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Dear Loved One

What Should I Say to the Chronically Ill?

The Communication Guide to Support a Health Crisis

Learn what not to say to the sick or chronically ill



A note to the disoriented and diseased...

If you've been dismissed by doctors and disbelieved by your family or friends, this is for you! Well, it's actually written to give to your loved ones. This ebook is a gift of knowledge on how to communicate with you. Send this link or ebook PDF to your loved ones to help them learn how to empower themselves to support you more effectively and compassionately as you face a difficult health situation or even a long-term chronic illness.

I know how devastating it can be to not feel supported when you're sick. I wish my own family would take this advice! I suffer from hypermobile Ehlers Danlos Syndrome (hEDS), once thought to be rare, and maybe it turns out to be just barely understood or rarely correctly diagnosed. I was rejected. My work colleagues, family, and friends could not face my unpleasantness, how I now needed help doing simple things and why I talked about my health issues too much. My life had crashed down, and where was the unconditional love I expected? This is a horrible truth that no one really talks about.

The ugly truth: Alienation from loved ones, even family, upon illness.

Your loved ones are scared - for you and for the others on your inner circle. They feel powerless. And as hard as it is, it can sometimes come across as invalidating if they distance from you. If you too have been alienated, chosen to step away or even cut-off from loved ones, share this definitive guide with them so they can learn HOW to support you better when they don't know what to say.

Dear Loved One,

Some things really are better left unsaid, especially if you're talking to one of the 133 million Americans who live with a chronic illness. According to the U.S. Centers for Disease Control and Prevention (CDC), nearly half - that's 40% of all American adults live with *at least* one chronic illness, such as MS, HIV/AIDS, COPD, lupus, Crohn's disease, and fibromyalgia—to name just a few. And as anyone with a long-term health issue knows, well-meaning friends, colleagues, relatives, and even strangers will sometimes "put their foot in their mouth" (or other body parts) when their intentions are usually good. Still, without meaning to, they are insulting or causing deeply hurt feelings and even damage your relationships.

Chronic illness can be complicated to deal with, both for the sufferer and their loved ones. It can be hard to know what to say or do to help make things better. The challenge that chronic illness sufferers face is that many people around them think their symptoms are all in their head and don't understand how it "looks or feels" to have a chronic condition, especially if it's an invisible illness like EDS or MS. The growth results your loved ones might experience from reading this is that they will know the best way to support you in getting through stressful times without being judgemental or dismissive. This ebook hopes to shed light on the trial of talking about unsaid things and provides a few tips on how not to, including better ways to talk to loved ones in need.

You should never say certain things to someone



who is suffering from a new diagnosis, a health scare

or a chronic illness, even if you mean well.

Dear Loved One

Some things that you should never say to someone suffering from a chronic illness include telling them to just pray about it, get over it, or snap out of it. You should also never tell them that their condition is all in their head or that they are just making up their symptoms. You should never compare their illness to your own experience or tell them that their disease is not as bad as others you have heard about.

Suppose you know a friend, parent, sibling, patient, a coworker with a chronic or invisible illness like Multiple Sclerosis, Ehlers Danlos Syndrome, or autoimmune disease. In that case, you may be unsure of how to talk to them and how to respond appropriately to their health.

It can be very tricky, especially since good intentions are often drowned out by poor word choice. You may want to reflect on where your comments are coming from—lack of knowledge on the subject, fear, difficulty empathizing, etc. However, the important thing is that you care and are self-aware enough to examine your own language and learn better ways to respond.

Below are examples of comments chronically ill people often hear, followed by "translations" meant to demonstrate how the words are actually heard and suggestions of what to say instead.

THE TOP 10 THINGS NOT TO SAY TO SOMEONE WITH A CHRONIC ILLNESS

1. "You're probably just stressed out."



Translation: "You brought this on yourself."

Dear Loved One

This kind of statement implies blame. It suggests that the person let this happen because they got too stressed and that they are, in fact, the root cause of their condition. It lacks empathy and disregards any other factors involved, including genetic predispositions or environmental triggers. Yes, stress can absolutely exacerbate issues, but it never acts alone. To assume so is to dismiss the person and devalue their own body's knowledge.

Instead: *"This has to be frustrating," "I hope you can find out what's wrong," "How can I best support you?"*

2. "You should do yoga."

*Translation: "You're probably just stressed" *see above*

Disguised as advice, telling someone to try yoga, meditation, or other similar suggestions implies one or all of the following:

- Your friend or family member never thought of trying yoga before
- You have the answer to their problems
- Your experience with *yoga* will be their experience
- They just need to destress, and they'll feel better

Instead: *"What are some things that help you feel better?" "What can I do to support you getting those activities into your life regularly?"*

3. "It could be worse."

Translation: "Suck it up" "Your experience isn't valid."

