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McBryde Johnson

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Worth Living
Harriet McBryde Johnson

Permit me to introduce myself. I am your worst nightmare. Nervously you ask why. I'll tell you, but be patient. First you need to know a few facts.

I inhabit one of the world's truly interesting small cities. For 12 years, I've been a self-employed lawyer. Freely I do what I please, when I please. I can undertake work that doesn't feed anyone's bottom line but satisfies my curiosity, my vision of justice, my sense of fun. Yet still, I have enough money to get everything I need and most of what I want.

You might call me better off dead.

As a local political functionary, I'm situated to hear good gossip. In election season, I have my choice of crab cracks, fish fries, and barbecues. I have marched in the East Side Community Parade, right behind the banner ladies, alongside the local Nation of Islam Imam.

You might say I have no quality of life.

I've eaten couscous in Paris, feijoida in New York. I've stared into the murky depths of Chichen Itza's Well of Souls and over the bright expanse of Havana's harbor. I have friends activist and contemplative, practical and theoretical, spiritual and profane, Socialist and Democrat and even an atypical Republican or two. If something fails to give me pleasure, I generally avoid it.

Does my life strike terror in your soul?

Chances are. Because there's more. Things I'll tell you now.

I can't move most of my body parts. My flesh is shockingly withered. Every morning, someone turns me over in bed, slides a bedpan under me, then cleans me up. She gives me a bath, puts clothes on me, lifts me into a power wheelchair. Without help, I'd be bed-ridden.

Oh yes. Disability, dependence. That's it. The fate worse than death.

Now that you know, will you look at me with horror? Will I

become in your mind a grotesque symbol of what happens when a person is kept alive who should have died long ago?

Maybe. Because there's something else. Some people - maybe you - consider me terminally ill. I have one of those neuromuscular diseases Jerry Lewis sobs about on his Labor Day telethon. It's progressive and incurable. Unless something else kills me first, it will prove fatal. I've had this "killer disease" for 43 years now.

So. Imagine it happens to you, or to your parent or child or the love of your life. What do you do? Rush out to buy *Final Exit*, the best-selling cookbook for quick and easy outs? Join the Hemlock Society's lobby for insurance reimbursed end-it-quick services? Hope they let Jack Kevorkian out of prison before it's too late?

Wait a minute, you may protest, I'm not like that.

OK. Maybe you're not the stranger who stopped me on the street, just the other day, to say you don't know where I find the courage to keep on going. Maybe you've never told me, flat out, that you couldn't handle living the way I do. Maybe you've never thought life would be unbearable without whatever abilities you have now, or that you'd be better off dead if you couldn't take care of yourself. Maybe you've never considered it "an act of mercy" when someone kills a disabled family member or makes it easy for them to kill themselves.

Maybe you haven't. But if you have, I'm talking to YOU.

Clearly you have no idea what it's like to live in a body like mine. I guess I'm just as clueless about you. I don't know where you get such ideas.

Here's one I hear a lot. You think it's humiliating, degrading, undignified, to let another person wipe your behind. I know yours is a common attitude, but to me your revulsion seems - well - neurotic. What's the deal? When you can't wipe yourself, of course someone else does it for you. Did you degrade your infant child when you wiped that silky rump nice and clean? Were you degraded? Certainly not. There's no shame, and without shame, there's no humiliation.

If you don't believe me, believe the Sun King. In periwigs and silk brocade, Louis XIV's noblemen competed for the privilege of tending to his personal hygiene, even though he was perfectly able to do it himself. Personal assistance can be a grand luxury. It brings physical sensations that are not the least bit unpleasant. If you'd open up your imagination, you'd probably come to envy my morning routine.

But, you say, you're not me. You're not Louis XIV either. You're not in the habit of having people in your intimate personal space - except for your lover, and that's different. OK, I'll give you that. And, sure, for you life's details have always been simple. You lack the organization needed for a life like mine. You lack logistical savvy. But you could learn.

Why do you deny it? You'd adjust. People do. You'd survive the realization that things are different, and going to get more complicated, more *interesting*, than anything you've ever known.

It takes time to see the possibilities, to throw away the prejudices of your former life, but it happens. Naturally.

Now, I confess I haven't experienced big transformations; I was born this way. However, running with a certain crowd has taught me a few things. For one thing, I know that with time even the most foolish, obtuse "normal" person can evolve into a very decent quadriplegic. I don't write anyone off. Not even you.

Once, a quadriplegic told me about the person he used to be. "That guy didn't want to live the way I live now. People told him he'd adjust, but he wanted to die. So he died. I'm someone else now. He had no right to make decisions for me." Now the quad who became my law school friend is dead too, but he had a great run. I'm glad he underwent his transformation back when suicide was messy and difficult and no one bought him a helium tank.

But, you say, it's a matter of choice. Individual rights.

