



Tackling communication challenges

Every person living with lupus should have a few trusty hip-pocket phrases ready to go for moments when the three lupus challenges—unpredictability, invisibility, and memory loss—come up.

A hip-pocket phrase is a statement that:

- You can use anytime, anywhere
- You can easily remember
- Others can easily understand

As you read through the examples on the next page, notice how the “recipe” for an effective hip-pocket phrase has 3 key ingredients:

1. An acknowledgement that lupus may be creating an inconvenience.
2. A demonstration of empathy with the other person’s position.
3. Information for the other person about how lupus is impacting you in the moment.

Step 1

On the next page, read the list of hip-pocket phrases for each of the three lupus challenges. Circle or write a phrase or two from each list that you think might work for you. Then, try writing your own hip-pocket phrase for that lupus challenge. You may even want to mix and match parts of different phrases to best suit you.

Step 2

On page 3, brainstorm a few situations when you might need to use one of your hip-pocket phrases. Practice writing your own hip-pocket phrases as you figure out what works best for you.

Step 3

Keep a list of your favorites on page 4 of this worksheet, along with situations when you’re likely to need them. And don’t forget to practice! It may take a few tries to get comfortable saying the words, but it’s worth it.

The better you become at saying your hip-pocket phrases out loud, the more confident you’ll feel about using them when the time comes!

✓ Make the most of this exercise

- Keep a copy of page 4 on your fridge or in your purse or wallet. You can fill it out digitally on your tablet or computer, or print it out and write your favorites by hand!
- Practice, practice, practice! Enlist help and take turns playing the roles of the person living with lupus and the other person. If you have children who are grade-school age or older, they often make great practice partners!
- Sometimes, others may not accept your efforts to explain how lupus is affecting you. No matter how they respond, remember that...
 - You can’t make anyone understand lupus who doesn’t want to understand lupus.
 - You can’t force others to be supportive or to respond in the ways you prefer.
 - You CAN love yourself and have gratitude for those who love you no matter what.



Hip-Pocket Phrase Examples

Unpredictability: due to lupus symptoms that can be ever-changing and confusing

I'm sorry I have to cancel today...

- I'm sorry I have to cancel today. I didn't expect to be sick, but lupus is very unpredictable. Severe swelling and pain can happen anytime with lupus and that's what's happening now.
- I'm sorry I have to cancel today. I'm really disappointed. With lupus, severe symptoms can come on very fast and that's what happened this morning.
- I'm sorry I have to cancel today. I'll tell you what my rheumatologist told me: Lupus can produce serious symptoms without any notice. I didn't even see this coming, but now I feel very sick.

Write your own hip-pocket phrase here:

Invisibility: due to lupus symptoms others can't see or hear

I know I don't look sick, but...

- I know I don't look sick, but I actually feel really bad. With lupus, most inflammation affects internal organs. So I feel it, but you can't see it.
- I know I don't look sick, but I feel terrible. Lupus is so misleading because it damages structures inside your body with almost no outward signs.
- I know I don't look sick, but sometimes I wish I did! Lupus is a serious disease that attacks the inside of my body, so there's no way people can see what's making me so sick.

Write your own hip-pocket phrase here:

Memory Loss: a slowing down or forgetfulness that may be caused by lupus

Would you mind repeating that, please?...

- Would you mind repeating that, please? I just need to write this down. Sometimes lupus makes it hard to keep multiple things straight in my head.
- Would you mind repeating that please? I have lupus, which can sometimes make it hard for me to keep track of what's being said.
- Would you mind repeating that, please? Just give me a minute to gather my thoughts. Lupus can sometimes make me feel forgetful, so it takes a little extra effort to keep up.

Write your own hip-pocket phrase here:



Prepare and Practice

Situations when you might need to use a hip-pocket phrase:

- Can't attend Grace's birthday lunch
- Can't host book club
- Can't follow what plumber is telling me about the sink
- Neighbor complains about my front yard, saying I look well enough to be gardening

Now add your own:

List a few examples from your own experience. Think about times when a hip-pocket phrase would come in handy.

Practice writing more hip-pocket phrases here as you come up with them:



My Hip-Pocket Phrases

Unpredictability

Invisibility

Memory Loss

When I Might Need to Use These Phrases

→ Ready for more?

Go to usinlupus.com/SolWants to download the next activity: "Wants and Needs."