

## Unpacking Questions

Today the grocery cashier, gesturing to my crutches, says: "What did you do to yourself to get stuck with those awful things?"

I get questions like this a lot – though I hadn't had one in a while, and I don't usually get all the elements expressed here in a single utterance. Most folks just pick one or two sentiments. (My friend Chris calls these sort of exchanges "bowl of petunias" moments, for the bowl of petunias in the Hitchhikers Guide to the Galaxy books, which when summoned by the improbability drive into orbit around Magrathea, about to crash into the planet, has only time to think: "oh no, not again.") There's so much in the question that needs to be addressed before I can give anything resembling an answer. But the checkout line at the grocery store, when one really just wants to buy a few things and get the heck home to make dinner, is not conducive to long talks deconstructing ableism. And the question hits so *many* buttons that I have to find the right words to navigate my anger, frustration, and exhaustion while being polite and reasonable enough, to the perfect stranger who initiated it all, that I have the hope of accomplishing anything at *all* by saying something. Angry, tired retorts don't help change anything, and just make me feel bad for my rudeness afterwards, but not saying anything to address the offense(s) contained in the question makes me feel I've betrayed myself and my people.

In this case, wanting to get home, wanting to not have to explain again to a stranger how wrong they just were, surprised and out of practice, I simply said "Nothing; this is how it is." She was shocked, and came back with "I hope I haven't offended you," another hard one to respond to: because she had, but there was no opportunity to explain why, and without being able to give her context to a "yes", she herself could feel rude and/or hurt – and while I'm not responsible, entirely, for how she feels, I don't believe in an eye for an eye, and I know she's only speaking from within the framework she

has been immersed in. I also don't want her to decide dis/ability is completely taboo; I'd rather she think about the assumptions she made and the effect they can have. So, I said to her, "Well, I get it a lot," which is true, even if lately I've been luckier (or more of a recluse...). I'm hoping that – if she thinks about the interaction at all after – this helps hint her towards the larger picture of bias and assumption about dis/ability in the world she lives in, and how they play out in the lives of dis/abled people... in things as simple as small talk at a cash register.

But her question still needs unpacking.

It has so many common elements to questions I've heard a million times now – even in the scant handful of years I've been 'out' or visible as dis/abled. I'm going to try to draw each one out and address where it comes from and why it doesn't work. Where I can, I'll suggest alternatives. Maybe you've wondered the same things, about me or about someone else, or maybe you've had these questions asked of you, to your frustration/confusion/sighs. I hope this helps. I don't get the chance to explain this all to everyone who asks – I have a life, too, and places to go, and other demands on my time/energy – but conceptually, I want to think about it, I want others to think about it, I want to tell it, I want people to *know*.

(I'm going to do some generalising, based on my experience, studies, and conversations with others, but take it with the caveat that individual experience of course may vary. I'll try to speak for myself, from my experience, primarily.)

**Part 1: "What did you do to yourself?"** I get this as a stand-alone question a lot. It's close cousins with "What happened to you?" though the two have slightly different implications, to me. Both include the concept of an event by which my disability was acquired – an injury/accident, or perhaps (in the latter case) a serious illness. People seem to think they are being funny when

they ask this sort of question, as if it's a lighthearted opportunity to share a story of an amusing or cutely embarrassing incident, the sort of "well, I slipped on a banana peel and sprained my ribs from laughing" or "oh, I just got SO mad at the photocopier" anecdote, usually resulting in a temporary disability. But for a disability that *doesn't* mesh that sort of narrative, the humour tends to fall flat. People with disabilities acquired through trauma/violence might not be comfortable discussing that with a stranger. People with lifelong disabilities typically didn't have anything "happen" to them – the same for people with disabilities like mine that accumulate over time. It makes me feel out of place, off-balance, proscribed, othered. The uncomfortable feeling increases with the angle of the event being self-inflicted ("what did YOU do to YOURSELF"). With a long-term/lifetime disability, we've often had plenty of shame, blame, guilt, stigma, etc leveled at us already – that something is *wrong* with us (mappable to this "bad event" narrative; related to "what's wrong with you/your [body part]?" which people *do* also ask, *often*, and the offensiveness of which should be clear) and that this thing that is wrong is *our fault*; that if we were less lazy, slow, stupid, etc we wouldn't *need* accommodations x, y, z; and on and on. When you ask "What did you do to yourself?" you're conjuring up these old memories, learned over years, internalised and struggled with, and you're forcing me to defend myself against them in a new guise – even if you don't mean it that way, even if you don't even know that that's happening. It has made me very angry and sometimes it has made me scared and sad, because I have struggled with the guilt, and I am still vulnerable to its influence. It makes it very hard to answer you.

(It's a common piece of advice in the crip – that's a dis/ability affinity term, folks – community to have a standby list of typically absurd made-up answers for questions of the "What happened to you?" genre. Like, "I wrestled a giant sharktopus" or "bouldering on Everest" or something. It helps, sometimes. Makes clear the air of surreal what-the-fuckness we feel, allows us to circumvent the internalised awkwardness/shame responses,

pokes fun back, provides a ready answer when we're too tired to deal with educating about ourselves yet *again*, and lets us get on with our lives in short order. But this response is not always appropriate or helpful.)

