



2025

Patient Advocacy Resource
Guide and Toolkit



About This Toolkit

Living with hepatitis B can be challenging, but your voice has the power to create real change, not just for yourself, but for your community and future generations. This toolkit is designed to empower people living with hepatitis B to become advocates in their own health journeys and to lead efforts that improve policies, programs, and quality of life for all those affected. Whether you're advocating for better healthcare, raising awareness, or pushing for the elimination of hepatitis B, this guide offers practical tools, emotional support, and strategic insights to help you take action. Grounded in community wisdom and lived experience, the toolkit includes sections on understanding patient advocacy, discovering your personal motivation, crafting and sharing your story with impact, setting boundaries, navigating stigma with self-compassion, practicing self-care, and taking your first steps into advocacy. No matter where you are on your journey, this guide is here to support you in speaking up, sharing your truth, and making a difference.

Understand and Engage in Advocacy

- Learn what patient advocacy is, why it matters, and how you can take action in your community and beyond.

Share Your Story with Impact

- Use practical tools and guidance to craft and share your personal experience in a way that educates, empowers, and inspires.

Prioritize Emotional Well-Being

- Explore self-care strategies, set healthy boundaries, and reflect on your journey with supportive activities and prompts.

TABLE OF CONTENTS

WHAT IS PATIENT ADVOCACY?

1

Learn what patient advocacy means in the context of hepatitis B and explore the different ways to get involved.

FINDING YOUR WHY

2

Reflect on your personal motivations and goals to discover what drives your advocacy journey.

YOUR CORE STORY

3

Craft your core advocacy story using a structured framework and tools to connect with your audience.

TELLING YOUR STORY WITH IMPACT

4

Combine personal experience with data to create powerful messages for different stakeholders.

READINESS AND BOUNDARIES

5

Understand how to set emotional boundaries and assess your readiness to share your story safely.

WORKING WITH STIGMA AND SELF-COMPASSION

6

Explore strategies for navigating stigma and building self-compassion through reflection.

SELF CARE FOR ADVOCATES

7

Develop a personalized self-care plan to support your emotional, physical, and mental well-being.

GETTING STARTED WITH ADVOCACY

8

Take your first steps with a practical action list and helpful resources to begin your advocacy work.

What is Patient Advocacy?

Advocacy in healthcare involves actively speaking up for oneself and others to promote equitable access, quality care, and informed decision-making. It is essential for addressing stigma, closing gaps in care, and challenging systemic inequities. By raising awareness, influencing policy, and empowering communities, advocacy serves as a powerful catalyst for meaningful and lasting change.

Types of Advocacy

COMMUNITY BASED

Community-based advocacy engages local populations through events, workshops, and outreach, particularly for hepatitis B. This includes awareness campaigns, educational sessions, and distributing materials to reduce stigma and boost testing and vaccination rates.

LEGISLATIVE & POLICY

This advocacy aims to influence laws and public health policies related to hepatitis B. It includes providing testimony to lawmakers, lobbying for research funding, and promoting equitable access to care for affected individuals.

MEDICAL & RESEARCH

Medical and research advocacy links patients and advocates with the scientific and healthcare communities. In hepatitis B advocacy, this includes participating in clinical trials, serving on advisory boards, and incorporating patient perspectives into new treatments and care models.

DIGITAL & SOCIAL MEDIA

Digital advocacy uses online platforms to raise awareness, share stories, and mobilize support. For hepatitis B, advocates might create social media campaigns, share personal narratives to combat stigma, or use digital tools to educate the public and connect with global communities affected by the disease.

ADVOCACY IS THE ACT OF TURNING LIVED EXPERIENCE INTO COLLECTIVE POWER, WHERE ONE VOICE BECOMES MANY, AND STORIES BECOME CATALYSTS FOR CHANGE.

The Power of Advocacy

Engaging in advocacy can be deeply fulfilling. It allows individuals to make a meaningful difference in the lives of others, raise awareness, and drive change. Through advocacy, people often discover their voice, grow as leaders, and become powerful agents of transformation within their communities.

Navigating the Challenges

While advocacy is rewarding, it can also be emotionally demanding. Advocates may face stigma, experience burnout, or struggle to balance their personal lives with their advocacy work. Recognizing these challenges is essential to sustaining long-term engagement and well-being.

Finding Your Why

Advocacy begins with purpose. Understanding why you want to speak out helps ground your efforts, sustain your energy, and guide your message. This section invites you to reflect on your personal motivations and the change you hope to create through your advocacy. Advocacy is deeply personal. Understanding your motivation helps you stay grounded and resilient.



Reflection Prompts

- What experiences have shaped your perspective on hepatitis B?
- What do you want others to understand or feel?
- What change do you hope to see in your community or the healthcare system?
- Who are you advocating for—yourself, loved ones, future generations?