Sounds nice. But you're progressive; you read *Point*. You recognize that "choices" are structured by oppression, that true freedom is possible only in the context of equality. Society encourages some choices, discourages others, often based on prevailing prejudices.

So let me ask you: What do you say... When a new widow doesn't want to go on without her husband? When a drug addict is sick of life in the streets? When a poor person is beaten down by despair?

Do you say, Go for it; I'll get you a prescription? I think not. You want these desperate people to transcend loss, conquer circumstances, fight back. You value their struggle. You think supporting them is essential to building a society fit for any of us to live in.

So why is it different when it's one of my kind?

You answer, Some problems can be solved, some sorrows relieved, but these disabilities and illnesses are incurable. There's no other solution.

Have you forgotten already? Some of us live long, interesting, incurable lives. Being incurable isn't so bad. Believe me. I know.

OK, you say, they're terminal. They're going to die anyway.

And you're not? Forgive me, but dividing the world between the living and the dying makes no sense.

I wish you'd purge your brain of the things you *think* you know and ask why real people "choose" death. When you get the facts, you find it's not disability. Typically, it's not even pain - although lack of access to narcotics and palliative care can be part of the story.

More often, it's being dependent on an abuser. It's being abandoned. It's watching unpayable bills pile up. It's being denied a chance to be useful. It's being told you are worthless. It's being locked up in an institution. These are the things that cause despair. Too often, they come with disability. However, even with the most severe disability, these miseries are hardly inevitable. When they come, they are hardly incurable.

The cure has been discovered. It's quite simple. All it

takes is money. Money well spent.

Cases in point: Larry McAfee and Ed Roberts. Two men, paralyzed from the neck down, breathing on respirators. Roberts, a founding father of the disability rights movement, revolutionized human services with Hell-cat gusto. McAfee, with the help of the ACLU and mass media, became the avatar of life-not-worth-living and poster child for the right to die.

Same disabilities, different lives. What made the difference? Money. Specifically, who controls the money.

McAfee, dependent on Georgia Medicaid, spent years being shunted between a hospital and a nursing home. In both places, he was a prisoner, with every moment of his day, every inch of his body, dominated by others. Roberts won the right to direct who tended his body, and how; he decided for himself what to do with his time. He was physically dependent, but in control. Eventually McAfee was freed from his medical prison. He finally got government benefits to pay people to help him in his own apartment. When free, he lost the will to die. Too bad the media paid no attention. The story no longer fit the prevailing formula.

With money and control over our care, we need not suffer abuse. With some basic resources, we need not become burdens. We can enjoy life, however long or short it may be.

But, you say, budgets are tight. We can't afford to pay the costs of a good quality of life.

But we can. We're paying now - billions to lock people up in medical prisons like the ones that drove Larry McAfee to despair. That same money, redirected to in-home services, could set people free. Freedom is cheaper than lock-up.

Think about it. In freedom, I get in my chair and roam the city streets alone. I have a paid assistant, but I have no need for a dietician or recreation therapist or any such personnel. Friends and family help me in countless ways, large and small. Instead of some miserable dayroom, I go to work. I earn money and pay taxes.

I'm lucky to have what I need to be free. But I know my freedom hangs by a thread. One family crisis, one financial setback, one health catastrophe, and I might find myself stuck in some facility wishing I were dead. If that happens, I hope you won't agitate for my right to end my life. I hope you'll fight to set me free.

Some of us have been fighting for decades to take the government money that now pays for lock-up, and use it to fund services that will keep us free. If I could make you believe that we terminal, incurable cases are worth saving, worth keeping around, I'm sure you'd join our fight.

But I don't expect that. You're not ready to accept that we're people just like you. That would mean accepting that you're a person just like us. Way too scary, huh?

So, we terminals and incurables will fight for ourselves. And whether you accept it or not, we will fight for you.

Inside you, waiting to be born, is one of our kind. Unless

it is your fate to be murdered, or run over by a train, or otherwise struck down suddenly in your prime, odds are you will someday need someone to turn you over, bring you a bedpan, get you dressed, and help you into your wheelchair. If you live long enough, you'll confront your limits and know you're mortal. It may happen when some illness overtakes you at age 95, or it may happen when you drive home from work tomorrow, with 40 years of life ahead of you.

Whenever it happens, you may come to be glad that we got here ahead of you. We're trying to get things ready, to see that you get what you need as a matter of course. When it happens, you might ask one of us to show you the ropes. If you're lucky, as I have been, the nightmare you fear could become the unexpected dawning of your best day yet. Whatever happens, I wish you joy.

In South Carolina, three people have been arrested for assisting suicides of ill and disabled people. Authorities dismissed all three cases, characterizing them as "acts of mercy" and saying it would be impossible to find 12 people willing to convict. Johnson is a Charleston lawyer.

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