

The Last Day

By Cindy Gabbert

There are moments in your life that cause you to pause, and then there are moments that stop you right in your tracks. I had an experience that has not only given me cause to pause, but to stop and reflect on the life we are given and how we decide to live that life. His name is Charles Harris. He was featured in the March issue of The Independent (article on page 3). Charles was an optimist. He saw the glass as half full even though his life was filled with many challenges. I was with Charles on Friday, June 1, 2012 when he took his last breath. I would like to share what I learned from Charles, but first let me share with you what happened a week prior to his death.

Charles was back in the hospital and I was visiting him when he told me he wanted to have a discussion to “prepare me.” His hospitalizations had become more frequent and were longer in duration. This time he was not bouncing back like he had before. Charles had made a decision to end his treatments and to “move on to the other side.” “I’ve had a lot of time to think,” he said. “Why stop the inevitable?” This also allowed Charles the opportunity to say goodbye to me and others close to him. As Charles said, “There’s so little opportunity to decide something like this. I want to make the most of it. I’m satisfied; I’m content.” What powerful words those were for me to hear from him, to learn from him, and now to share with all of you.

Independence meant so much to Charles. During his last few days, we talked about his thirteen months living in his own

apartment. Independent living wasn’t always easy for him, but as he shared, “I was shriveling up in the nursing home.” Since 2010, he kept his focus, advocated for himself, and never gave up until his body said it was time to transition to another stage in his life. That brings me to his last day, June 1, 2012.



Charles Harris

When I arrived at the hospital, Charles was asleep. I had brought a book I was reading called *The Energy Bus*, by Jon Gordon. I had just started reading it when Charles woke up, and he asked me to read it to him. Charles always wanted to learn, and this day was no different. During his last day, Charles remained an eternal optimist. He was calm and at peace with himself and his life. He had learned to make his own choices and decisions and right up to the end he had a plan. He had things in order, including his advanced directives. He smiled throughout the day even when his eyes were closed. I read off and on and then about an hour and fifteen minutes before his death, one paragraph moved him enough and he opened his eyes and spoke some of his last words. “That was nice,” he said. Here is the paragraph:

“It’s because I love life, it’s because I love you. And it’s because I love me. How can I love myself if I don’t love you? How could I love myself if I don’t love everyone? You see, we’re all connected and I love it all. Even the ones who are hard to love.”

– Jon Gordon, *The Energy Bus*

Rest in peace Charles Harris, and thank you for all of the gifts you have given me and all of those who have had the fortune to cross your path.

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INSIDE

From Where I Sit

By Nate Aalgaard,
Executive Director

At age 22, the ADA is still ignored

For me, 1990 seems like a long time ago. People have been born, graduated from high school, and finished college since then. Surely in all that time the basic accessibility problems that the Americans with Disabilities Act (ADA) was intended to eliminate would be a thing of the past. Not so--not by a long shot.

Here are a few recent examples. First, a coffee shop in Jamestown ignores official letters from the City that they need to come up with a plan to provide access to people with mobility impairments. Eventually a citizen files a complaint with the ND Department of Labor, which conducts an investigation and determines that a reasonable cause of discrimination exists. The Attorney General's Office is now involved.

A new restaurant mere yards from Freedom's Fargo office opens. I go there for lunch, only to find only high top tables, completely useless to wheelchair users such as myself. They pledge to fix the problem. I'll be back to check.

Another new Fargo pizza restaurant opens with a few patio tables. Again, all high, and these are even worse. You can't even get close because the seats are attached to the tables. A small town bar I drive by frequently puts on a huge patio, with no ramp. I suppose nobody in a wheelchair goes there anyway. Of course not.

The U.S. Justice Department recently announced an extension for owners of existing swimming pools to comply with the 2010 Americans with Disabilities Act (ADA) Standards for Accessible Design. Pool owners now have until Jan. 31, 2013 to comply. The new standards were developed to ensure that buildings and facilities - including swimming pools - are accessible to more than 54 million individuals with disabilities. The department will issue a technical assistance document in the near future to help pool owners understand and comply with the requirements. The hotel industry has been fighting these regulations, in effect, refusing to provide equal access to guests with physical disabilities.