Vision Mapping

Vision mapping helps you visualize the change you want to create through advocacy. It's a creative and reflective exercise that turns your ideas, values, and goals into a clear direction for action.

1 Identify Key Issues You Care About

- Think about the hepatitis B issues that matter most to you, such as reducing stigma, improving access to care, improving health equity and health care access or supporting immigrant and refugee communities.

2 Define Your Target Communities

- Consider who you want to reach or support—this could include people living with HBV, healthcare providers, policymakers, or specific age groups in your community.

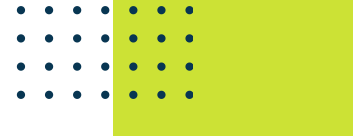
3 Clarify Your Advocacy Goals

- Reflect on the changes you want to see, like more inclusive policies, greater public awareness, or stronger support systems.

4 List Actions You Feel Called to Take

- Think about the steps you're ready to take, such as sharing your story, joining an event, speaking to a representative, or creating educational content.

YOUR CORE STORY



Your story is a powerful tool for change—but advocacy doesn't have to start with disclosure. Whether you're just beginning your journey or have been advocating for years, your voice matters. You don't need to share your hepatitis B status if you're not comfortable. What's most important is your perspective, your passion, and your commitment to making a difference. This section will help you craft a clear, compelling story that reflects your truth and resonates with different audiences—wherever you are in your advocacy journey.

Storytelling Framework

Beginning

Who are you, and what is your connection to hepatitis B?

Turning Point

What moment changed your perspective or inspired you to act?

Call to Action

What do you want others to do, feel, or understand?

Tailoring Your Story to Your Audience



When speaking to policymakers, focus on urgency, statistics, and policy gaps to show how systemic changes—like expanding screening—can save lives and reduce costs.



For scientists and researchers, highlight gaps in knowledge or innovation, emphasizing how your experience reveals the need for better tools like early detection methods.



When addressing healthcare providers, center your story on communication and care, sharing moments where clearer guidance or empathy could have made a difference.



For the general public, use relatable emotions and personal experiences to foster connection, helping others feel less alone in their journey with hepatitis B.

Telling Your Story with Impact

A compelling story goes beyond events to convey their importance. By combining emotion and evidence, you enable audiences to feel and grasp the issue's scale and significance. This section helps you craft impactful messages that resonate and inspire change.

Lived Experience + Data = Impact

One powerful way to increase the influence of your story is to pair it with facts or evidence.

- "I was diagnosed at 19, but I didn't know what hepatitis B was. Like me, 2 out of 3 people with HBV don't know they're infected."
- "My family faced stigma in our community. Studies show stigma is a major barrier to care for people living with HBV."

Message Starters for Different Audiences

- Policymakers**
 - "My experience shows how policy gaps leave people behind—expanding screening and education could save lives and reduce long-term costs."
- Healthcare Providers**
 - "I wish my doctor had explained the long-term effects of hepatitis B—better communication could have changed my care journey."
- Researchers**
 - "Living with hepatitis B has shown me how much we still don't know—my story highlights the need for early detection tools and inclusive research."
- Funders or Grantmakers**
 - "My story reflects the urgent need for community-based support—funding programs like these can make a real difference."
- General Public**
 - "I felt isolated after my diagnosis—sharing my story helps others feel less alone and encourages open conversations."

Storytelling as Strategic Advocacy

Advocacy Setting	Strategic Impact
Policy Testimonies	Real voices humanize statistics and help lawmakers understand the real-world impact of policies.
Funding Applications	Personal stories show the relevance and urgency of research, helping secure support for HBV-related projects.
Clinical Trial Design Input	Sharing your experience can help researchers design more inclusive, ethical, and patient-centered studies.
Health Campaigns	Stories break down stigma, raise awareness, and bring urgency to public health messaging.
Provider Education	Your story can help healthcare professionals better understand patient needs, communication gaps, and cultural sensitivity.

Readiness and Boundaries

Advocacy through storytelling can be empowering—but it also requires emotional readiness and clear boundaries. **There are over 250 million people living with hepatitis B around the world—you are not alone.** At the Hepatitis B Foundation, we're proud to uplift the voices of over 170 storytellers who share their journeys to inspire, educate, and advocate for change. This section helps you reflect on your comfort level, set limits, and choose advocacy activities that align with your energy and well-being.

Key Challenges in Advocacy

- **How much to share:** You don't have to tell everything. Choose what feels safe and meaningful.
- **Privacy and safety:** Consider how public sharing may affect your personal or professional life.
- **Vulnerability and exposure:** Emotional openness can be powerful, but it also requires care and support.

