A good friend and I went to see the "Bodies" exhibit at the Carnegie Science Center last week. It was a stark, discomforting display.

About a dozen human bodies sliced, diced and laid bare.

As Ann wheeled me around from display case to display case, all I could think was, "If this was done to these people, why not to me?"

You see, the dignity and beauty of their bodies had been deconstructed. Now they looked like sides of meat, or worse, road kill.

Along with their former humanity, another commonality they appeared to share was that they had died from diseases. Several had ugly, black lungs. A few had scarring on their hearts. One severed head had a scarred brain.

I too have a disease that threatens my life.

Over the last year I have developed onset amyotrophic lateral sclerosis, or Lou Gehrig's disease. The disease got its nickname from the great New York Yankee first baseman who died from it in 1941.

The cause of the disease is unknown. So is a cure.

About one in 30,000 Americans have the malady at any time and about 5,000 are diagnosed annually.

What happens is that the body's motor neurons, cells that comprise the strands of nerves attached to voluntary muscles, cease functioning. Those are the muscles that move limbs; hands and fingers; feet and toes; tongue and lips. Eventually the diaphragm freezes, too. Only the eyes continue to move normally. Fortunately, or unfortunately, the mind is not impaired.

When the diaphragm stops helping the lungs breathe, the person with Lou Gehrig's either gets permanently fitted for a respirator or she dies.

In 2005, when my tongue began feeling lazy and then in 2006, when I started tripping because my right ankle kept giving out, I had no idea what was happening. In fact, I attributed the tongue thing to dental work I'd just had and the ankle trouble to a slip in the bathtub.

What was worse, though, the neurologist I went to see in December 2006 hadn't a clue either.

Also known as ALS, the disease is notoriously difficult to diagnose. I did not get a positive diagnosis for six months despite seeing three neurologists and an otolaryngologist.

By then, I needed an appliance to keep my foot from dragging and was unable to process the half-gallon of saliva we all produce every day.

Once told, I didn't despair, exactly. My husband and I have cried and at first we tried to fend off the shock.

Of course, it was an unexpected blow, one that has changed our lives drastically. For instance, everything takes longer to do. I cannot run or dance anymore. I cannot speak. I take an array of supplements in hopes of slowing the disease's progress and I cannot eat anything with gluten for the same reason. Both seem to be helping some, although I need a wheelchair for long distances. I still walk with the help of a cane, however, and I am driving safely. I can still type, obviously. I am still cooking for...
my dear husband, too.

It's not something I'd wish on anyone else, but I know that it is God who decides these things and he is not known for mistakes or for unkindness. Even now, I know that he can make my troubles someone else's blessing, perhaps via this column.

Anyway, to get back to the "Bodies" presentation: The show got me to thinking about the fact that these people probably had families they loved, jobs, hobbies, favorite foods, favorite games, favorite places to be, etc. But here they were trussed up like eight-point bucks at a hunting camp.

It seemed wrong.

Some of those bodies could've housed minds capable of changing the world. And, even if their hands had only caressed the cheeks of grandchildren or rubbed the back of tired spouses, aren't the memories of such tenderness worth some reverence? Because they died, had their dignity suddenly been stripped away? Were they now simply so much useless flesh? Or were they useless flesh even in life? If so, where does that leave me?

I guess these are the kinds of things you think about when you become conscious of your mortality.

In the weeks to come, I hope to continue to chronicle here the developments of this disease and my subsequent observations. And I promise, sometimes I will be amusing.

Staff writer M. Tinsley-Crabb can be reached at health@post-gazette.com.

First published on February 13, 2008 at 12:00 am