Dear Loved One

This is trying to be optimistic, but it hurts. You could make this case in pretty much any situation. For example, you find out that your significant other is cheating on you and a friend responds with, "It could be worse. It's not that big of a deal. At least he wasn't abusive." Can you imagine the guilt, shame, and embarrassment that could cause?

"It could be worse" is a comment aimed at providing comfort while devaluing personal experience. It rejects a person's right to feel angry, frustrated, sad, disappointed, hopeless, or any other number of emotions that come with navigating a chronic illness daily.

Instead: Try putting yourself in their shoes for a moment and experience what they are going through. Or maybe, simply listen and be there for them. If you don't know what to say, be honest and tell them that.

4. "Just stop eating *gluten* - you'll be fine."

Translation: "It's not that hard."

This is an oversimplification of a very complex situation. As if dietary changes alone will cure you. Yes, they can help ease inflammation, just as reducing sugar consumption and increasing water intake can - like we all know. But for example, people with celiac disease (and those with suspected gluten sensitivity) often hear this from their doctors or even from others who do not quite understand what going gluten-free truly means.

Changing their lifestyle includes several factors, such as social pressures to eat carbs and "fit in," extreme sensitivity even to crumbs in a toaster or flour dust in the air, relearning how and what to cook, triggering ingredients hidden in familiar foods, anxiety when going out to eat, recovering from a gluten reaction for sometimes days, and the list goes on.

Dear Loved One

Plus, for many people with celiac disease or gluten sensitivity, just taking care of the gluten in their diet is not enough to eliminate symptoms. There are often more pieces to the puzzle-like getting it out of products like toothpaste, lipstick, and so much more. Don't simplify their genuine issues.

Instead: Ask about their health journey, how and when they found a diagnosis, what their most significant challenges are (or will be) when living gluten-free, etc. Even consider joining them in their lifestyle changes.

5. "You should do ____, it worked for me."

Translation: "You obviously haven't tried the right things."

The intention may be to help, but this really misses the mark. It is lovely to hear how a particular therapy or practice has helped you feel better. But at the moment, it's not about your journey. It's about theirs. Although you may be fatigued and even exhausted by their needs, they really need you more than anything.

Unless the person you're addressing specifically asks for advice, comments like this can be less than helpful. Don't you agree it sounds like you assume that they have not heard of the practice before, that they aren't doing everything they can to improve their health, and that they will have the same experience as you did? Not likely for anyone- sick or healthy.

Instead: Ask, "What are some things that have helped you feel better before?" "Is there anything new you've been wanting to try?" "Let me know if there's anything I can do to help."

6. "I think you should talk to someone."

Translation: "I don't believe you," "It's all in your head," or my personal favorite - "You're crazy."

Therapy can be an invaluable tool for anyone, including people living with chronic health conditions. But this comment is dismissive and lacks empathy, implying that what the person is dealing with is purely psychosomatic. People with unexplained symptoms are often told (even by their doctors) that they're not actually sick, which prolongs diagnosis and feeds frustration and distrust in the medical system and harboring shame, confusion, and isolation. Telling people, they are "mentally ill" when their physical body is betraying them is a double whammy. It was suggested to me that I consider going to a mental hospital. There goes that relationship!

Instead: *"That has to be frustrating," "I hope you find out what's wrong," "How can I best support you?"*
"What can I do, if anything, to help you?"

7. "Disease is a state of mind. Think positive!"

I get this too often. Well-meaning people sometimes try to "help" by telling me that I can positively *think* my way out of feeling ill. I was told to look at the half-empty glass differently several times. Chronic illness is not about perspective. Don't you know we would choose to change things if we had the power? Even a tiny bit if we had even the slightest chance! Beware of suggesting that positive thinking is the cure someone needs. While a positive attitude may help, you never want to make someone feel bad about feeling bad. Remember, they want to feel heard and understood. A positive attitude can help them learn to grieve the losses and learn coping skills for dealing with a chronic illness, but allow them to come to terms with it on their own time- don't try to force it upon them.

8. "But you don't look sick."

Translation: "You're faking it," "I don't believe you," "You're a hypochondriac," "There's really nothing wrong with you."

If you notice yourself even thinking this in response to a coworker leaving early because of their illness, please, please, please take a step back. Try to think about times when you haven't felt well or even had a headache. In those trying moments, should you have to prove to everyone around you that you have a headache by *looking* like you have a headache to make it true, to validate the pain you're feeling?

According to the CDC, a quarter of people living with chronic conditions say that they experience significant limitations in daily activities, but many of those people don't have visible symptoms. What we see on the outside never tells the whole story.

Instead: *"Let me know if you need anything" or "I'd like to better understand what you're going through. I'm here to listen if you'd ever like to share."*

9. "You're so brave."

