

A GUIDED WORKBOOK

16 PAGE
WORKBOOK

Sharing Your Chronic Illness Story



GUIDED WORKBOOK

Intro & Disclaimer



Hi! I'm Haley James and I'm so glad you found your way to this workbook!

I made this workbook because when I got sick, I had no idea how to talk or share about what had happened and I know I'm not the only one who has felt that way.

Whether you are wanting to share with your family and friends or more publicly on social media - hopefully working through this workbook will help you come up with the best way to share your story with others.

These five steps will help you feel better prepared, in control, more informed, and will (hopefully!) give you the confidence to navigate this chapter of your life more easily and comfortably.

I encourage you to stop at the end of each section and ask yourself the thought-provoking questions provided at each checkpoint - whether you just answer them in your head or write your thoughts down in a journal or in the workbook, what matters is that you are asking and listening to yourself so that you can make the best choices for you.

I know it's not easy to do, but in being brave and doing so - you are creating a safe space for others to be brave too.

I'm so glad your here and ready to share your story.

I love you, I mean it.

xx, Haley James

TIP #1

Share Your Story With Yourself First

When you first receive a diagnosis, there can be seemingly endless thoughts all running around in your brain at the same time. It can honestly be a little chaotic in there. One of your first thoughts might be to immediately tell somebody what you're going through. This is probably especially true if you are the type of person that feels most supported when you're in the company of others (as opposed to the type of person who handles almost everything by themselves... raises hand). No matter which category you might fall into, though, this first step remains the same - before you share the news with others, you should share the news with yourself first.

Now, you might be thinking - huh? I literally just heard the news directly from my doctor. Yes, you heard it - but did you really hear it? Did you feel it? Have you sat with it and asked yourself how it made you feel? Not just present you, either - how does it affect your past self, and how does it affect your future? These are all things that you should think about before you decide to share your journey with others. It's important to know, too, that this doesn't just affect people who are newly diagnosed. Even if you've had a diagnosis for a decade, that doesn't mean that you have taken the time to truly react to it, sit with it, let yourself feel it, and process it. This is especially true if you've been living in survival mode ever since, which is common for many of us.

TIP #1

Share Your Story With Yourself First

Don't get me wrong - there is nothing wrong with sharing the news immediately with your most trusted person or people, whoever that might be. It could be your parent, sibling, best friend, or partner. They can be a source of comfort and help you process and grieve if that's what you need. Before you start to share on a wider scale, though, you should take time yourself to feel your feelings, think your thoughts, and be alone with those things for a while. You will be better prepared to share with others when you've had the time to take it in, respond, and become more comfortable with your own reactions before you have to deal with theirs.



Quick Check-In

How did you feel immediately after receiving your diagnosis? What about when you got home from the appointment? How is that different from how you feel now?

What would you tell your past self, if you could? What do you think your future self would say to you now?

What “negative” feelings do you have about your diagnosis (fear, anger, sadness)? What about “positive” ones (relief, validation)?

TIP #2

Research. Research. Research. Research.

So, what does this have to do with sharing your story? Once you start telling your story, others will see themselves in it - others that perhaps haven't taken the time to sit with it, react to it, or do their research as thoroughly as you have. In addition to having knowledge to back you up and becoming your own best advocate, you might also become a beacon of light for other people who may be dealing with a similar situation but might be too afraid or ashamed to share. You don't have to become a guru on your condition and walk people through a treatment plan (please leave that to their doctors), but being able to point people in the right direction towards resources - even if it's just sharing a couple of links and some words of solidarity and encouragement - can go a really long way.



TIP #2

Research. Research. Research. Research.

When you're in the wake of a new diagnosis (or even an old one), knowledge truly is power. The more information you have, the better advocate you will become. Being able to advocate for yourself at doctors' appointments is an invaluable skill, especially when it comes to chronic conditions that can oftentimes be invisible. Many doctors won't investigate further than surface level unless you ask them to. Sometimes, you have to be very persistent, and it's hard - but you can go in armed with knowledge and research to back you up.

Once you have that knowledge, you have complete control over what you decide to do with it.

You can use that information to better manage your own symptoms. Maybe there's a certain supplement that's really helped other people with your condition, or maybe there's a certain diet that can improve symptoms. Sometimes, as chronically ill people, we can feel helpless as so many things happen to us that we have no control over - so just taking a little bit of control back here and there, where we can, can be really powerful for us.

Quick Check-In

What questions do you still have about your condition? How do you think you could find answers to those?

Do you have a support system? If you do, do they understand and relate to what you're going through on a first-hand, personal level? If not, where could you find people that do?

If somebody were to approach you who had the same condition as you, overwhelmed and looking for a place to start, what would you say to them?