Do you sense some frustration? You better believe it. We've got a lot of work to do here. We need people who care about basic fairness to advocate for equal access for everyone, including people who have mobility impairments. Like I pointed out to one establishment, accessible tables (low enough to work for someone using a wheelchair) are also good for kids, and people with arthritis and other conditions. Sometimes it seems we are

stuck in the past--being ignored.

But then there are rays of hope. Just the other day Joyce, my coworker in Wahpeton, told me a story of how the Chamber of Commerce is embracing the issues of equal access for their "Crazy Days." They are going to start a campaign to make sure the curb cuts stay open and people can get around without being stopped by racks of merchandise and other obstructions.



Nate Aalgaard

On a recent trip downtown Fargo through a construction zone I came across, believe it or not, temporary ramps. It was great. I just went down into the street and up onto the sidewalk again a few feet further down. No problem, thanks to someone having the awareness to think about accessibility.

Yes, there is some progress, albeit much slower than some of us would like. As the 22nd anniversary of the ADA comes on July 26, let us as advocates do what we can to be out there educating people on our rights and if necessary filing complaints to enforce the law. If we don't do it, who will?

To Know

- 1) According to the Bureau of Labor Statistics, the disability workforce shrank by over 10% during the recession, five times faster than the non-disability workforce.
- 2) Only about 37% of working age adults with disabilities are in the workforce.

End of Life Decision Making

In remembrance of Charles, we'd like to provide others with some important information on the importance of being prepared for end of life decision making. The following information was obtained from the National Hospice and Palliative Care Organization.

Q: What is an advance directive?

A: "Advance directive" is a general term that describes two types of legal documents:

- 1) Living Will
- 2) Healthcare power of attorney

Q: What is a living will?

A: A living will allows you to put in writing your wishes about medical treatment for the end of your life in the event that you cannot communicate these wishes directly. Its purpose is to guide your family and doctors in deciding about the use of medical treatments for you at the end of life.

Q: What is a healthcare power of attorney?

A: The person you appoint usually is authorized to deal with all medical situations when you cannot speak for yourself. Thus, he or she can speak for you if you become temporarily incapacitated.

Q: Why bother with an advance directive if I want my family to make the necessary decisions for me?

A: Depending on your state's laws, your family might not be allowed to make decisions about life-sustaining treatment for you without a living will stating your wishes. Some states' laws do permit family members to make all medical decisions for their incapacitated loved ones. However, other states require clear evidence of the person's own wishes or a legally designated decision maker.

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Q: When will my advance directive go into effect?

A: Your advance directive becomes legally valid as soon as you sign them in front of the required witnesses. However, they normally do not go into effect unless you are unable to make your own decisions.

Q: How can I change what is in my advance directive?

A: If you want to change anything in an advance directive once you have completed it, you should complete a new document. For this reason you should review your advance directive periodically to ensure that the forms still reflect your wishes.

Q: What should I do with my completed advance directive?

A: Make several photocopies of the completed documents. Keep the original in a safe but easily accessible place, and tell others where you put them.

Charles Harris and his Journey to Independence

By Tyler Axness

What life holds for us and the road we take through it is very uncertain. I don't think I've met one person in my life who has ever been certain they'll spend their later years in a nursing facility. If someone does talk about "going into the home" they're usually joking about a period in their life way off in the distance. You know, "down the road." But what if being placed in the home happens much sooner, say when you're in your mid 50's? That's when Charles Harris found himself in the confines of a local nursing home thinking it would be impossible to get out.

Today, Charles lives in his own apartment. I wanted to find out how a middle-aged man was placed in a nursing home and how he successfully got out, so I went to his apartment to have a visit. As I rode the elevator to his 9th floor apartment, questions began to enter my mind. My anticipation grew as I knocked on the door and a soft voice told me to come in. Everyone has a story to tell and I couldn't wait to hear Charles'.