If you were to choose to climb Mt. Everest and survive - that is brave. But illness is not a choice, and it is not something to falsely admire someone for. I don't feel "brave" (not having volunteered for EDS as it is genetic- thanks, Dad and Grandma!), but rather, I think "strong." Many patients identify as 'pain warriors' or similar due to the constant state of discomfort they experience.

Dear Loved One

Instead: There's a big difference between pity and empathy. Sometimes, you don't have to say anything. Just being there is enough. Checking in on them if you don't live close by or sending thoughtful reminders that they are in your thoughts is encouraging to most.

10. "I'm sorry."

Please don't apologize for something no one is responsible for because I got a disease. It's a natural thing to want to say because you feel bad. But I feel bad too. I am often riddled with guilt, even shame for the change in my life plans illness has brought. Everyone's life turns out a bit different than they planned.

Instead: Try changing it a bit to *"I'm sorry this is happening to you."*



Take the Pulse:

Comments like "but you look so good" or "you're always sick, it must be in your head" can make the person feel invalidated and frustrated.

It's essential to be supportive and understanding and ask how you can help instead of making assumptions.

When a friend or loved one is suffering from a chronic illness, it's important to be supportive and understanding. Ask how you can help instead of making assumptions about what they need. Offer your support and kindness, and be there to listen when they need to talk.



WHAT YOU SHOULD SAY INSTEAD

Here are 10 suggestions from others who have a chronic illness on what you should say instead...

- 1) ***"I wish I knew what to say, but I really care, and I'm here for you."*** Ultimately this is the truth behind any other heartfelt statement, so it's an excellent all-around sentiment to express when nothing else comes to mind.
- 2) ***"I believe you."*** This is one of the most powerful things you can say to someone with a chronic illness such as EDS or MS that has invisible symptoms. It might even seem strange to you that they need to feel believed, but it is vital to your loved one. It is very validating and comforting. You have no idea of how alone we can feel. I remember crying in a doctor's office when he said that to me for the first time.
- 3) ***"Can I bring you anything? Or is there a chore around the house I can help with?"*** Doing the dishes or putting together even a simple meal can be a huge energy drain when fatigue sets in, so it can be a significant relief when others take care of these tasks.
- 4) ***"I know how hard you're trying."*** This acknowledgment can be a massive motivator to someone who feels that no one understands how difficult it can be to push through the tough times.
- 5) ***"Don't feel bad if you have to cancel plans at the last minute. I understand."*** Guilt from having to cancel plans because of not feeling well, or not having the energy, is common for people with chronic pain and illness. When someone expresses understanding, it's a great relief.

Dear Loved One

6) "*You look so good, but how are you feeling?*" When someone says you don't look sick, they think they're paying you a compliment most of the time. It's nice to hear someone acknowledge they understand you may look good but not feel well.

7) "*I hope you're as well as possible.*" No matter how hard you try to 'be well,' a chronic illness limits your well-being. Good wishes that give the nod to those limitations take the pressure off and let you know they 'get it.'

8) "*It must be difficult to be in pain or feel sick all the time.*" The idea is to let someone know you've really heard what they've told you by reflecting that back to them in your own words. When you actively listen to someone, they feel validated, essential to people with a chronic illness.

9) "*I just wanted to check up on you and let you know I miss you!*" After being out of the loop for a while, it's nice to know that your friends miss you and think of you — and that they want to be around you whenever you're up to it.

10) "*You're doing everything you can.*" This one can be such a relief to hear instead of another piece of unsolicited advice. Guilt from feeling like you should be doing more is common, so having someone recognize that you are doing everything you can is uplifting.

It Boils Down to This

When we're not feeling well or are frightened about our health, advice is often the last thing we want. What's more important is simply being listened to—and knowing that we're being heard. So a sentence like, "*I hear you saying that things seem pretty hopeless right now,*" or, "*It sounds like the pain is horrible today—how can I help?*" opens the door more to an expanded, supportive conversation, unlike unsolicited advice.

Dear Loved One

Much of the time, compassion is what people are looking for when they talk about a challenge in their health journey. Not pity, not solutions, not unsolicited advice, and especially not judgment—just a listening ear, maybe a hug, or an "I believe you" or "I'm here for you." If they want your opinion or suggestions, they will almost always ask!

If they really need help, consider hiring a patient health advocate to support their needs during a confusing and challenging time. You can find a directory of health advocates with search parameters by geography and condition at <https://advconnection.com/>.

Finally, remember that every person is different, and every relationship is different. When in doubt, tread lightly, or even ask how to proceed: *"I am here for you, but I'm not sure how to discuss things. Tell me as much about your condition as you are comfortable sharing and what you prefer."*

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Say you love them better.

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Share this guide with your loved ones or friends who don't know what to say. Help them learn how to better communicate with you during your time of need and preserve the relationships that matter most.