

Long-time Warrior Reflection

Podcast Companion Tool

1. Start with acknowledgement

You have lived with HS for a long time. That matters.

Prompt:

How many years have you been living with symptoms (even if you didn't have a name for them yet)?

Optional: When did you first realize “something isn't right”?

(Hint: it doesn't have to be a dramatic moment — most of us have gradual stories.)

2. Looking back at the version of you who first faced this

Prompt:

What do you wish you could tell the younger version of you who dealt with this alone?

Start with:

“You didn't know it then, but...”

3. Your pain tolerance isn't weakness — it's endurance

Long-time warriors learn to normalize pain in ways most people never will.

Prompt:

What are 3 things you've quietly endured that others probably don't understand?

- _____
- _____
- _____

4. Healthcare fatigue

You've likely been dismissed, ignored, misdiagnosed, or treated like you were exaggerating.

Prompt:

Write down 1–2 healthcare experiences that shaped how you view doctors today:

Now add:

"What do I wish that provider had said or done differently?"

5. Permission to try again

If you've been out of medical care for a while, there's usually a reason: trauma, burnout, expenses, exhaustion, hopelessness.

Prompt:

What has stopped you from going back?

Check any that resonate:

- ☐ I had a bad experience
- ☐ I don't want to be judged
- ☐ I'm tired of repeating my story
- ☐ I feel like nothing will help
- ☐ I hate being touched or examined
- ☐ I'm scared of meds or side effects
- ☐ I'm tired of being "the patient"
- ☐ Other: _____

Now ask yourself:

"Would I allow someone I love to suffer alone because of these experiences?"

☐ Yes

☐ No

If no, what would you encourage THEM to do?

That advice applies to you, too.

6. New medical landscape

You don't need to list treatments. Just acknowledge they exist now.

Prompt:

What would it feel like to walk into a dermatology office where the doctor already knows HS, instead of you teaching them?

Try to answer without fear language:

7. Your contributions matter

Some people don't realize that long-time patients built the HS community. They made TikToks, posted photos, joined forums, advocated, survived.

Prompt:

What are 2–3 ways you have already contributed—even indirectly?

Examples:

- **I survived years of not knowing what it was.**
- **I helped normalize scars for my friends.**
- **I showed up to work when it was hard.**
- **I raised kids while living through flares.**

Your turn:

8. Write yourself a message

Talk to yourself the way you would talk to someone else who has lived in pain for 5, 10, or 20+ years.

Start with:

“You have carried this longer than most people will ever understand, and...”

9. Hope is not naïve

Prompt:

What is one area of your life that could get better even if HS stays with you forever?

10. Takeaway sentence

Complete this:

“My story isn’t over. I deserve _____.”