Emotional and Mental Health Checklist

Before

- Reflect on your emotional readiness
- Decide what you're comfortable sharing
- Set boundaries and expectations
- Identify a support person or plan

During

- Breathe and stay grounded
- Pause if you feel overwhelmed
- Remember: you can skip or redirect
- Focus on your message, not perfection

After

- Debrief with someone you trust including other advocates or storytellers
- Practice self-care (rest, journal, etc.)
- Celebrate your courage and impact
- Take a break if needed

What Does Advocacy Look Like for You?

Advocacy takes many forms. You don't have to speak on a stage to make an impact. Reflect on what feels right for you right now. What advocacy activities feel aligned with my energy and comfort right now? Your answer may change over time—and that's okay.



Writing

- Sharing your story through blogs, articles, personal essays, social media.



Speaking

- Participating in panels, interviews, podcasts, or community events.



Mentoring

- Supporting others who are new to advocacy or living with HBV.



Listening

- Holding space for others' stories and being a compassionate ally.

STIGMA AND & SELF COMPASSION

Stigma can be one of the most painful parts of living with or advocating for hepatitis B. It can lead to silence, shame, and isolation. This section helps you explore how stigma has affected you, and how self-compassion can be a powerful tool for healing, resilience, and advocacy.

Stigma thrives in silence but storytelling, reflection, and self-compassion can break that silence and create space for healing. You deserve to be treated with dignity, including by yourself.

REFLECTION ACTIVITY: STOP / START / CONTINUE

Use this simple framework to reflect on how you're navigating stigma and caring for yourself:



WRITE A COMPASSION LETTER

This powerful writing exercise invites you to speak to your younger self with kindness and understanding. It's a way to release shame, honor your journey, and recognize your growth.

Prompt

- Write a letter to your younger self at a time when you felt confused, scared, or ashamed about hepatitis B. What do you want them to know now? What would you say to comfort or encourage them?
- **Example:** "You were never alone, even when it felt like it. You didn't deserve the silence or the fear. You are stronger than you know, and your story matters."

SELF-CARE PLANNER



Use the reflection prompts and self-care activities to check in with yourself, recharge, and stay grounded as you make a difference.

Daily Reflection Prompts

What is one thing I did today that made me feel proud?

How did I take care of my physical or emotional health today?

What challenged me today, and how did I respond?

What is one thing I'm grateful for today?

Emotional Check-in

How are you feeling today? Circle or color the emotions that apply:

Happy

Overwhelmed

Anxious

Tired

Hopeful

Calm

Motivated

Frustrated

Inspired

- Take a walk in nature or spend time outdoors
- Connect with a friend or support group
- Journal or reflect on your advocacy journey
- Do something creative (art, music, writing)
- Take a break from social media or advocacy
- Celebrate a small win or progress made

Weekly Self Care Rituals



GETTING STARTED WITH ADVOCACY

Advocacy is a powerful way to raise awareness, fight stigma, and influence change for people living with hepatitis B. This section will help you find resources and ways to begin your advocacy journey.

SHARE YOUR STORY

- Submit your story to the [Hepatitis B Foundation](#) to be featured in campaigns.
- Speak at community events or webinars.
- Create a social media post about your experience.

JOIN AN EVENT

Participate in events:

- Hep B United's Advocacy Days
- Liver Cancer Connect webinars
- Community research showcases like the Hep B Community Research Showcase
- [Hep B Community Forum](#)

CONNECT WITH RESEARCHERS AND HEALTHCARE PROVIDERS

- Get Involved with the Hepatitis B Foundation
 - The Hepatitis B Foundation can help you find advocacy opportunities that match your interests and comfort level. [Email info@hepb.org to learn more.](mailto:info@hepb.org)
- Attend Conferences & Forums
 - Share your story and learn from experts at events like the B Informed Patient Conference.
- Join Research Advisory Panels
 - Help guide research by offering your lived experience and community insights.
- Support Community-Based Research
 - Assist with outreach, recruitment, and translating findings into advocacy messages.
- Educate Healthcare Providers
 - Share personal experiences to raise awareness and reduce stigma in clinical settings.
- Advocate for Policy & Treatment Access
 - Work with experts to push for better treatment guidelines and healthcare policies.

[HEP B BLOG](#)

The Hep B Blog shares updates on hepatitis B research, policy, and personal stories. It features expert insights, community voices, and advocacy news to keep you informed and inspired.

[B HEPPY PODCAST](#)

This podcast explores real-world issues around hepatitis B through interviews with patients, researchers, and healthcare providers. Topics include stigma, access to care, and global health challenges.

[HEPBSTORIES.ORG](#)

A storytelling platform featuring real people living with hepatitis B. Through video and written stories, the site aims to reduce stigma, raise awareness, and promote testing and treatment.