TIP #3

Start Making A Plan

If you're reading this, it's probably because you have something that you want to share, and there is someone - or multiple someones - that you want to share it with. The scope of the actual sharing will differ based on your situation, but whether you're disclosing to just one person or all 5,000 people on your Facebook page, you'll want to have a plan going in. This will allow you to maintain a feeling of control over the situation, which is always the goal.

So, now that you've given yourself the time and space to process your own journey and become your own expert advocate, now it's time to really think about how and when you're going to tell your story. Just remember this: nobody can force you to share anything, and you don't ever have to tell a soul until you're ready and feel comfortable and safe doing so.



TIP #3

Start Making A Plan

THE HOW: This is the part that's going to depend on you and your situation the most. Are you only telling one person or a small group, or are you going totally public? Maybe this is going to look like a one-on-one private conversation, or maybe it's going to be a substantial social media post. The nature of how much you're sharing and who you're sharing it with is what's going to dictate this. No matter the scope, though, the first thing you should do is think about the method you're going to use to share. In person? A phone call or FaceTime? A social media post? A blog? A YouTube video? All of these are valid options. Next, plan out what you are going to say in advance. This is definitely easier if you're making a post or a video, but you can also do it for in-person conversations.

If you are sharing with somebody face-to-face, try to plan in advance for how the conversation might go, so you can be prepared for whatever direction it may head in. You can jot down notes in a journal, on the Notes app on your phone, or if it's a social media post, blog, or email, you can even save it as a draft. It's sometimes better to get ALL your thoughts out first, then go back, edit, and give it some more structure later.

TIP #3

Start Making A Plan

THE WHEN: Timing may or may not matter to you. Perhaps you're announcing a diagnosis during your condition's particular awareness month, or maybe you are just waiting until the next time you see a certain person. Maybe it's just going to be a random, regular Tuesday - and all of these options are okay! Specifically when you actually decide to share isn't as important as you choosing a day so that you can be prepared. It helps to have control over that because it means that you can give yourself as much time as you need. It's just one more way that you can know what to expect and take some of the guesswork out of the whole equation.

AND THE WHY: If you get stuck on any part of this step, go back to the basics. Try to stop worrying about others and turn the focus back to you. Remind yourself of the reasons that you want to share this story - is it so that someone you love can understand you better? To reclaim your power? To spread awareness? Our reasons are as unique as we are, and there are no wrong answers. Staying true to yourself will always guide you down the right path.

Quick Check-In

What's your biggest reason for wanting to share your story?

If someone reacted positively to your news, what might that look like? What might they say, and how would you respond to that? Do the same thing for someone responding negatively, someone responding in a way that surprises you, and someone responding with a similar story.

What would be the best possible outcome? The worst? What would be somewhere in the middle?

TIP #4

Check In With Yourself Again

Yeah, I know - we just did this, didn't we? Well, we're doing it again - because it's that important! By now, you've gone through some steps. You've shared your story with yourself and given yourself time to process it. You've done some research. You've made a plan to make a post on your Instagram on the third Wednesday of next month at exactly 6:28 PM as the sun is setting and the - okay, you get the point. You've already come so far, and you really should be proud of yourself. This is not easy stuff to do, and even just thinking about doing it takes a lot of courage. So, take a moment to sit with that. Appreciate your bravery, and give yourself gratitude and compassion. You deserve it.

Before you go ahead with the actual sharing part, I want you to revisit the first step that we went through together earlier - check in with yourself. Now that sharing your story is a real, tangible event that you've planned - how do you feel about it? Do you feel more nervous than before? Do you feel more confident? Are you excited, scared, or maybe even both? Don't stop at just asking yourself how you feel right now, but ask yourself how you might feel during and afterwards, too. Remember that you, and you alone, have the final say. If it doesn't feel right, there is absolutely no reason that you have to go through with sharing. You can wait until you're ready, and even if that day never comes, that's okay too. At the end of the day, the main reason that you should be sharing your story is because you want to.

TIP #4

Check In With Yourself Again

Throughout this entire process, it's so important to take care of yourself and give yourself the love and compassion that you deserve. If you are able, take walks and breathe some fresh air. Do things that you enjoy; get lost in your hobbies. Get your favorite scent of bubble bath. Smile. Laugh. Listen to your favorite music. Live, and be you. Indulge in what's important to you, and remember that you are loved!



Quick Check-In

It's important to be in tune with how you feel in the present, but how would your past self feel if they knew what you were about to do? What would your future self say to you now, as you're preparing to share your story?

How might you feel in the moment, while you're sharing? How can you respond to that?

What are some ways that you can plan to practice self-care after sharing?

TIP #5

Hit Send!

