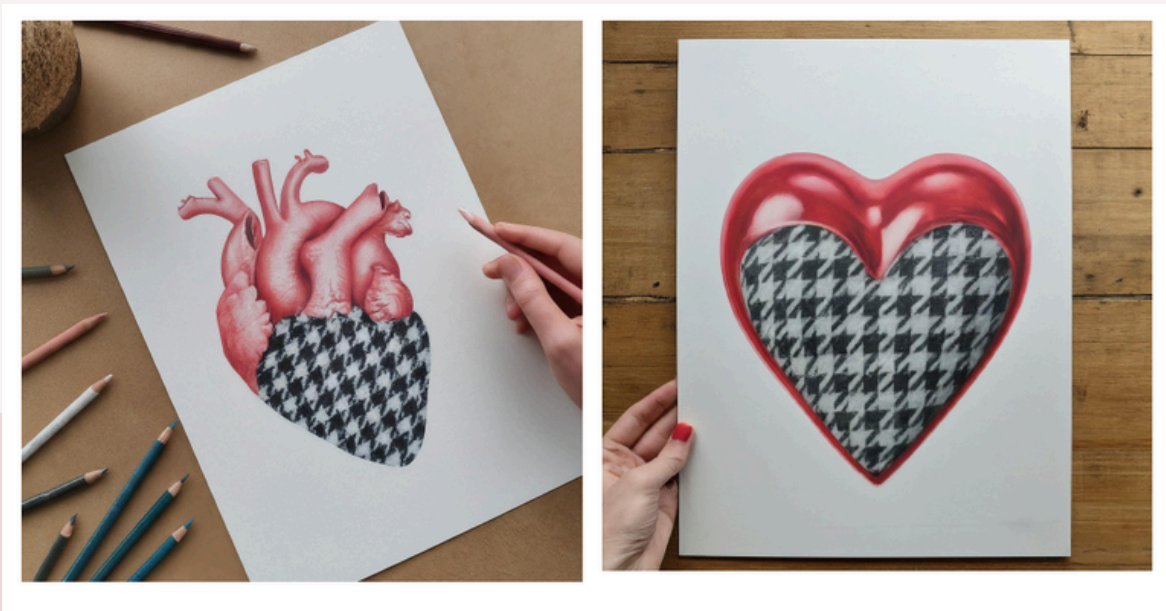


LIPODYSTROPHY STORYTELLING WORKBOOK

JULY, 2024



Amplifying Lipodystrophy Voices:
The Transformative Impact of
Storytelling!



How to use this workbook

Since the founding of Lipodystrophy United, I have received messages from countless individuals who have felt a profound connection and a renewed sense of hope after hearing the stories of others living with lipodystrophy. Stories resonate deeply, prompting many to reach out and share their own experiences, creating a ripple effect of empathy, understanding, and solidarity.

We created this workbook as a resource to help guide you in writing your unique lipodystrophy story. It is designed for individuals with lipodystrophy, caretakers, family members, and advocates. Feel free to disregard any unhelpful information and skip activities that don't suit you. The questions are suggestions, not requirements. Share only the personal details you are comfortable with in your stories

Remember, you own your story. Any stories shared with Lipodystrophy United are shared for the purposes of awareness, understanding, and connection. We will not use your personal information in any way without your consent.

Thank you for being a part of our community and for considering the powerful role your story can play in making a difference. Let us come together to amplify our voices and create a lasting impact.

Andra Stratton

Andra Stratton, President & Co-Founder



Lipodystrophy United

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01

PURPOSE

Why does my story matter?

Your story matters for many reasons.....

- **A lack of stories in our community:** Many individuals in the lipodystrophy community have tirelessly searched for stories similar to their own, often without success. There are only a few stories about people with lipodystrophy accessible on the web, and the stories available require extensive digging.
- **Lifeline:** Your story could help diagnose others and serve as a beacon of hope for people recently diagnosed.
- **Raising awareness:** Sharing your story can help researchers, doctors, and supporters gain a deeper understanding of the human side of the work they do and the importance of patient involvement.
- **Connection with other people with lipodystrophy:** Sharing your story could bring a supportive community of other people who want to talk about their lipodystrophy experiences directly to you.

02

SETTING AN INTENTION

Why am I sharing my lipodystrophy story?

Set an **intention** that is consistent with the format of your story.

- Are you writing your story and sending it to LU?
- Are you filming a video and sharing it with LU?
- Are you writing a blog or posting on your personal social media?

