Fifty things NOT to say to chronically ill people

Knowing what to say and how to support those around us who are chronically ill can be a challenge, particularly when we ourselves do not understand their plight and carry misconceived ideas about chronic illness, whether it be of a physical or mental nature. The way we react can affect the person's ability to thrive at work and establish meaningful relationships with colleagues. **Odessa Hamilton** led an informal survey with a diverse group of people experiencing chronic illness and pooled together a list of comments, some reported as coming from even the most well-intentioned acquaintances.

A recent article "Fifty Things NOT to Say to Black People" opened discourse apropos race, but it also exposed a wider tendency for people to, intentionally or otherwise, say inappropriate things on a number of other themes. Illness is one such theme. Particularly, as it relates to chronic illnesses that cannot be seen, whether that be physical or mental illness, which are two sides of the same coin. Chronic illness can present in a plethora of ways and yet it can have homogenous effects on the ability of those afflicted to optimally engage in the occupational milieu and experience adaptive, fulfilling alliances with colleagues.

Disability continues to be synonymised with wheelchairs and older age, which fails to give an accurate representation of the estimated 1 billion disabled people across the globe; ~15% of the world's population (The WHO, 2022). Despite these persisting clichés, only 2% of disabled people are wheelchair bound (Wagner, 2021), and of the 10 million people with disabilities in the UK, 6.8 million are of working age, corresponding to one fifth of the total working age population (United Nations, 2022). It is conceivably why the word '*disabled*' itself has become stigmatised, with many who definitionally meet the criteria for disability rejecting the term, or deciding not to '*tick the box*', because they do not feel '*disabled enough*'.

Still, a recent report revealed that 80% of disabilities are unseen (Wagner, 2021) – that is indiscernible to the untrained eye – or as is commonly said, *invisible*. But this invisibility is no superpower! They are often misunderstood, and humans have a tendency to mistrust what they cannot see (Villanueva, n.d.). So, what of non-visible disabilities such as cancers, blood-borne viruses (e.g., human immunodeficiency virus), and disorders of neurology (e.g., epilepsy), allergy (e.g., asthma), endocrinology (e.g., diabetes), autoimmunity (e.g., fibromyalgia), and haematology (e.g., sickle cell)? The elusiveness that shrouds them can reduce social support and validation at work, and their long-term nature can lead to compassion-fatigue among teams (Brennan & Creaven, 2015).

Although mental illness is the least declared form of chronic illness, <u>GlaxoSmithKline</u> (2003) places it as the third most common occupational illness, accounting for half of all sickness absence; double that of physical illness. So, what of psychologically based disabilities, such as disorders of mood (e.g., dysthymia), anxiety (e.g., agoraphobia), eating (e.g., bulimia nervosa), impulsive control (e.g., obsessive-compulsive disorder), psychosis (e.g., bipolar disorder), or personality (e.g., narcissistic personality disorder)? The undue stigma and ignorance-based fear not only leave those afflicted with reduced support and validation at work (Hamilton, 2021) but too frequently they are belittled, avoided for collaborations, and socially rejected (Hipes et al., 2016).

These workplace dynamics make those with chronic conditions more likely to hide their suffering because of the likely detriment to their wellbeing and career. But this conscious attempt to hide one's daily reality is an extra burden on their health (Hamilton, 2021). Because of this concealment, we often fail to understand the instances when chronic illness may underlie changes in behaviours, performance, conduct, or relationships with colleagues (Goldman & Lewis, 2008). Because of this concealment, we often fail to offer support and reasonable adjustment that could have a huge impact on the afflicted person's wellbeing, contribution, and identity at work.

Date originally posted: 2022-05-13

Permalink: https://blogs.lse.ac.uk/businessreview/2022/05/13/fifty-things-not-to-say-to-chronically-ill-people/

Knowing what to say and how to support a colleague who is chronically ill can be a challenge, particularly when we ourselves do not understand their plight and carry misconceived ideas about chronic illness. We are not, after all, monolithic beings. Some will be better placed to provide helpful support, and some will be more receptive to that support. There are certainly, however, things that are entirely inappropriate to say, and can be a harmful use of language (Hamilton et al., 2022). We should bear in mind that chronically ill people must already face the trauma of their diagnosis, along with the associated stigma that typically comes with a judgement of their professionalism and a constant burden of proof. Capturing the lived experiences of professionals encumbered with chronic illness is a small step toward legitimising their struggles and indicates to others what things are NOT appropriate to say– even in jest!

Qualitative data was informally collected to quantify and qualify the experiences of a small, yet diverse selection of people who have experienced issues with health in Britain. Contributors, male and female, were aged between 22-71, across the social strata, ethnic representation across four continents, with religious representation including Christians, Muslims, Hindis, Jewish people, and atheists. Eligible responses were experienced first-hand. For brevity, fifty are reported, results included seventy-two unique entries; omitting replications and those of an extreme nature. As with any thematic analysis, entries are grouped by theme.

Given the focus on Mental Health Week, it would be especially remiss not to forewarn readers of the potentially psychologically triggering nature of the comments that are to follow. Please, therefore, be mindful of this as you peruse the list and engage with the wider material. Be kind to yourself by acknowledging and attending to any undesirable emotions that could jeopardise your wellbeing and seek help whenever necessary (Mind | 0300 123 3393).