“Hit send” in this instance might be literal (if you’re making a post on social media or writing a blog) or a metaphor. Even if sharing your story is going to be an in-person conversation, the sentiment remains the same. Your feelings have been felt, your research has been researched, and your plans have been planned. You’ve done everything there is to do except actually... do the thing. So, hit send. You’ve got this - you’ve prepared for this. You’ve taught yourself what to expect. You’ve come ready with information, wisdom, and confidence.

When you’re ready, we are all standing right here behind you.

From someone who’s been there, there is something so incredibly freeing about sharing your story with other people and being your full, vulnerable, authentic self. It’s not even so much about the responses that you get from others as much as it’s about how it feels to break free from something that you may have been hiding for a long time. By being open and speaking your truth, you are taking back your power and regaining control over your own story, your own narrative, and your own life - and nobody will ever be able to take that from you.

I’m so proud of you, and I hope you’re proud of yourself, too.

Quick Check-In

Ah, You did it!!! How do you feel? Are you nervously waiting for responses? Are you getting emotional? Whatever you are feeling is COMPLETELY valid! It is a big deal to share this with your loved ones and I am proud of you for doing so!

So just to check in - how do you feel?

Now while you wait to hear back, take a breath and know that I AM SO PROUD OF YOU! I would love if while you wait for the responses, you would send me a message and let me know that you did it so I can celebrate with you too! DM me @itshaleyjames_ or send me an email info@itshaleyjames.com - I cannot wait to celebrate this with you!

HERE'S SOME

Support

I hope this workbook was able to provide you with some ideas that will hopefully help you feel empowered, supported and not alone on your health journey.

If you found this helpful (which I really hope you did) and are looking for more supportive content - on the next few pages you will find some of the resources and content I have created to continue to support you on your journey!

If you are viewing this on a device you can just click on the images on the next few pages and they will take you to the designated site page - making it super easy to access!



HERE'S SOME

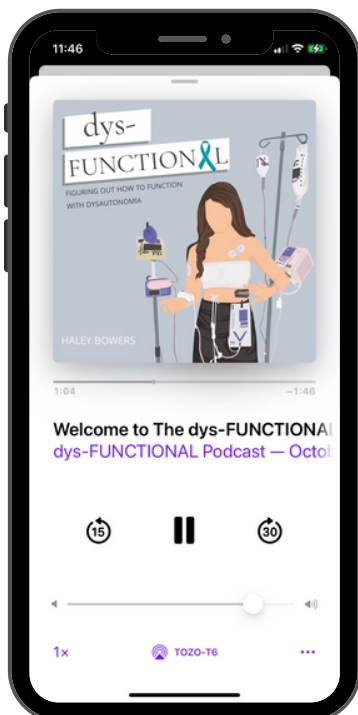
Support



WATCH ON YOUTUBE

Others on YouTube shared their stories & gave me hope when I needed it most & that made all the difference for me on my health journey & finding my purpose. My goal here on this channel is to be able to do the same for you!

You can expect all things chronic illness experience & education, advocacy, chats about passion & purpose, and a lot of me just sharing who I am & who I am working to become. I hope you'll join me!



DYS-FUNCTIONAL PODCAST

Each episode, we feature a fellow Dysautonomia warrior, medical professional, researcher, specialist, caregiver and more as we talk through some of the biggest and most common questions you have about Dysautonomia.

We're talking about friendships, advocacy, treatments, dating, medications, laws, relationships, research, self-confidence and so much more, all with the focus being on how to navigate and find joy despite the conditions we have or the circumstances we are in!

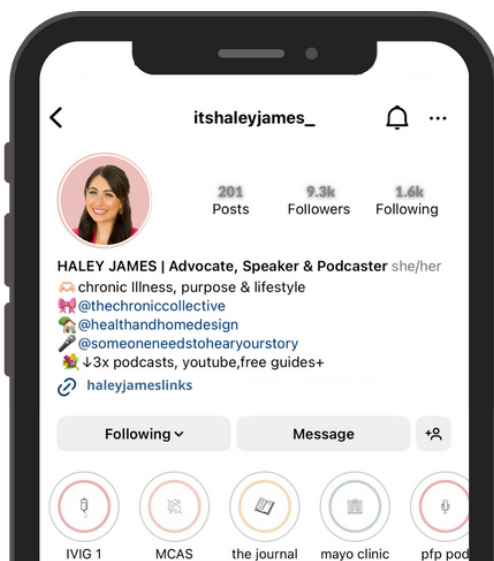
HERE'S SOME

Support



SHOP THE STORE

We know that how we choose to show up in our lives matters – that can include how we dress and choose to express ourselves! That's why I created some timeless & style-versatile options that can help us start conversations and opportunities to share our stories that I know can truly make a difference in our lives and in the lives of others!



CONNECT ON INSTAGRAM

Be sure to follow and connect with me on Insta where I share my life and chronic illness, the things I am going through, and learning!