Bright colored drawings filled Charles' apartment, accompanied with homemade woven hats. I took a seat and asked how he was doing. "I'm just happy to be a part of the land of the living," he quickly responded with a smile. That's when I knew it was going to be a lively conversation.

Charles was born with juvenile rheumatoid arthritis (JRA), a disability that limits his range of motion throughout his body. Due to his disability, Charles' hands are naturally closed and he struggles to lift his head fully. My thoughts went back to his colorings on the walls and the hats he had crocheted and determined he must have patience to complete such beautiful work.

Early in his life, Charles lived in Washington D.C. where he worked at the Department of Labor for over 10 years. After 10 years, his disability began

to take its toll and he had to stop working. He had to apply for Social Security, which he still receives. Because of his loss in income Charles looked at the Section 8 housing program across the country. Mandan, ND, was on the list and eventually was the first to respond. "Fate brought me here," he said. "I've loved North Dakota since day one; I think it was meant to be."

However, it was when Charles moved to Mandan that he began to struggle with personal challenges. After much deliberation, he was told to go to Cooperstown for treatment. After a full year there, Charles ended up living in a nursing home in Fargo. I asked what it was like in a nursing facility. "Once you know the ropes it was ok, I got along with the other residents, he said." But there were difficulties. "Sometimes, aides would walk right by. They also had rules about automatic chairs. I had to go through a lot of red tape to be able to use one." Due to arthritis in his hands, he needs the power wheelchair to get around.

"I'm so grateful for Freedom and this whole program."

A lifelong battle with juvenile rheumatoid arthritis has caused other disabling conditions for Charles. He had both legs amputated because of stasis ulcers that affect a person's lower extremities. He believes that poor circulation to his legs was a result of his JRA. The loss of his lower legs demanded the use of his power chair even more.

The conversation turned to successfully removing himself from the nursing home and how Freedom helped facilitate this transition. Cindy Gabbert, one of our Independent Living Advocates, approached the social workers at Charles' facility to talk about the program Money

Follows the Person (MFP). To summarize, MFP is to assist people out of a nursing facility and into their own home or apartment. Freedom Resource Center contracts with the North Dakota Department of Human Services to facilitate MFP transitions.

Cindy learned of Charles' wishes to live in his own place through her conversations with the social workers. "I just wanted to know my options," Charles had told the social workers. Together, Cindy and Charles began the conversation about moving to his own place. "The most difficult thing about this process was being in the right frame of mind. Decisions are mine, I'm responsible and I wouldn't be controlled like in the nursing home, Charles said." He also explained he was concerned about his physical safety if he was to live on his own without the immediate care he could rely on in the nursing facility. He pondered his options and decided he wanted to do it.

"With Freedom, I've realized there are so many programs and services I can utilize in the community," he said. "I'm so grateful for Freedom and this whole program (MFP). Without it, I think I would have just stayed in the home. I don't think I could have made the transition without you guys."

We are approaching one year of Charles' successful transition to independent living. Through the assistance of Freedom, Charles has bridged over obstacles and utilized programs to ensure his independence. Two prosthetic legs await the start of rehabilitation in Charles' closet. "Next time you see me, I hope to be up walking around," he told me as our conversation drew to a close. In July, Charles will celebrate his 58th birthday, a birthday he can celebrate wherever he wants because of his returned independence.

Information

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RETURN SERVICE REQUESTED

*“Helping Bridge Your
Path to Independence”*

What’s Wrong With This Picture?



Summer in the upper Midwest can be short, so when it is here we like to enjoy the weather at our local restaurant patios. Unfortunately, not all patios have accessible tables for people with mobility impairments. This photo shows a restaurant in Fargo that has three raised tables with connected chairs. There are no low tables meaning many people with disabilities cannot sit at this patio.