Work

- 1. You get paid to do a job, if you're not happy, leave
- 2. You had a panic attack being bullied by peers, but you wouldn't react like if it was a stranger
- 3. If you wanted to skip work you could have just said
- 4. Return to work when you've recovered (My condition is chronic so that will be never)
- 5. You just want fancy equipment (Yes, illness is my master plan)

Appearance

- 6. But you don't look sick
- 7. You seem to be able to smile and 'act normal' (Sorry I wasn't taught how to 'act depressed')
- 8. You look too young to be diagnosed with something like that
- 9. But you're so pretty
- 10. I wish I looked and sounded like you when I'm sick
- 11. It's a shame you're in a wheelchair because you are just so stylish

Miraculous cures

- 12. Are you sure you need that medication? (Nope, I take it for fun)
- 13. A witch doctor will heal you
- 14. You are just really unfit and need to start going to the gym (I already exercise daily)
- 15. You just need more sleep

Date originally posted: 2022-05-13

Permalink: https://blogs.lse.ac.uk/businessreview/2022/05/13/fifty-things-not-to-say-to-chronically-ill-people/

16. Now you have less hair on your scalp, you should try X to grow it back (Can we start with "you look nice"?)

17. You just need to try X (e.g., lemons/dates/raw onions/turmeric... You're right, the entire medical field would be stunned by the simplicity of this miracle cure a.k.a. useless dietary suggestion)

Medical comparisons

- 18. At least you don't have cancer
- 19. Ignore her, she's got Munchausen (Please don't act like I'm not here)
- 20. You sound like a smoker (I have long-COVID)
- 21. Are you sure you're not just PMS-ing? (I'm clinically depressed and suffer from anxiety)
- 22. Can she talk? (I'm in a wheelchair, I don't have a hearing or speech impediment)
- 23. Gosh, you look six months pregnant (Steroids have that effect)

Misplaced empathy

- 24. You're so unlucky
- 25. Well, not everyone can be Einstein
- 26. Try to develop a thick skin to withstand pressure
- 27. Why get stressed over something so trivial (Well, I have anxiety)
- 28. Was there always something wrong with you?
- 29. Life must be sad for you (It wasn't until you expressed some presumptive pity)

Cynicism and scepticism

- 30. If you get sick so easily how come you can do X?
- 31. You are such a hypochondriac, there is no way you're always this sick
- 32. You can't use your hormones as an excuse (A diagnosis isn't an excuse)
- 33. Are you allowed to park there? (I wasn't given a disabled badge for my likability)
- 34. If you're not shifting the weight, maybe you just eat too much and don't exercise enough
- 35. You can't be this tired all the time, sounds more like laziness? (I have hypothyroidism)
- 36. And yet you can sit perfectly still without fidgeting (ADHD is so much more than fidgeting)

37. It can't be that bad, you have periods every month, surely by now you're used to it (*I have premenstrual dysphoric disorder*)

Unadulterated ignorance

- 38. I thought only cats and old people suffered from rheumatoid arthritis
- 39. Isn't asthma a thing for kids not adults? (Asthma is not age specific)
- 40. Why don't you pay attention (Why don't you? You know I have ADHD)

Date originally posted: 2022-05-13

Permalink: https://blogs.lse.ac.uk/businessreview/2022/05/13/fifty-things-not-to-say-to-chronically-ill-people/

- 41. Try not to get stressed so easily (I wish anxiety were that easy)
- 42. Can't you just pull it together (Nope)
- 43. You talk too fast and take too long to get to the point (I have ADHD)

Just insulting

- 44. You're too messed up to have kids, they'll come out like you
- 45. Are you sure you're depressed and not just stupid?
- 46. Why bother get out of bed
- 47. You need to see a shrink literally!
- 48. When you walk you must rattle with all those pills
- 49. You've definitely inherited your mother's 'schizo'
- 50. There's nothing wrong with you, you're just a drama-queen

Now consider yourself living with a chronic condition and having to face such taunts. We often look at illness as something that happens to others, or we draw arbitrary parallels between illness and older age, but illness can creep in from conception and has any age onset, often without notice. Illness is inevitable, differing only in severity and permanence. Two per cent of the working-age population becomes disabled each year, with 40% predicted to have a chronic condition by 2030 – up to one in four before they reach retirement age (Sayce, 2018; GOV, 2010). Therefore, discourse around illness, how we conceptualise it, manage it in ourselves, and see it in others is a fundamental occupational concern.

Notes:

- This blog post represents the views of the author(s), not the position of LSE Business Review or the London School of Economics.
- Featured image by <u>SHVETS production</u> on <u>Pexels</u>
- When you leave a comment, you're agreeing to our <u>Comment Policy</u>.

Date originally posted: 2022-05-13

Permalink: https://blogs.lse.ac.uk/businessreview/2022/05/13/fifty-things-not-to-say-to-chronically-ill-people/

Blog homepage: https://blogs.lse.ac.uk/businessreview/