

Table 1. Never-words, their impact, and suggested alternatives.

Never-Words	Explanation and Impact	Alternative
"You don't look sick".	Many patients may appear healthy, but feel very sick with various symptoms, including fatigue and pain.	Please refrain from commenting on their appearance.
"You need to stay positive".	Saying this to patients with debilitating symptoms with limited treatment implies that the patient did not stay positive or that the patient's attitude is to blame for feeling or staying sick.	"I know it can feel discouraging to feel so sick, and especially for so long. We will work on this together".
"At least it's not cancer".	Minimizing symptoms and disabilities is not well-received by patients who are suffering with non-terminal, but debilitating, and disabling conditions.	Comparing diseases to make a patient feel better is a strategy that is best avoided, since it usually has the opposite impact.
"Learn to live with this".	While this may be practical advice, many patients have already adjusted to living with their illness, but they want to live better and be more functional.	"I know this illness can really disrupt your life. What did you do in order to adjust to this?"
"Good news: Your tests are all normal".	This is good news for medical professionals, but patients may not care about the numbers or test results if they feel sick. This may also imply to patients that because their tests are normal, they have no reason to feel sick.	The tests we have run so far are not showing any abnormalities, and the good news is that we have excluded certain conditions based on the results of these tests.
"Many people have it worse".	Deflecting the patient's suffering can be perceived as gaslighting by the sufferer.	Please refrain from comparing patient's diseases and experiences.
"Have you tried___(lifestyle measures: yoga, going for a walk, diet, etc.?)"	Many patients have already tried various lifestyle measures without benefits and are seeking further treatment from healthcare professionals, not recommendations of the same lifestyle measures.	What are the things you have tried that have or have not helped you?
"You feel sick because you are___(psychological label: anxious, depressed, stressed)	Many patients with chronic illness do have comorbid depression, anxiety, PTSD, and other psychiatric disorders, but in many patients, it is not an explanation nor a justification for why they feel ill. Further, it is important to note that people living with a chronic complex condition experience many losses due to having that condition.	If you are suspecting significant psychological or psychiatric comorbidities, please refer your patient to a mental health professional to address these issues.
"You feel sick because you are___(fitness label: deconditioned, overweight, underweight, out of shape)	Many patients have been previously healthy and active, and many patients want to restart exercising and lead an active lifestyle but cannot due to fatigue, pain, and post-exertional malaise.	Please refrain from commenting on the patient's fitness level or body habits. A referral to a physical therapist with expertise in chronic fatigue may be helpful.
"You feel sick because you are___(hormonal status: perimenopausal, menopausal, postmenopausal, postpartum, pregnant, menstruating, ovulating)	Many patients with Long COVID, MECFS, and other chronic disorders are women who can often differentiate between hormonal symptoms and symptoms of chronic disease. Additionally, hormonal influence on symptoms is well-documented but is not an explanation or the cause of the underlying disease.	Please refrain from commenting on the patient's hormonal status. A referral to a gynecologist or endocrinologist might be appropriate if there are concerns of hormonal abnormalities or need for hormonal supplementation.
"You need to ___(instruction as cures: lose/gain weight, start exercising, get fresh air, get out of the house/bed, get a job, get a hobby, start dating etc.)"	While a healthy lifestyle is important, the patient did not choose to stop it: the lifestyle changed as a result of the illness. Additionally, while lifestyle measures are important, they are unlikely to cure or effectively treat the underlying medical condition.	"When you feel better, we will work together toward a common goal of improved quality of life and a healthier lifestyle".
"You look too___(appearances: good, young, skinny, pretty)___to be sick".	Comments on appearances are inappropriate because patients with chronic illness may not look sick like patients with acute illness. Many actually hide their ill-appearing looks, especially when seeing a healthcare professional.	Please refrain from commenting on patient's appearance.
"We don't have any treatment for your illness".	While this may be true for some illnesses, given no FDA-approved therapies, symptomatic treatment is available, and the patient should not be made to feel like they are being abandoned by the medical team.	"We will talk about the available treatments we have that can make you feel better".
"You need to stop thinking about your symptoms so much".	In our experience, improved symptom control results in many patients improving their function and decreasing the negative thoughts and feelings about their symptoms. In those patients who continue to perseverate about their symptoms, psychological support, and cognitive-behavioral therapy may be appropriate.	"You have good awareness of your symptoms. I'm wondering if we can come up with a way for you to easily track them, so we that we can see the small changes when you begin to feel better".
"You have to find something productive to do with your time".	This statement assumes that patients are bored or have too much time on their hands, whereas, for most patients, having complex chronic illnesses is time- and energy-consuming and may be equivalent to having a full-time job managing disease and medical care. Additionally, many patients are not physically and/or cognitively well enough to be productive.	"Try to distract yourself with doing pleasurable and meaningful things that you can still do for short periods of time".
"Don't confuse your Google search with my medical degree".	This statement has become popular among healthcare professionals, given various online information platforms and social media groups that patients use to obtain medical information. However, we find that many patients with complex chronic illnesses had to become educated in their disorder out of necessity, given limited help from medical professionals.	"I am glad you're reading about your illness and educating yourself on possible tests and treatments. Thank you for bringing this information to me. I will look through it and let you know my thoughts".