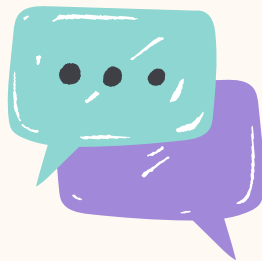


EXPLAINING *The invisible*

A conversation guide for CHRONIC ILLNESS



Talking about chronic illness can be hard—especially when you're trying to explain something you barely have words for yourself. This guide gives you simple ways to begin honest conversations with the people you love.

You don't have to explain everything at once

Choose the relationship or situation that matters today, and begin there.

HOW TO USE THIS GUIDE



Choose the person you want to talk with.



Pick one or two prompts that fit.



Change the wording to sound more like you.



Pause when you need to. Connection matters most.



Some prompts are things you might say. Others are questions you can talk through together.

The People Closest to You



HUSBAND OR PARTNER

These conversations can help your partner understand what life is actually like inside your body—not so they can fix it, but so they can walk alongside you.

- ☐ One thing I wish you understood about my energy is...
- ☐ When I say I'm tired, what I mean is...
- ☐ The hardest part of my illness that you don't see is...
- ☐ When symptoms flare, I feel most cared for when...
- ☐ One thing I miss doing together is...
- ☐ A smaller or more accessible version of that could look like...
- ☐ When plans change, what I need from you is...
- ☐ I feel like we're a team when...

PARENTS OR FAMILY

For when you want them to understand and support you in a new way.



- ☐ Something I wish you understood about my illness is...
- ☐ I know you want to help. The thing I need most is...
- ☐ When you tell me to push through, here's what happens...
- ☐ One way you could encourage me is...
- ☐ The biggest misconception about my illness is...
- ☐ What I need from you most looks like...
- ☐ One thing I wish you would ask me instead of assuming is...
- ☐ One thing I wish you knew about how chronic illness has changed my life is...

TALKING WITH CHILDREN

Simple language works best. Keep it honest and age appropriate.

- | | |
|--|--|
| ☐ Mom's body gets tired faster because... | ☐ I may not always be able to... and that's okay. |
| ☐ When I need to rest, it doesn't mean... | ☐ My favorite thing to do together on hard days is... |
| ☐ One thing you can help me with is... | ☐ What questions do you have about my illness? |



Friends & Extended Family



FRIENDS

*Good friends usually want to help.
Sometimes they simply don't know how.*

- ☐ I still want to be included, even when...
- ☐ If I cancel, it's because...
- ☐ Here's how we can still spend time together...
- ☐ The kind of text I love the most is...
- ☐ I don't expect you to fix anything, I simply need...



EXTENDED FAMILY

For family gatherings, expectations, and helping others understand your limits.

- ☐ I may not be able to stay for the whole gathering, and that's okay.
- ☐ Even when I look okay, my body may be working much harder than it seems.
- ☐ The best way to support me at family events is...
- ☐ When I leave early, it isn't because I don't want to be here...
- ☐ The hardest part about family gatherings isn't always my symptoms... it's...

WHEN I NEED TO CHANGE OR CANCEL PLANS



- ☐ "I still want to be included, even when I can't always come."
- ☐ "I need to cancel today. I'm disappointed too and I hope we can try again."
- ☐ "My body needs extra rest today."
- ☐ "I may need to leave early. That helps me participate without paying for it for days after."
- ☐ "Thank you for understanding."

Places where it can be harder to explain



WORK OR SCHOOL

For talking to your boss, co-workers, or teachers

- ☐ Here's what helps me do my best work...
- ☐ My symptoms can change from day to day...
- ☐ If I ask for flexibility, it's because...
- ☐ One thing that makes a big difference for me is...
- ☐ Here's one accommodation that makes a huge difference...

MEDICAL APPOINTMENTS

For getting more out of your appointments



- ☐ The symptom affecting my life the most is...
- ☐ My biggest concern today is...
- ☐ What I hope we accomplish today is...
- ☐ I don't feel heard when...
- ☐ What worries me most about this symptom is...

CHURCH OR FAITH COMMUNITY

Faith communities can become incredible support systems when they understand what you're experiencing.



- ☐ Some Sundays my body will not cooperate, even when I want to be there.
- ☐ Missing church does not mean my faith is weak.
- ☐ One way you could support my spirituality is...
- ☐ I would still love to participate through...
- ☐ Please ask what I need rather than assuming.
- ☐ "Would you be open to hearing how chronic illness has changed my experience of church?"

You don't have to have the perfect words



QUESTIONS THAT HELP

To help others ask you questions.

- ☐ What does today feel like?
- ☐ Would you like help, company, or quiet?
- ☐ Do you want advice or do you need me to listen?
- ☐ Is there anything I can take off your plate?
- ☐ What has been the hardest part of this lately?
- ☐ What do you wish people understood?
- ☐ How can I make this plan more accessible?
- ☐ How can I pray for you?

THINGS YOU CAN SAY

What others can say to you to help.



- ☐ I believe you.
- ☐ You don't have to prove how sick you are to me.
- ☐ I am not disappointed in you.
- ☐ We can change the plan.
- ☐ You are not a burden.
- ☐ You don't have to make me feel better about what you are going through.
- ☐ I'm here, even when I can't fix it.
- ☐ You don't have to explain yourself to me.

A GENTLE REMINDER

You are allowed to explain your needs without defending your worth.

You can begin with one honest sentence. That is still a conversation.

You are not alone

Every honest conversation creates a little more understanding.
You don't have to explain your whole illness today.

One conversation at a time is enough.