

## Rest Ministries

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**From:** Diane Safley [dsafley@law.uoregon.edu]  
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### State Bar of Michigan Volume 3, Issue 4, November 2007

Committee on Justice Initiatives and Equal Access Initiative Disabilities Project

## Disabilities Project Newsletter

### 'But You Look So Good!' and 7 Other Things NOT to Say to a Person With a Non-Visible Disability by Robyn Heller Gerbush

If you have a friend, relative or coworker with an illness or disability that isn't obvious, you may think you're doing the right thing by saying he or she "looks so good." You can't even tell the person has a disability, and that's a good thing, right? Wrong.

Why do people with disabilities take offense to this comment and others like it? Ninety-six percent of illnesses are invisible to the average person, according to [InvisibleIllness.com](http://InvisibleIllness.com). To comment on a person's outward appearance dictates, intentionally or otherwise, that they should feel the way they look: just fine.

However, non-visible or chronic illnesses, such as diabetes, mental illness, lupus, multiple sclerosis and fibromyalgia, can be debilitating.

"The term 'invisible disabilities' refers to a person's symptoms such as extreme fatigue, dizziness, pain, weakness, cognitive impairments, etc., that are sometimes or always debilitating. These symptoms can occur due to chronic illness, chronic pain, injury ... and are not always obvious to the onlooker," according to [The Invisible Disabilities Advocate](http://The Invisible Disabilities Advocate). "A person can have an invisible disability whether or not they have a 'visible' impairment or use an assistive device like a wheelchair, walker, [or] cane."

Keeping a good game face is required in corporate America, as it is considered unprofessional to bring personal problems into the workplace. But looking good and feeling good are two very different things—and the impact of a disability or illness is as much psychological as it is physical. From the glares people with non-

visible disabilities get after parking in a handicapped spot to the "You're so lucky you get to stay in bed all day" comments, the ignorance of the limitations of life with a chronic illness or disability can hurt as much as the actual pain.

### **Open Mouth, Remove Foot**

"Comments that compare the appearance or ability of a person with a disability to a person without a disability have the same underlying message as saying to a woman, 'Your report was well done, for a girl,'" says Susan Henderson, managing director of the Disability Rights Education and Defense Fund (DREDF). "We understand the impact of that statement on our daughters and our culture—the same is true for comparative comments about disability."

Josie Byzek, managing editor of *New Mobility* magazine, has multiple sclerosis. Over the course of her disease, she has heard more than that she "looks so good."

"I also get the 'Well, *everyone* has memory problems as they age,' and 'That happens to everyone,' and lots of other stuff that's supposed to be comforting but is actually awfully minimizing," she says.

Other real-life hurtful comments that should not be uttered to a person with a disability, and why:

1. "It's probably just stress." This undermines a diagnosis given by a qualified medical professional and makes it seem as though the person with a disability is exaggerating.
2. "My [insert relative] had that, and she manages just fine." The effects of a disease can and often do manifest themselves differently from one person to the next. Measuring the extent of a person's disability against the condition of another person is insulting.
3. "No pain, no gain!" This cliché does not apply when it comes to disability.
4. "It's all in your head." This is especially infuriating for people who struggled to get a diagnosis for their symptoms. Just because symptoms are not visible to others doesn't mean a person doesn't have an illness or disability. Leave the medical interpretations to the experts. This occurs frequently for those with mental illnesses. According to the Mayo Clinic, "To some, the word 'mental' suggests that the illness is not a legitimate medical condition but rather a problem caused by your own choices and actions."
5. "You're just looking for attention/pity." Hardly. Many people think that those with disabilities are helpless, broken and weak. The stigma is one that newly diagnosed people often have to grapple with in their own minds, which makes it even more hurtful to hear this from other people. But the stigma is wrong.
6. "You're here! You must finally be better." This fallacy can be

maddening. For those with chronic illness, there is no cure, and hearing a comment such as this one proves that the illness is not understood—and that no effort was made to understand it.

Becoming accustomed to an illness or disability is a personal journey that everyone makes at his or her own pace.

7. "I really admire your courage/how you pretend nothing's wrong." People with disabilities learn to adapt their lives around their disability. It is not a show of courage or denial to carry on, and to insinuate such is offensive.

### **Mobilization**

This year, Sept. 10-16 is National Invisible Chronic Illness Awareness Week. Since 2002, the week has been recognized nationally each year to unite and mobilize people with non-visible disabilities and illnesses and their allies to educate government, healthcare companies, and the general public about the 133 million people living with a chronic condition. That number is expected to increase by more than one percent a year to 150 million by 2030, according to a study for The Robert Wood Johnson Foundation, and 42 million of those will be limited in their ability to go to school, to work, or to live independently. [Read the full study.](#)

### **This Means You**

If you think this won't be a concern until old age, take note: 75 percent of people with chronic conditions are younger than 65.

One of the biggest obstacles in the disability community is the attitude of the temporarily able-bodied. When Lawrence Carter-Long, director of advocacy for the Disabilities Network of New York City, gives lectures to college students, he asks, "What is the difference between a person with disability and a person without?" After getting the usual answers—having a wheelchair, using a cane or a hearing aid—Carter-Long reveals the real answer: "About five seconds."

"Most of the problems regarding access have more to do with proximity than with malice. If it's not you, it could be your brother coming back from Iraq, it could be your aging parents, it could be your niece being born with a disability," he says.

Carter-Long and other disability-rights advocates urge action by those who think "it's not going to happen to me" so that when disability does affect you, access to basic needs—such as housing, employment, healthcare, assistance—won't be a problem.

Byzek says, "The greatest gift the independent-living and disability-rights movements can give our society is the freedom to just be people. We've created a society that wants people to adjust to systems. This is backwards. SYSTEMS should adjust to PEOPLE.

We come along with our limps, our canes, our wheelchairs, our dodgy eyesight, our brilliant minds wrapped in fatigued bodies and say, 'Hey, can you just wiggle this rule?' and are becoming adept at pointing out how this is actually civil rights."

She continues, "We have the right, as citizens, to participate fully in our own society. What would happen if everybody had the ability to wiggle their environment, our systems, to make their lives easier? We'd be a happier, more relaxed society. We'd have fewer stress diseases, we'd live longer, we'd be more productive."

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