I love meeting people and hearing their stories so please come join me over there and be sure to say hi! @itshaleyjames_

HERE'S SOME

Support: 1:1 Call



When I began my health journey and started to get diagnosed with multiple medical conditions, I began following others going through the same thing online. I would DM them asking them just some of the millions of questions I had and anxiously awaited their answer. Many of them were too sick or had too many DM's to get back to me and I thought – wow I wish I could just pay to talk to them because it would truly be so helpful.

SO now almost a decade into this journey, that's what I want to offer here – something I desperately needed and wanted – an opportunity to talk to someone who has been there and would be willing to share their experience, tips/tricks, resources etc. So if you are reading this and think this might help click the image to be taken to the site to learn more!

HERE'S SOME

Support: Support Group



Trying to navigate chronic illness by yourself can feel so overwhelming, isolating and just impossible at times. After spending years trying to find a solid support group, hosting some through organizations and being in multiple types myself - I decided to start my own!

I would love to have you come join me and the community at our free monthly virtual support group!

HERE'S SOME

Support: Monthly Events



One of the most important things to help you navigate chronic illness is community – but due to symptoms, accessibility etc., that can sometimes be hard to find. That's why I'm excited to invite you to our monthly event designed specifically for individuals living with chronic illness!

Mark your calendars for the 3rd Wednesday of each month because that's when we have our monthly event and bring together panels, guest speakers, interviews with professionals, influencers, doctors, patients, advocates, and even members of Congress to help support you on your chronic illness journey!

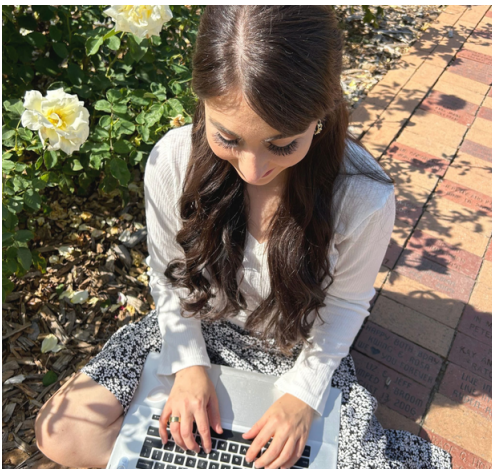
HERE'S SOME

Support



PARTNERSHIPS

Do you have a brand, product, service, or business that aligns with what I do? Great! I offer many unique ways that we can partner, such as affiliate and ambassador programs, sponsorships, advertisements, reviewing, and more. I can't wait to work with you!



EDUCATIONAL CONTENT

I believe in reliable information and accessible education for all. That's why I've created downloadable resources, informative e-courses, engaging media, and more. Whether it concerns chronic illness and health or finding your passion and purpose, there's something here for everyone!

HERE'S SOME

Support



SPEAKING & TEACHING

Sharing our stories is what unites us. I'm passionate about sharing what I've learned over the years to inspire empowerment, create awareness, motivate others, and impact change. Not only do I know what it's like to be a rare chronic illness warrior, but I've also endured incredibly challenging times, overcome impossible obstacles, and come out the other side – resilient and knowing my purpose – and now I want to help others find theirs.



SNTHYS

As I said, I am super passionate about helping people share their stories, that's why I created, "Someone Needs To Hear Your Story" a street interview series to help encourage people to own and share their stories and experiences with the world.

HERE'S SOME

Support



ADVOCACY

Do you have a brand, product, service, or business that aligns with what I do? Amazing! I offer many unique ways that we can partner, such as affiliate and ambassador programs, sponsorships, advertisements, reviewing, and more. Let's spread the word together!



CONSULTING

My consulting service is designed to help healthcare organizations, and businesses develop more inclusive environments and improve patient experiences. With my understanding of the challenges faced by individuals with chronic illnesses and disabilities, I provide valuable insights, guidance, and practical strategies to promote accessibility, equity, and patient-centered care. I can't wait to work with you to create something that truly improves the lives of patients!

Thank you!

Thanks so much for taking the time to check out my site, my content and supporting all that I do. It really truly means so much.

As someone with a bunch of chronic conditions, being able to create businesses that I can manage while sick, are in areas that I am passionate about AND help people - is such a blessing and I couldn't do it without the love and support I get from you, so thank you.

I am incredibly grateful to be able to live out my dreams and purpose in this way and want to be able to continually thank you by creating content that actually helps you!

So with all that being said, I would love to hear any suggestions of things you are looking for or needing on your journey so that I can figure out the best way to continue to make content that supports you!

You can get in touch with me through my contact page, or find me on Instagram @itshaleyjames_ and send me a message there.

Thanks again for your love & support. I couldn't do this without you.

As always - I love you, I mean it ♥