**Part 1b:** Quick backtrack to trauma and violence in acquisition of disability – and sometimes, coming to terms with a disability can be agonisingly difficult even without a discrete event – and how one might not wish to discuss this with strangers. It's most immediately understandable in the form I originally stated - that someone whose body has been changed by violence/trauma might not wish to share that experience at all, let alone *with a stranger* – but it's more widely true. It's related to a concept in education around transgender/transsexuality education & awareness: it is inappropriate in most situations to ask about the particulars of a stranger's transition, medical procedures, and/or current bodily configuration. It is an intimate subject, not the business of strangers or casual acquaintances. Our bodies are the most personal things we have. Culturally, we have largely agreed that they are private, too, to be shared, with consent, only with those we deem appropriate. Dis/abled bodies are no different. (There's a lot of good writing out there about how this concept has been ignored by medical and other establishments over the years, but I won't go into that in depth here. Suffice to say we've been objectified and exhibited, historically.) Our bodies are our business. Prying into their inner workings is at best just that – prying. At worst it feels voyeuristic, fetishistic.

I will share information about my disability, when I feel it is appropriate to do so, where I feel it will be helpful to increase knowledge about it. It's also possible to ask about what my disability is and how it works without being rude or offensive. Simple is best, especially if it indicates *why* you want to know, rather than just demanding information. "Why do you use the crutches?" and/or "Do you find that they are helpful?" "Do you have a disability? What is it called?" "You move a lot like my friend/relative/etc, do you also have a collagen disorder?" All of these are improvements to various

degrees on "What's wrong with you?" Remember politeness too, though – this knowledge is not your right, it's a privilege that I may choose to deny, for whatever reason based on what's going on with me right then (pain, running late, just not wanting to talk), which I also do not have to disclose to you. You are also not the first to ask; you may be the millionth, and it gets old. "May I ask..." "Excuse me, but I was wondering..." "I'm not sure how to say this, so please correct me if I'm rude, but..." And for goodness' sake, at least introduce yourself and get through a bare minimum of social interaction protocol first, don't just holler down from a window somewhere.

**Part 2: "stuck with"** Bluntly, I'm just plain not "stuck" with the crutches. I chose them, actively, from a variety of options. (I actually argued my medical supplier into ordering these particular ones special for me.) I could try to make do without, and some days, I do; I could also go for a chair, and soon, I think I will add that to the options I keep on hand. Of course this isn't true of everyone; for some folks they are the only option, probably, but for me and many others, they're the *best* option. Additionally, and largely because they are the best option, I *like* them; they're not some sort of doom. I may curse at them when they fall over or knock into things, but they are not a ball and chain. They're mine. They're part of me, now, my metallic body parts – something that, magically, can be both me and not-me, as I *choose*, and by the nature of their use. And this brings us to part 3.

**Part 3: "those awful things"** This is a nice little nugget. It sums up so much of the assumptions about what it means to be dis/abled – how overwhelmingly negative and shameful it must be, how lesser, how demeaning, how unfortunate and miserable, how *awful* – and makes the crutches the symbol, like my sticks are somehow this albatross around my neck. No, the real albatross is the stigma they attract, though that is unfair to albatross, which are astonishingly mobile, independent, beautifully graceful-yet-awkward birds.

The crutches are "things", technically, but as noted above they're things that function as part of me.

And I am *so glad*.

They are not "awful".

Even though I chose them, knowing I needed them, I was initially afraid (in an inner, secret part of my brain) that they would be a detractor, that they would impede me, shackle me. I bought into the prevailing opinion a little, basically. I could not have been more wrong about that. The part of me that was determined to take care of myself by having them – because they do function in that way, therapeutically; buying them was an act of self-care – was absolutely in the right. I did not become more robotic or awkward, slow or encumbered. I gained entirely new forms of grace and absolutely un-dreamt-of speed. My body can glide and flow with their support. I can go on walks with my sweetheart – though, true, we can't hold hands. And buffets are a serious pain in the arse now. But they let me be out in the world more often, with more freedom. With them, I can dance again. I have the physical strength and the energy to try more things. The list goes on. Physically, they have given me much.

Incorporating them as part of me, myself, has also given me additional emotional strength. I know that I have them because they are good for me, that they are a sign of me caring for me, that they are stable and reliable even when my body is not, that they create opportunities, that they are a physical validation of my bodily experience, that they open the world.

I feel naked if I am out somewhere and have to put them aside. It shocks me if someone else touches them without my permission. I have proprioceptive awareness of where they are. They're included in my sense of myself, not just attached to my physical body.

Some days the weight of the stigma comes down hard, and I feel ashamed and awkward; some days my hands and shoulders ache; and some days I hate not holding hands, I hate stairs, I hate stares, I hate buffets, I hate people who block corridors. I have never hated the crutches. They have never been awful.

**In conclusion:** the question I was posed tonight was problematic in every particular, and enough so to be nearly impossible to handle in the moment, but in essential, important ways. Negative ways, yes, but that is what we are dealing with, what we are (it feels like) daily up against – that is ableism. Her question shines a light on subtler attitudes and assumptions about dis/ability and the people who are dis/abled. It shows how much is not known, or wrongly known, or known but not understood. It is an *important* question. I just wish I weren't asked it like this.