

US face transplant patient promotes organ donation

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Connie Culp, who underwent the first face transplant surgery in the U.S. talks with the Associated Press at the Cleveland Clinic on Tuesday, Sept. 14, 2010 in Cleveland. The woman who had the nation's first face transplant is asking Ohioans to register as organ donors. (AP Photo/Jason Miller)

(AP) -- There is an initial shock upon first glance at Connie Culp, the woman who received the nation's first face transplant nearly two years ago. She taps her way through the hospital waiting room, feeling along the floor with a cane and smiling hesitantly at a visitor, even though she can only make out shadows and shapes.

Her face is wide and square-jawed. It is altogether too large for her diminutive frame, and therein lies the jolt of surprise: Up close, it's clear that this face does not belong to that body.

Her nose is long and straight. Her skin is cream-colored and smooth. She's wearing a soft gray shirt with a rhinestone brooch pinned to the collar. Ever since her husband shot her in the face in 2004, Culp doesn't concern herself with what other people think of her appearance.

"It don't matter what you look like, somebody's gonna find fault with you," she says, waving a hand dismissively. "Either the way you talk or something, you know? Nobody's perfect."

Life is on the upswing for Culp, 47, who underwent her final surgery in July. In an interview with The Associated Press on Tuesday at the Cleveland Clinic, Culp discussed her plans to become an advocate for [organ donation](#). It was the choice of one anonymous donor that spared her from a life of eating and breathing through a tube, she says.

"My whole family had a hard time even coming around me because of the way I looked," she says. "We're closer than ever now." She stops, looking uncomfortable. "I mean, I hate to say that about my family. But it's hard."

The most recent surgery - essentially a face-lift - removed the flaps of skin that hung from her cheeks and chin, which weighed down her face and caused frequent headaches. The result, to her delight, is a face that's much thinner and more shapely. She can smile more easily now. She can feel the lips of her 3-year-old grandson when he kisses her on the cheek. And she recently ate a steak for the first time in years.

"This is still swelling from the surgery," she says, touching her round lower cheeks, "so this will eventually go down, too."

Her voice is muffled and slurs a bit, owing to the slow movement of her jaw. The nerve endings in her face are still growing back, so some patches of skin are more sensitive than others. Part of her recovery

involves facial exercises that teach her face how to move again.

In photographs taken before the transplant, Culp's face was gnarled. Her nose was destroyed. All vision in her right eye was gone. The blast shattered her cheeks, the roof of her mouth, her lower eyelids, her upper jaw and her palate. All that remained were her upper eyelids, forehead, lower lip and chin.

Thirty operations later, she still couldn't eat solid food or breathe on her own. Doctors had installed metal screws where she was supposed to get new teeth.

"I never received the teeth," she says. "So I kind of looked like I was a dragon or something. I had this nose that come down straight with the little holes in them. I looked pretty bad."

It was difficult for her family to see her that way, knowing they could do nothing to ease her pain, Culp says.

Then, in December 2008, she was told that doctors at the clinic had found a donor: a woman about her age who had recently died. That's all Culp ever learned about her donor.

In an operation that took 22 hours, a team of doctors used that woman's face to replace 80 percent of Culp's, using the bone, muscles, nerves, skin and blood vessels. It was the world's fourth [face transplant](#). Without that donor, Culp says, she might have waited years more for another match. The surgery gave her the freedom to eat solid food, drink from a cup, smell, taste, breathe on her own and smile.

"Just one person can make a difference by donating your organ," she says.

Earlier this week, Culp spoke at an event organized by LifeBanc, a nonprofit organ and tissue recovery organization in northeast Ohio. In this new phase of her life, she plans to do more advocacy work on behalf of organ donation. She already had signed up to be an organ donor on her driver's license before she was shot.

During the interview with the AP, she frequently refers to that time "before" - before her husband shot her, then turned the gun on himself. Her husband, who is serving seven years in prison for attempted aggravated murder, is set to be released in October 2011.

She prefers not to answer questions about him, yet speaks of him as if he might be waiting for her outside.

"Oh, I used to cut wood and everything with my husband," she says. "We'd have fun out in the woods."

Together they ran a painting business in the small town of Unionport, near the Pennsylvania state line. They painted everything from fast-food restaurants to schools, their children often pitching in to help. Later, they bought a tavern.

"We should've stuck to painting," she says.

She misses that. And she misses being able to read and mow the lawn, one of her favorite things to do when her eyesight was clear.

But she can play with her grandson, Maddox, a little boy who never knew his grandmother before her face was destroyed, when she was a pretty brunette with high cheek bones and a wide smile.

After her most recent surgery, Culp pulled down her face mask and showed Maddox the changes. He said, "OK Grandma," and happily

climbed onto the bed next to her.

"Don't you wish all people was like kids?" she says.

She still gets headaches sometimes, usually when it's very hot or very cold. In the years to come, she will continue taking immune-suppressing drugs and having regular checkups at the hospital.

As Culp ambles down the corridor, heading for the elevator, doctors and nurses stop to hug her. Here, she is a celebrity, a symbol of the marvels of modern medicine. Someday she would like to meet Isabelle Dinoire, a French woman who underwent the first partial face transplant in 2005.

"I haven't really met anybody that had transplants yet," she says. "I'm looking forward to it."

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