surprising, but welcome.

Quadriplegic fighting for right to die moving to care facility



Dan Crews has been trying for two years to get Froedtert Hospital to remove his ventilator, after years of his disability. Because he can no longer afford in-home care along with his existing medical debt, he is planning to move to a long-term care facility. Credit: Rick Wood

By [Tia Ghose](#) of the Journal Sentinel

Dan Crews, the quadriplegic fighting to have his ventilator removed, is planning to move to a long-term care facility sometime this week, he said. He must sell his Antioch, Ill., home in order to pay a mountain of medical bills from the last several months.

"I feel horrible about it, but it doesn't look like there are many options," Crews said. Even if he somehow managed to pay off his bills, he estimates that he would need \$10 million to live out his life.

Crews, a quadriplegic since he was in a car accident at age 3, uses an artificial respirator to breathe. He began a battle to die over a year and a half ago with Froedtert Hospital in Wauwatosa. Crews wanted the hospital to remove his ventilator because he deemed his quality of life poor and did not anticipate it ever improving. Physicians at the hospital worried that depression and money concerns were clouding his judgment. He initiated a hunger strike last summer, which ultimately failed.

After [the Journal Sentinel published Crews' story](#), he was inundated with supportive letters and phone calls. Some people even offered to help him with his expenses.

Two radio programs interviewed him, and one, Marc Germain's Talk Radio One, liked Crews' on-air presence and television savvy, so they gave him a spot on a weekly TV and movie review program. He did his first show two weeks ago.

"I had a ball," Crews said.

A nonprofit organization called the Wheelchair Recycling Program read about Crews' broken chair and began the process to get him a new one, although that is still up in the air, he said.

But his financial situation was worsening by the day. He applied for Medicaid several months ago, hoping that it would pay for in-home care. If the application is approved, Medicaid would pay for 16 hours of nursing care, with his family picking up the rest of the time. As of Thursday, his application was still pending.

A week ago, his money completely ran out.

Meanwhile, he already owed Froedtert roughly \$100,000 for his two stays in the hospital (one was during his hunger strike and another was an unrelated emergency visit). He owes Assured Healthcare, his home nursing provider, at least \$25,000, he said.

Because he can't pay what he owes, Crews doesn't know how much longer Assured Healthcare will provide care. He has already dropped from round-the-clock staff to just one nurse overnight. His family scrambled over the past week to take care of him. From 8 a.m. to midnight, his mother looks after Crews. His father, Gerald Crews, also spent about 20 hours last weekend caring for his son, he said.

When his family sat down to look at his bills, they realized there was no way Crews could pay what he owed. It was simply too much.

Crews plans to sell his house in Antioch and all his other assets to pay off his debts.

This isn't the end of money troubles for Dan's mother, Cheryl Crews.

"I don't have any money, I don't have a job, I don't have any health insurance. It's all gone," Cheryl Crews said.

She will also have no home once they move out. Initially, she had planned to live in her minivan, but now her ex-husband, Gerald Crews, has offered her the possibility of staying in an apartment he owns while she gets back on her feet, Crews said.

Meanwhile, Dan Crews is making his peace with the impending move to a long-term care facility. He is considering Alden Estates in Barrington, Ill., (He has not yet applied and doesn't know whether the facility will provide the round-the-clock supervision he needs.)

"It's the last thing I wanted for him," Cheryl Crews said.

Dan Crews doesn't know how much independence he would have in the facility, whether he will get along with the people there, or how often he will be able to see his family, he said.

"I imagine I'll stay there for the rest of my life, however long that is," Crews said. "I have no idea what to expect."

Jan 8, 2011