Intention Examples:

1. You want to **help others gain a diagnosis** with a much easier path than you.
2. You want to **build connections** with other people in the community with similar experiences.
3. You want to urge others to **take a specific action** to help the LU community.
4. You want to **inspire** an emotional reaction, gratitude, inspiration.

*Note: Your story has a broad impact. LU's website and social media reach doctors, lipodystrophy researchers, potential patients, and patients.

03

BRAINSTORMING

Disasters, Adventures, Mishaps, Triumphs, Setbacks,
Turning Points

Make space for brainstorming the key moments and events that shape your lipodystrophy story. Our goal right now is to generate as many ideas as possible, without worrying about their quality.

- **What stands out the most in your memory?**
- **What are the stories you often find yourself sharing?**

On the next page is a brainstorming worksheet with prompts to help you think about these moments cohesively. Try to come up with three ideas for each prompt. Don't worry if your ideas don't fit the prompts perfectly - they're just here to inspire you.

Disasters: Think of moments when things went wrong or challenges you faced.

1.)

2.)

3.)

Adventures: Recall exciting or unexpected experiences related to your journey.

1.)

2.)

3.)

Mishaps: Consider any small accidents or humorous incidents along the way.

1.)

2.)

3.)

Triumphs: Highlight your achievements and victories, no matter how big or small.

1.)

2.)

3.)

Setbacks: Reflect on setbacks or disappointments and what you learned from them.

1.)

2.)

3.)

Turning Points: Identify key moments that changed the direction of your story.

1.)

2.)

3.)

04

SCENEBUILDING

How do we transport our audience?

Narrative transportation is the state of being so immersed in a story that it becomes your whole mental world. Building a cohesive world can be done with vivid sensory detail.

Choose one of the memories/events that you brainstormed on the previous page and transport yourself back to that memory.

I could hear in the background...

I could see someone _____ who said to me...

My skin felt ...

The air was...

I was wearing...

I was waiting for...

In front of me was...

I felt...

Now paint a picture of what was happening in this moment in detail and how that moment is impactful to you now.

05

WRITING YOUR LD STORY

What should I talk about in my story?



Advocacy

My skills to help the community

Medical Care

My experience with doctors along the way



Diagnosis

Journey to Diagnosis

Support

Finding people who support my experiences



Knowledge Sharing

What I wish I would have known



Continued Challenges

Symptoms, day-to-day experiences



Experience and Insight

How I live with lipodystrophy



My **message** to doctors, patients, and potential patients



The Five W's and One H

Who....

- Who are you?
- Who first started noticing something unusual?
- Who diagnosed you with lipodystrophy?
- Who are your biggest supporters?

Where...

- Where do you live?
- Where do you receive treatment?
- Where do you go for information about lipodystrophy?
- Where do you find the most emotional support?

What....

- What do you do on a day to day basis?
- What makes you happy?
- What was your diagnostic process like?
- What symptoms do you struggle with in your day-to-day life?
- What treatment or management strategies have been most effective for you?

- What resources do you think the lipodystrophy community lacks? What would you need to feel supported in your condition, if anything?
- What would you like to share with doctors?
- What would you like to share with other lipodystrophy patients?
- What would you like to share with the broader community?

When...

- When did you first develop symptoms?
- When did you first hear about lipodystrophy?

Why...

- Why are you sharing your story?
- Why is it important to raise awareness about lipodystrophy?

How...

- How long did it take to get a diagnosis after you started exhibiting symptoms of lipodystrophy?
- How did you feel after diagnosis?
- How has living with lipodystrophy impacted your relationships?
- How do you manage your condition on a daily basis?

06

RESOURCES

Resources used for this guidebook:

<https://www.storycollider.org>

<https://globalgenes.org/blog/using-storytelling-to-raise-awareness-for-your-rare-disease/>

<http://rareaction.org/wp-content/uploads/2016/09/nord-ran-toolkit-2016-how-write-patient-story.pdf>

Coming Soon: A Sneak Peek at New Workbook Resources...

Self Advocacy Resource

<https://globalgenes.org/wp-content/uploads/GG-Toolkit-Becoming-An-Empowered-Patient.pdf>

Creating a care notebook

https://globalgenes.org/wp-content/uploads/2018/11/GG_toolkit_care-notebook_FINAL1.pdf



Want help or have questions?
Email us at
info@lipodystrophyunited.org



*This workbook is dedicated to our lipodystrophy sister
and friend, Natalie Embry, and all others we have lost
whose stories continue to inspire*

www.lipodystrophyunited.org